



'One dead bedroom': Exploring the impact of Obsessive-Compulsive Disorder (OCD) on women's lived experience of sex and sexuality

Elicia Boulton

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**Department of Health and Social Sciences, Faculty of Health and Applied Sciences
University of the West of England, Bristol**

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Acknowledgments

Abstract

Background: There is very little research, and no qualitative research, to date that has explored the lived experiences of sex and sexuality for women with obsessive-compulsive disorder (OCD). It is thought that OCD could impact on sexuality because obsessive thoughts can reflect the concerns of the wider society (Friedrich, 2015) and society is saturated with information about sex and sexuality (Barker & Hancock, 2017). This research highlights the many ways in which OCD experiences result in significant distress for women in relation to sex and sexuality. Without an evidence base around women's experiences in this area to inform interventions, it is difficult to know how therapy can best help women with OCD. The study also supports the fulfillment of sexual rights for this group of women, such as the right to pleasurable and consensual sex (The World Association for Sexual Health, 2014).

Aims: This study begins the investigation of experiences of sex and sexuality for women with OCD by listening to women's voices and exploring how women manage the impact of OCD on their sexual identity and practices, as well as exploring their experiences of seeking support from mental health professionals for related difficulties. I focus on women because of the well-documented gendered nature of sex and sexuality (e.g. Braun, Gavey, & McPhillips, 2003; Farvid & Braun, 2006; Morgan & Davis-Delano, 2016; Nicolson & Burr, 2003), which means that women with OCD navigate their sexual experiences and identities in a heteronormative world that privileges, and encourages women to prioritise, men's sexual desires and needs.

Method: The experiences of women aged 18 and older who had received a diagnosis of OCD or who had sought treatment for OCD were gathered using an online qualitative survey. An online survey afforded participants a high level of felt anonymity and a degree of control over their participation; this was important given the sensitive nature of the topic. One hundred and thirty-four women completed the survey. One *Skype* interview was also undertaken at the request of the participant. The data was analysed using experiential thematic analysis, informed by critical feminist theory on sex and sexuality.

Findings: Four themes were developed: 'OCD as fake news'; 'OCD as sex killjoy'; 'What is normal sex?'; and 'To share or not to share?'. It was difficult at times for many participants to differentiate between OCD intrusive thoughts and 'normal' thoughts. This resulted in some women putting themselves into sexual situations in which they were potentially vulnerable to abuse. The women managed their intrusive thoughts and compulsions around sex and sexuality through avoidance of sex and felt that women without OCD experienced more frequent and better, more pleasurable sex than they did. Women who reported talking about sex with their therapist stated that they experienced judgements about their sexuality, sexist advice and well-meant, but ultimately unhelpful, therapeutic interventions.

Conclusion: Counselling psychologists and other therapists require further training around sex and sexuality, particularly training informed by critical feminist literature. Such training will ensure that when therapists work with women with OCD, they will feel confident talking openly about sex and will be able to empower women to have consensual and pleasurable sex that 'works' for them.

Keywords: Feminism, critical sexuality, counselling psychology, qualitative survey, thematic analysis

Introduction

Overview

The introduction will consider a number of research areas to provide a context and rationale for my study. I begin with an overview of how OCD is understood and treated, which is predominantly through cognitive behavioural therapy (CBT) and exposure and response prevention (ERP). I provide a brief overview of treatment for intrusive thoughts focussed on sexuality and examples of interventions for OCD from counselling psychology, which offer alternative ways of working with OCD. I consider the quantitative research on OCD and sexual problems, which indicates that women with OCD experience sexual problems but provides little insight into the lived experience of those problems. I also discuss anecdotal accounts of OCD and female sexuality because of the dearth of literature in the area exploring women's experiences.

As there is no research within counselling psychology around OCD and sex, the limited literature around sexual difficulties is considered; however, I do discuss the benefits of adopting a counselling psychology perspective on OCD, sex and sexuality, because of the prioritisation of subjective sense-making in counselling psychology research. The medical approach to treating female sexual dysfunction is considered and contrasted with feminist approaches to women's sexual problems. This section includes discussion around sex and consent and the gendered nature of sex and sexuality. The introduction ends with a statement of my aims for this research and a consideration of the relevance of this research for counselling psychology.

OCD: Incidence and Interventions

At the core of OCD is trying to prevent harm to self and others because of feeling a sense of responsibility for managing such threats (Veale & Willson, 2011). Obsessions are involuntary thoughts and can focus on contamination, responsibility for preventing something bad from happening (harm, disasters, mistakes or bad luck), sex and morality, violence, religion, symmetry, order, relationships and sexuality (Abramowitz & Jacoby, 2015). Sexual obsessions can include fears of being a paedophile, fears of being a different sexuality than the person identifies as, engaging in sexual activity that is considered inappropriate, becoming pregnant, or intrusive sexual images that can include aggression or religious

figures (Williams, Crozier, & Powers, 2011; Williams & Wetterneck, 2019). Sexual-orientation obsessions (SO-OCD) or 'homosexuality OCD' (HOCD), on which there is a very little literature, focuses on fears around the alteration of sexual-orientation, of being perceived as gay or of having suppressed same-sex desires (Williams, 2008; Williams, Crozier, & Powers, 2011; Williams & Farris, 2011). OCD compulsions can include both overt actions (such as hand washing) and covert mental rituals (for example, counting silently), and commonly include decontamination, checking, repeating routine activities, ordering/arranging and counting (Abramowitz & Jacoby, 2015). It is common for people to carry out a compulsion to reduce anxiety, but the urge to repeat the compulsion increases each time it is engaged in (OCD Action, n.d.). The cause of OCD is unknown (Brander, Pérez-Vigil, Larsson, & Mataix-Cols, 2016).

OCD is estimated to affect 2–3% of the world's population (Monteiro & Feng, 2016) and is considered to be debilitating for those affected as well as costly to the economy because of sick leave, periods of unemployment and treatment expenses (see Hollander et al., 2016). In the industrialised world, OCD is the tenth most common medical condition (Eisen et al., 2006) and "the fourth most common psychological problem after depression, alcohol and substance abuse, and social phobia" (Veale & Willson, 2011, p. viii). The impact of OCD on people's quality of life has been quantitatively measured by various questionnaires including the World Health Organization Quality of Life Assessment (WHOQOL-100). Research using such questionnaires has demonstrated that OCD negatively impacts people's quality of life, including their "academic, occupational, social, and family" lives (Stengler-Wenzke, Kroll, Riedel-Heller, Matschinger, & Angermeyer, 2007, p.282; see also Albert, Maina, Bogetto, Chiarle, & Mataix-Cols, 2010; Fontenelle, et al., 2010; Hauschildt, Jelinek, Randjbar, Hottenrott, & Moritz, 2010; Hou, Yen, Huang, Wang, & Yeh, 2010; Remmerswaal, Batelaan, Smit, van Oppen, & van Balkom, 2016).

The incidence of OCD for women has been reported in some studies as somewhat higher than for men (Hyman & Pedrick, 2005; see also Fireman, Koran, Leventhal, & Jacobson, 2001; Menchon, 2012). This slightly higher incidence is also noted by OCD UK, along with the fact that 75% of people seeking support for OCD are women (OCD UK, 2018). The charity suggests that the higher number of women than men seeking support may be a

result of cultural gender differences, such as women being more comfortable talking about emotions, and thus seeking support. In one study, women were reported to experience greater distress than men over same sex sexual-orientation obsessions (Williams, Wetterneck, Tellawi, & Duque, 2015).

O'Neill (1999), in a qualitative study of a young woman with OCD, stated that people are rarely 'cured' from the condition and argued that it is one of the most challenging psychological problems to treat. Cognitive behavioural therapy (CBT), combined with exposure response prevention (ERP), is widely considered to be the most effective treatment for OCD (Abramowitz, 2006; Pearcy, Anderson, Egan, & Rees, 2016; Whiteside, Brown, & Abramowitz, 2008). It is also the recommended treatment in the UK by the National Institute for Health and Care Excellence (NICE) (NICE, 2005). ERP involves the person with OCD using a variety of "therapeutic techniques aimed at teaching an individual to approach, rather than avoid, fear-producing stimuli (exposure)" without engaging in compulsions to neutralise the anxiety ("response prevention") (Himle & Franklin, 2009, p.29). However, people with OCD often receive inadequate treatment or are not treated at all, with dropout rates ranging between 17% and 57% (Mataix-Cols & Marks, 2006). It is also common for people with OCD not to seek help for up to ten years after first becoming aware of their difficulties (Rasmussen & Tsuang, 1984).

Research on treatment of sexual or sexual orientation obsessions, although limited, suggests that CBT, ERP, mindfulness and acceptance and commitment therapy (ACT) can reduce obsessions and compulsions (for a discussion of ACT, see Abramowitz, Blakey, Reuman, & Buchholz, 2018; Bluett, Homan, Morrison, Levin, & Twohig, 2014; Hayes, Strosahl, & Wilson, 2011). Reassurance-seeking compulsions can include heterosexual people engaging in frequent sex to provide evidence they are not gay, internet searching to provide evidence that their sexuality will not suddenly change and avoidance of dating or sex (see de la Cruz et al., 2013; Moulding Aardema, & O'Connor, 2014; Palmer, Schlauch & Darkes, 2019; Williams, Slimowicz, Tellawi, & Wetterneck, 2014; Williams, Tellawi, Davis, & Slimowicz, 2015). Sexual-orientation OCD is also experienced by those who identify as lesbian, gay or bisexual (Goldberg, 1984).

Within the counselling psychology literature, few papers specifically discuss general treatment for OCD. Vandenberghe (2007) argued that functional analytic psychotherapy (FAP) is a useful intervention for OCD (for information on FAP, see: Kohlenberg & Tsai, 1987; Kohlenberg & Tsai, 1991). FAP focusses on treating OCD within the therapeutic relationship as it occurs, for instance, the therapist not offering reassurance and using behavioural experiments (ERP) to challenge compulsions (Vandenberghe, 2007). O'Connor, Fell and Fuller (2010) examined a psychoanalytic approach to OCD treatment and considered OCD to be a means of achieving mastery over problematic past experiences through repeating ruminations or rituals. The authors implied that past experiences needed to be worked through and consolidated, rather than being repeated in a continuous loop. OCD has been described within psychotherapeutic research as “an imaginary narrative fiction” (O'Connor & Robillard, 1999, p.359). I have not been able to identify any counselling psychology literature on treatment and interventions for OCD that explicitly discusses treating problems related to sex and sexuality.

OCD and Sexual Problems

There is little research on the topic of OCD and experiences of sex (Buehler, 2011). Quantitative research on OCD suggests that sexual difficulties are a concern for people with OCD (see, Abbey, Clopton, & Humphreys, 2007; Aksoy, Aksoy, Maner, Gokalp, & Yanik, 2012; Doron, Mizrahi, Szepsenwol, & Derby, 2014; Fontenelle, et al., 2007; Freund & Steketee, 1989; Ghassemzadeh et al., 2017; Kendurkar & Kaur, 2008), but there is very little research that focusses specifically on women's sexual difficulties.

Aksaray, Yelken, Kaptanoglu, Oflu and Ozaltin (2001) quantitatively compared the impact of OCD on women's sexual function with the impact of generalised anxiety disorder on sexual function. Women with OCD were more likely to be sexually avoidant, struggle to orgasm and at risk of sexual problems. Buehler (2011, p.42) stated that women with OCD may experience problems with “vaginal lubrication and orgasm” and feel disgusted about sexual experiences. Raeisi et al. (2016) examined sexual function and marital satisfaction in thirty-six women with OCD through quantitative questionnaires. The majority (80.6%) of women reported experiencing sexual dysfunction, which was correlated with higher marital dissatisfaction. Vulink, Denys, Bus and Westenberg (2006) also used quantitative

questionnaires to examine the experience of sexual pleasure between women with and without OCD. They found that women with OCD reported “low sexual pleasure, high sexual disgust and diminished sexual functioning” (p. 19) and these issues were not solely linked to medication side effects or the type of obsessions experienced. It was noteworthy that despite these findings, the authors found that women with OCD reported similar frequencies of sex with their partner as the control group and sex was considered equally as important for them. They suggested that women with OCD still engaged in sex with their partner for the sake of their relationship (for instance, worrying that their partner may leave if they do not engage in sex).

Minnen and Kampman (2000) utilised quantitative questionnaires to examine the difference in sexual functioning in women with OCD and women with panic disorder and agoraphobia and compared the women’s experiences with that of their (male) partner. The results found that compared to the control group, women with panic disorder and those with OCD experienced lower sexual desire and less sexual contact with their partner (in contrast to Vulink et al.’s, (2006), findings). Also, the women with OCD reported more sexual dysfunction and less satisfaction with sexual experiences compared to women with panic disorder. The authors concluded that problems with sex might be experienced more generally by those with mental health conditions. However, there were only seven women in the OCD group compared to twenty-seven in the panic disorder group and thirty-four in the control group. Small sample sizes in quantitative studies examining OCD and sexual problems limits the generalisability of the research (see Real, Montejo, Alonso, & Menchón, 2013).

Data from quantitative questionnaires suggest sexual obsessions are common in both children and adults with OCD, with between 9.9% and 11.9% of those with OCD experiencing this type of obsession (see de la Cruz et al., 2013; Pinto, et al., 2008; Wetterneck, Siev, Adams, Slimowicz, & Smith, 2015; Williams & Farris, 2011). Grant et al. (2006, p.325) stated, “the obsessions of OCD may ... focus on various sexual themes: unwanted sexual thoughts about friends, family, or children; thoughts of violent sexual behavior; obsessions of engaging in homosexual activity; and thoughts of sex with animals.” Grant et al. (2006) examined how men and women with OCD and sexual obsessions may be

different from those with OCD and no sexual obsessions on a range of clinical domains (for example, symptom severity, insight into how their OCD manifests, and quality of life). Although sexual drive and interest were not found to be different between the two groups, there was no exploration about how these thoughts might be managed during sex. However, Gordon (2002) published a case study of a fifty-year-old married woman whose intrusive thoughts were predominantly experienced during sex and reported that she managed the issue through avoiding sex as much as possible. Millar, Salkovskis, and Brown (2016, p.70) examined what the authors termed a 'dirty-kiss' ("an imagined scenario of a non-consensual kiss") using questionnaires to measure the impact of imagined contamination on women without OCD. They found when imagining a non-consensual kiss, there was an increase in women wanting to wash generally and more specifically their mouth, both when the kiss was from somebody known and unknown.

Although understanding of OCD and its treatment has improved in recent decades, the understanding of people's experiences of OCD has moved at a slower pace (Olson, Vera, & Perez, 2007). Knapton (2016) argued that it is imperative that OCD research moves away from measures that are predominantly quantitative, which decontextualise the condition. However, there are very few mentions of sexual problems within the qualitative literature on OCD.

Although quantitative, a PhD study, conducted in the US, explored the impact of OCD on romantic relationships (Abbey, 2005). However, the study included one open-ended question inviting participants to comment on their OCD symptoms and their relationships with a current or past partner. The participants (both female and male) reported that OCD interfered with their sexual relationships and sexual development. The responses were categorised into the following areas: the impact OCD generally had on romantic relationships and sexuality; the secrecy around obsessions and compulsions; delayed development and "social difficulties" (p. 42); and romantic partners' misunderstanding of OCD symptoms. The results of the study indicated that OCD could be detrimental to relationships and that participants with contamination fears also feared being contaminated through sex with partners. There was a brief reference to the sexual experience of one female participant who feared she may have harmed her partner during sex with "left over

menstrual blood” (p.80). The study did not report the sexuality of participants, and this information was not requested in the demographic questionnaire.

One of the few qualitative studies to touch on OCD, sex and sexuality is a focus group study with women and men that explored how OCD impacts relationships with partners (Walseth, Haaland, Launes, Himle, & Håland, 2017). Although sex was not a focus of the study, one female participant mentioned contamination fears prevented her from engaging in sex with her partner, and if sex was engaged in, it would have “to be preceded by extensive cleaning rituals” (p.212). The participant acknowledged the difficulty of discussing sex in the group setting but on numerous occasions stated how important it was to consider. The authors made reference to other participants silently nodding, but they did not contribute their experiences and the researchers did not pursue questioning as there was an uncomfortableness in the group. Also, in an autoethnographic study by Brookes (2011, p.255), she detailed that the deciding factor for seeking help for her OCD was when she “winced” at her husband’s “loving touch” and decided her behaviour was inappropriate from an intimate partner.

Lastly, Williams (2008) provided examples, from an OCD-themed website and discussion forum, to show how people experienced ‘sexual-orientation OCD’ because of the dearth of literature at the time. One female participant commented that “[i]n the beginning, sex was awesome, and now it’s all I can do to make it through sex without crying because I feel like I’m going insane. And at times I feel so full of sadness and depression, that I forget how much I love (or think I love) my boyfriend” (p.199). Overall, Williams emphasised the importance of therapists recognising the existence and impact of ‘sexual-orientation OCD’, rather than assuming the person is experiencing a sexual orientation crisis, because such an assumption would exacerbate OCD distress.

Overall, the research around sex and OCD suggests that women do experience problems with sex and sexuality, including that they may not find sexual activity enjoyable or pleasurable, but instead experience anxiety. Examining the lived experience of people with OCD in relation to sex and sexuality is essential for reducing the stigma and pathologisation that accompanies experiencing mental health ‘conditions’ within society (Murphy & Perera-

Delcourt, 2014). Lived experiences are also essential to develop effective and ethical therapeutic interventions for working with women with OCD around their experiences of sex and sexuality. Examining women's experiences in this area also orients to The World Association for Sexual Health's (2014) Declaration of Sexual Rights through recognising that women should be empowered to have pleasurable, consensual sex and to have the autonomy to make choices about what kind of sex they want. Given the dearth of literature on this topic, it is unsurprising that there have been calls for further research. For example, Abbey, Clopton and Humphreys (2007, p.1189) argued that "[r]esearch is needed that examines the specific sexual behaviors of individuals with OCD to gain a greater understanding of the specific ways in which OCD affects sexual functioning."

Anecdotal Accounts of OCD and Female Sexuality

Although the empirical evidence on OCD and sexuality is limited, there are various anecdotal accounts written by women living with OCD, some of which touch on their experiences of sexual difficulties (e.g. Bailey, 2016; Cartwright, 2019; Colas, 1999; Gordon, 2016; Hodges, 2017; Limburg, 2010; Simone, 2015; Veale & Willson, 2011).

The main themes throughout these stories of OCD centre on shame, the frequent wish to end life, being socially isolated from friends and family, and depending on whether there were contamination fears, delayed sexual experiences. Drugs and alcohol were used to escape perpetual anxiety, and addiction was an issue for some. Late diagnosis was also common because of the shame of the intrusive thoughts and the lack of general knowledge about OCD. Limburg (2010) acknowledged that she would not have written anything about her sex life if it had not been pertinent to her story.

In an edited book, 'Taking Control of OCD', one woman mentioned that when she was aged nine "seeing copulating dogs... made me a little aroused and I thought, 'Am I attracted to animals?'" By aged sixteen she was very fearful of getting pregnant and at seventeen "feared" she was gay (Veale & Willson, 2011, pp.4-5). Gordon (2016, p.55-56) in her book 'Mad Girl' briefly wrote about her experience of OCD and masturbation:

“When I masturbate, which given I am a seventeen-year-old girl, is often, terrible images flash into my head unbidden – images of children playing in parks, or walking to school. It is horrific, a real passion killer. ‘I only like GROWN ADULTS’ I will chant for the next hour, in order to convince the world that... I am also not a Paedophile. Alone in my room, I tug at my hair in disgust. I hit my scalp in horror and pinch my skin as punishment. I want to pull at my head, and replace it with a new one. And on and on it seems to go, this endless cycle of self-loathing and despair.”

Lastly, Limburg (2010) stated that she would not wear her glasses when going to visit her director of studies at university, so that she could not see properly and her supervisor would not be able to read the inappropriate thoughts in her head. Limburg (2010, p.89) later realised that there was nothing “unusual” or “pathological” about her sexual intrusive thoughts; only the amount of attention she was giving to them.

Overall, the anecdotal accounts of experiences around sex for women with OCD highlight the distress, shame and isolation women experience because of the taboo nature of their intrusive thoughts. Therefore, further research is needed in order to challenge the silence in society about taboo or sexual-themed intrusive thoughts and to help women who experience such thoughts be kinder towards themselves rather than self-punishing.

Counselling Psychology Literature and Sexual Problems

Within the counselling psychology literature, there is no research, to the best of my knowledge, addressing OCD and sexual problems. Additionally, research around sexual problems in general is scarce. A paper in *The Counselling Psychologist* by Husted (1975) recommended desensitisation procedures for women to overcome their sexual problems. Husted presented the case of a woman who sought help regarding vaginismus and who had only had sex with her husband once a year for seven years, and as a consequence her marriage had broken down. However, this research was problematically underpinned by the medical model that prioritises biological explanations for sexual problems, and heteronormative discourses of gender and sexuality, both of which limit the conclusions that can be drawn. Heteronormative discourses are underpinned by the assumption that heterosexuality is the ‘norm’ and non-heterosexual sexualities are invisible and ‘other’

(Rubin, 1984). These discourses also perpetuate sexist stereotypes of how men and women 'should' behave (both in public and private spheres) (for a discussion of the term 'heteronormativity' see Marchia & Sommer, 2019). Liss-Levinson (1979), in the same journal, wrote about women with sexual concerns and offered some advice for psychologists to follow, such as being educated about women's sexual problems and acknowledging societal issues and power dynamics. Liss-Levinson also argued that women seeking therapy for sexual issues would more than likely approach somebody who was either not versed in women's sexuality, or a best-case scenario, was minimally informed.

With regard to sex and sexuality in a broader sense, counselling psychologists have mainly researched and written about LGBT concerns, sexual abuse and violence (see, Ollen, Ameral, Palm Reed, & Hines, 2017). However, there is very little counselling psychology research that focusses on working with sexual difficulties. The third edition of 'The Handbook of Counselling Psychology' did not include any information regarding working with sexual difficulties (Woolfe, Strawbridge, Douglas, & Dryden, 2010). However, it did include a chapter on feminism and sexual identities (Hicks & Milton, 2010; Tindall, Robinson & Kagan, 2010). The fourth and latest edition of this text did not contain the words 'feminism' or 'sex' in the index (Douglas, Woolfe, Strawbridge, Kasket, & Galbraith, 2016). As many counselling psychologists have argued, there is a need both in counselling psychology training and in the counselling psychology literature to address how women experience sex (see Hicks, 2010; Hicks & Milton, 2010; Milton, Coyle, & Legg, 2002; Moon, 2010; Roughley & Morrison, 2013; Smith, Shin, & Officer, 2012; Shah-Beckley, Clarke, & Thomas, 2018; Spinelli, 1997). Consequently, therapists may lack the necessary skills to help women with OCD when they are experiencing difficulties with sex and sexuality.

Counselling psychology was, in part, developed as a reaction against the medical model that dominates clinical psychology and psychiatry. Therefore, the profession takes a critical stance when categorising and labelling people with mental health problems, questioning the use of discrete diagnostic categories, such as those related to anxiety disorders, in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD). These classification systems have not been consistent with regards to which 'symptoms' belong to which disorder, as disorders have been renamed or re-classified

in subsequent editions (Starcevic, 2014). Before World War II, anxiety was referred to as distress. However, after labelling it as anxiety post World War II, there was a demand from people in society for a 'fix', and with the publication of DSM-III in 1980, discrete diagnostic categories for anxiety related disorders were developed (Horwitz, 2013). Consequently, anxiety disorders have become reified and are predominantly accepted in society as unquestionable constructs. Within society, diagnoses are treated as explanations for people's experiences and if given by a mental health practitioner, can be taken at face value (Kendell & Jablensky, 2003). Counselling psychology research and practice is underpinned by a number of philosophies and approaches with potentially contradictory philosophical underpinnings: scientist-practitioner, reflective practitioner, humanistic values, post-structuralism and postmodernism (Larsson, Brooks, & Loewenthal, 2012). Therefore, one of the challenges of counselling psychology is to traverse the contradictory nature of using diagnostic labels as a common language and valuing the subjective experience of those experiencing mental health difficulties (Regier, First, Marshall, & Narrow, 2002).

As previously noted, research about OCD is predominantly quantitative and located within the medical model, which is not reflective of the ethos of counselling psychology. Counselling psychology places people's experience at the centre of the discipline and uses qualitative methods to analyse people's nuanced experiences (House & Feltham, 2016). The current research is grounded in an experiential qualitative approach, which explores people's experiences and how they make sense of the world (e.g. Clarke, Hayfield, Ellis, & Terry, 2018; Fahs & Gonzalez, 2014; Holmqvist & Frisé, 2012; Opperman, Braun, Clarke, & Rogers, 2014). This broad approach is appropriate to the topic and research aims because experiential research aims to explore and interpret people's experiences and subjective sense-making, while recognising this is located in a wider social context (Braun & Clarke, 2013).

My research is relevant to counselling psychology because it ultimately aims to help to ameliorate "psychological distress" for women with OCD and focuses on their "subjective experience" (Nielsen & Nicholas, 2016, p.6). Counselling psychology is underpinned by humanistic and relational values, aimed at both understanding an individual's view of the world and how the world and others impact the individual (The British Psychological Society,

2019). The current study takes into account the wider social context, through exploring the way OCD is experienced and navigated within partner and sexual relationships, in relation to the women's sense of self and identity and within their wider social environment and the discourses that govern and regulate sexual practices (Hollway, 1984; Nicolson, 1993).

Counselling psychology explicitly uses "phenomenological and hermeneutic inquiry" (The British Psychological Society, 2019, pp.6-7). This study embraces the counselling psychology ethos of taking a critical view of OCD as a 'diagnostic label'. OCD is not considered a discrete entity located within the body, but is a manifestation of a combination of factors (e.g. biological, cultural, experiences, genetic, and psychological) (see Abramowitz, Taylor, & McKay, 2009). This combination of factors is referred to as the biopsychosocial model and has been considered "both a philosophy of clinical care and a practical clinical guide" for those working in medical professions (Borrell-Carrio, Suchman, & Epstein, 2004, p.576). Strawbridge (2008) has argued that as the number of people 'diagnosed' with 'mental health disorders' has increased, so has the use of the medical framework by counselling psychologists. Thus, she argued that the profession of counselling psychology should remember the social aspect within the biopsychosocial model.

However, the biopsychosocial model is not free from criticism. For example, Cromby, Harper and Reavey (2013) have stated that the developer of this model, Engel (1977), never wrote about how he developed the model, what it would look like or the theory that underpinned it. These authors argue that those applying the model place greater emphasis on the biological element and that the three areas of the model (biological, psychological and social) are usually treated as separate elements rather than as interconnected. Qualitative research into women's sexual problems has advocated a holistic approach, considering all elements of the biopsychosocial model as well as "relational" and "cultural" factors, and this is the approach that I will adopt in my research (Bellamy, Gott, & Hinchliff, 2013, p.3240).

A discussion of the medical and critical literature on sexual dysfunctions or problems will now be presented to provide a context for my research. I firstly consider female sexual dysfunction and its treatment to provide an example of how women's sexual problems are medicalised, and the problems are perceived as being located within the women

themselves. This is useful to provide a context for how women's sexual problems are viewed and treated in the wider society, which then impacts on how women view themselves (Lavie & Willig, 2005).

Female Sexual Dysfunction (FSD) and Medical Approaches to Treating Sexual 'Disorders'

In the DSM-V, there are three classifications of female sexual dysfunctions: female sexual interest/arousal disorder, female orgasmic disorder and genito-pelvic pain/penetration disorder. The DSM-V requires that the disorder is experienced 75%-100% of the time and is accompanied by significant distress (IsHak & Tobia, 2013). However, it is not considered a sexual dysfunction if it is more appropriately explained through a mental health disorder, serious relationship issues (including violence) or other reasons for significant stress (IsHak & Tobia, 2013). Therefore, a woman with OCD is unlikely to be classified as having a sexual disorder because her sexual difficulties are anxiety driven. However, within the DSM-V there are new criteria called "associated features", which does include a category entitled "psychiatric comorbidity (e.g. anxiety)" (IsHak & Tobia, 2013, p.2). Because OCD is anxiety driven, this category could potentially include women with this condition. Corretti and Baldi (2007) have suggested when people are assessed for anxiety disorders, information about their sexual experiences should also be obtained.

CBT is the recommended treatment for OCD and sexual problems, along with antidepressant medication such as fluoxetine either in the short-term for mild to moderate forms of OCD or the longer term for more chronic cases (Buehler, 2011). A known side effect of antidepressants is decreased sexual desire (Frohlich & Meston, 2002; Lorenz & Meston, 2012; Werneke, Northey, & Bhugra, 2006). As a therapeutic technique for managing OCD when it interfered with sex, Buehler (2011, p.45) discussed the use of just "[l]etting go and enjoying pleasure", which she argued was more difficult for women than men but did not elaborate as to why that may be. In terms of 'letting go', Buehler (2011) discussed using mindfulness to enable people to focus on pleasure in the moment. Mindfulness involves staying in the 'here and now' by focusing on bodily sensations and acknowledging thoughts but not paying specific attention to them (Kabat-Zinn, 1994).

Mindfulness has been found to help alleviate the anxiety of OCD in some studies (Fairfax,

2008; Fairfax & Barfield, 2010; Fairfax, Easey, Fletcher, & Barfield, 2014; Hertenstein et al., 2012), although it is still an area in need of further research. Furthermore, there has been little use of qualitative methods to explore people's experiences of mindfulness interventions (Sguazzin, Key, Rowa, Bieling, & McCabe, 2017). One qualitative study highlighted that the risks of mindfulness interventions for people with OCD include distracting oneself from intrusive thoughts, rather than accepting the thoughts, as well as aiding thought suppression and reassurance (being mindful when completing a compulsion to make sure, for example, something had been checked) (Bond, 2015). Mindfulness has also been used to treat sexual interest/arousal 'disorder' in women without OCD and has had mixed results (e.g. Paterson, Handy, & Brotto, 2017).

I will now explore the critical feminist literature on sex and sexuality, which challenges the assumptions embedded in the medical model, and provides an alternative conceptualisation of sexual problems for women. Feminist critical approaches locate sexual problems within the context of women's lives and relationships and the wider social context, rather than considering sexual problems as a failure of the biomechanics of the body or individual psychology.

A Feminist View of Sexual Problems and Consent

In the feminist literature, sexual problems are viewed as reflecting a combination of "inter-related socio-cultural, political, economic, interpersonal, and psychological factors" (Cacchioni, 2015, p.viii). For Tiefer (2004), classification systems such as the DSM result in the perpetuation of dominant norms and discourses, which influence people's identity development. The (now ended) New View Campaign (2018), which was developed by Leonore Tiefer, among others, responded to the medicalisation of female sexual dysfunction and aimed to protest against inaccurate information about sexuality that pharmaceutical industries used to sell drugs. The group campaigned against the US Food and Drug Administration (FDA) approving the drug Flibanserin, because of a lack of research demonstrating its effectiveness for women's sexual problems. Flibanserin is considered the "female Viagra" and was approved in the US by the Food and Drug Administration (FDA) to treat a lack of sexual arousal in women (Segal, 2018, p.460).

With regards to diagnosing women with sexual dysfunction, feminists have highlighted that

diagnoses can be a product of societal values and beliefs in order to control unwanted behaviour (Marecek & Gavey, 2013). Instead, the New View Campaign developed a biopsychosocial approach to permit women to "identify their own sexual problems", which were described as "discontent or dissatisfaction with any emotional, physical, or relational aspect of sexual experience" (Tiefer, 2001, p.86). In the New View formulation, women's sexual problems were classified under four main areas: socio-cultural, political or economic factors; partner or relationship; psychological factors; and medical factors (Tiefer, 2004). Crucially, Tiefer (2001) took into account the inherent power dynamics between women and men and the consequent impact on women's sexual experiences, as well as the impact of cultural norms that can make women feel as though they are not engaging in sex 'correctly' or that they are not physically attractive enough. Furthermore, Tiefer (2001) acknowledged that a lack of communication about sex can cause difficulties and women may not want to engage in sex because of feeling tired from daily responsibilities, worries around sexually transmitted infections, sexual pain, previous sexual trauma, or the side effects of medication. What is emphasised is that women not wanting to engage in sex does not automatically mean that there is a biological defect needing to be 'fixed' with medication or that there is something inherently 'wrong' with them.

Research on heterosexual anal sex provides a clear example of how power imbalances between men and women frequently result in men using coercion to initiate sex that is not always pleasurable for women, and even results in physical (and psychological) pain. Thus, this is not a sexual problem that resides within the individual but from the context in which sex occurs (see Fahs, Swank, & Clevenger, 2015; Fahs & Gonzalez, 2014; Marston & Lewis, 2014; Maynard, Carballo-Diéguez, Ventuneac, Exner, & Mayer, 2009; McBride, 2019; Reynolds, Fisher, & Rogala, 2015).

A qualitative study exploring the experiences of predominantly straight teenagers engaging in anal intercourse found that coercion of women was to be expected (Marston & Lewis, 2014). It was also considered normal to have to persistently ask women for anal sex and women who did not express that they enjoyed it were considered as defective in some way. Anal sex was considered predominantly a sexual achievement for men, and men considered pain for women inevitable and concern about this was not expressed. This study highlighted

the importance of discussing consent in relation to specific sexual practices, which men seemed to consider their right to engage in (Hinchliff, Gott, & Wylie, 2012).

Fahs and Gonzalez (2014) have argued that consent is not as simple as saying 'yes' or 'no'. They use the concept of 'partial consent' to explore the ways in which consent is not a 'one-off' decision but an on-going negotiation between sexual partners, and consent can be enthusiastic or partial, and is located within the context of relational obligations and expectations (e.g. women may submit to anal sex as a 'reward' for her male partner or to increase her relational bargaining power). Furthermore, Fahs and McClelland (2016, p.400) note that people can give "pseudo-consent", which could also be defined as "partial consent" or "sort of consent". This may consist of agreeing reluctantly to engage in sex, which is not fully desired, engaging in painful sex for the benefit of their partner, or submitting to sex as a result of coercion and pressure.

Barker and Hancock (2017) argued that many people subscribe to a notion of 'proper sex', which is informed by social norms about how we 'should' have sex and what constitutes 'real' sex. These ideas can then lead to feelings of guilt and shame when these norms are not upheld and can ultimately lead to people avoiding relationships or sex with others and/or engaging in sex that is not consensual. The authors highlight the impact of societal messages on the construction of self as sexual beings: "the world around us is saturated with messages about sex... [which] have a major role in shaping how we think and feel about sex, and, therefore, our experience of sex itself" (pp. 1-2). They posit that these messages produce the idea that there is a 'normal' or 'right' way to have sex, which can then remove our ability to be in the present when having sex and knowing what we like and do not like because of being distracted by what we think we should be doing and liking. Barker and Hancock (2017) stress that sex is something done between people not to people and therefore it is relational, not a set of skills (see also Tiefer, 2001; Tiefer, 2004; Tiefer, 2006). They invite us to consider what we want from sex and how we can achieve this in our own individualised way, but at the same time advocate talking this through with our sexual partners so we can have consensual sex. They also use the term "sexual imperative", to capture the normative notion that relationships with a partner "must be sexual" (p. 108),

which can be damaging because it positions sex as a necessity not a choice and therefore not fully consensual (for a further discussion of sexual consent, see Popova, 2019).

Theorising Sexuality

The gendered nature of sex and sexuality has been well documented by feminist scholars in psychology and other social science disciplines and informs my decision to focus solely on women with OCD (e.g. Braun, Gavey, & McPhillips, 2003; Farvid & Braun, 2006; Morgan & Davis-Delano, 2016; Nicolson & Burr, 2003). In order to examine how women may 'live out' and manage difficulties with sex in relation to OCD, it is vital to consider feminist and other critical literature on sex and sexuality (e.g. Jackson, 2005; Potts, 2002; Tiefer, 2004). This literature highlights that power dynamics between women and men create a set of social scripts (messages from society about how women should behave and what 'normal' sex is) (Frith & Kitzinger, 2001). Women may adhere to these social scripts consciously or unconsciously, which creates a dichotomy of 'normal' and 'abnormal' sexualities (Rubin, 1984). Regulation of 'normal' sexualities and sex are perpetuated in various ways, which will now be explored through considering the literature around compulsory heterosexuality and dominant discourses, gender power dynamics and cultural sexual scripts.

Compulsory Heterosexuality and Dominant Discourses of Sexuality

The concept of "compulsory heterosexuality", first developed by the writer and poet Adrienne Rich (1980), posits that "institutionalized, normative heterosexuality regulates those kept within its boundaries as well as marginalizing and sanctioning those outside them" (Jackson, 2006, p.105). Heterosexuality is regarded as the 'gold standard' of sexuality or 'normal' and anything outside of it is judged as 'abnormal' (Rubin, 1984). Rubin (1984) discussed a hierarchy of sexualities and conceptualised the dominant and normative aspects of sexuality (e.g. monogamy, marriage, heterosexuality) as constituting the 'charmed circle of sexuality'. In the 'outer limits' of the charmed circle were those whose sexualities were considered as 'bad' or 'abnormal', which could include sexuality practiced by those who were unmarried, gay, or 'promiscuous'.

Hollway (1984) argued that society conceptualises heterosex through the lens of three dominant discourses. The first is the male sexual drive discourse in which women are

positioned as the object of (hetero) male desire and provide an outlet for men's biologically driven 'sex drive'. The second is the have/hold discourse, which highlights the responsibility of women to make relationships with men successful, and instead of women being permitted an active sexuality, they must prioritise love and romance. The third discourse is the permissive discourse, which on the surface appears to provide entitlements to both men and women to express their sexuality freely. However, because of the inequality of power between men and women, permissiveness for men can translate into having sex whenever they want, and for women it can mean acquiescing to pressure from men to have sex (Hare-Mustin, 1994). This discourse also alludes to the sexual double standard applied to women, where they can have as much sex as they want but they will be judged harshly by society through being slut-shamed (Interligi & McHugh, 2018).

Nicolson (1993) has also described a further three dominant discourses about sexual behaviour: the biological imperative, coital imperative and the orgasmic imperative. The biological imperative positions heterosexuality as biologically-driven with women as passive and "men as active" (Nicolson, 1993, p.60). This discourse, therefore, deems non-heterosexual sexualities as 'un-natural'. The coital imperative serves to maintain the notion that 'normal' sex is between a man and women and involves penis in vagina intercourse (PIVI) (see Hayfield & Clarke, 2012). Lastly, the orgasmic imperative asserts that the goal for both men and women engaging in PIVI is to orgasm. Both the coital and orgasmic imperatives have been noted to be perpetuated through advice pages from women's magazines and self-help sex books, which promote a certain view of 'good' and 'normal' sex (see Barker, Gill, & Harvey, 2018). Dominant discourses around sex also underpin sexual scripts, which can be thought of as "the idea that sexuality is *learned* from culturally available messages that define what 'counts' as sex, how to recognize sexual situations, and what to do in sexual encounters" (Frith & Kitzinger, 2001, p.210).

The concept of 'emotion work' in partner relationships is also important to consider. Hochschild (2012, p.7) argued emotional labour requires "one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others..." In other words, put others first and ignore the emotional toll of suppressing your own needs. Fahs and Swank (2016) discussed a 'third shift' for women: doing a full day's

work; completing domestic and childrearing duties on return from work; and the emotional labour demanded from women in their sexual relationships, namely, meeting the demands of their romantic relationship and surviving the imbalance of power within relationships. This reflects Hollway's (1984) notion of a have/hold discourse.

Because of the impact of culture and dominant discourses on the lived experience of OCD, it is essential for counselling psychologists to consider sexuality from a feminist as well as critical sexuality perspective. Friedrich (2015, p.31) argues: "the obsessive concerns of a particular time cannot be separated from the general issues and fears of that era." As a culture, we are increasingly 'obsessed' with sex and sexuality (Barker, Gill, & Harvey, 2018; Plummer, 1995). It is no wonder, therefore, that for a number of people, their OCD experiences are focussed on sex and sexuality, because everybody wants reassurance that they are 'normal' with regard to sex (Barker, Gill, & Harvey, 2018). People fear being 'abnormal', and this is reflected within what is termed by people within the OCD community as SO-OCD (as already discussed), 'relationship OCD' (R-OCD) and 'paedophilia OCD' (P-OCD). Those with R-OCD focus on their relationships, for example, repeatedly doubting their feelings for their partner and their partner's feelings for them (see Doron, Derby, Szepsenwol, & Talmor, 2012; Doron, Mizrahi, Szepsenwol, & Derby, 2014). P-OCD involves "excessive worries and distressing intrusive thoughts about being sexually attracted to, and sexually violating, children" (Bruce, Ching, & Williams, 2018, p.389; see also Vella-Zarb, Cohen, McCabe, & Rowa, 2017). These particular manifestations of OCD reflect common themes within society, such as keeping children safe, the continued dominance of heterosexuality as the 'norm', and media depictions of finding the 'one' and certainty in relationships (see Hefner, 2013).

Fahs (2011a, p.17), although not referring to OCD, captures exactly how experiencing OCD can exacerbate issues located within society around sex – "further entrench[ing] people into the muck of violence, imbalanced power relations, cultural hang-ups, and the snarled interplay between our imperfect selves and our imperfect society." Fahs (2011a, p.3) also considered how sex is performed and negotiated, again by women without OCD, and found:

“... one theme reappeared time and time again: women live in a state of contradiction, beholden to cultural scripts that lay down precise rules about how they can think, behave and experience themselves, while they also struggle to define their sexuality on their own terms.”

This means that women with OCD may harbour shame and embarrassment when it comes to sex and sexuality, because they are not able to follow ‘the rules’ about how sex ‘should’ be engaged in or sexuality defined. Without OCD, sex and sexuality are complex to navigate, and I would suggest that OCD makes this process even harder because OCD casts doubt on everything. Difficulties in defining sexuality are not something exclusive to women with OCD, but are experienced by all women (Albury, 2015; Thompson & Morgan, 2008). Women with OCD may try even harder to stick to the dominant social ‘rules’ of sex and sexuality because they want to appear ‘normal’. This raises questions around how much choice women can exercise when having sex or defining their sexuality, because of the embedded ‘rules’ arising from dominant discourses around sex and sexuality in society. Also, there is a lack of language to discuss sexuality outside of dominant discourses. It may be that women with OCD will draw more heavily on dominant discourses around sex and sexuality to provide a sense of certainty that they are adhering to the ‘rules.’

The key message from feminist and critical sexuality research that is relevant to this study is that all women have to navigate power dynamics around consent, gender and heteronormativity. This raises questions around how women with OCD can negotiate a sexual identity and their experiences of sex without these being overdetermined by dominant social discourses, especially given that the expression and content of OCD thoughts and compulsions draws on, and is embedded within, societal dominant discourses (Friedrich, 2015). Although there are no absolute answers to these questions, it is essential to explore women's voices about sex and sexuality, and how their experiences of pleasure, safety and identity are impacted by OCD, in order to eventually help to answer some of these questions.

Aims of The Proposed Research

The current project aims to listen to women's voices and understand their experiences of sexuality and sexual practices when they have been diagnosed with or undergone therapy for OCD. It will explore: how women experience and make sense of sex and sexuality in the context of OCD; how women negotiate difficulties with sex and OCD; the impact of their sexual difficulties on their relationships; and how therapy has helped or not helped with their sexual difficulties, including identifying examples of good and unhelpful therapeutic practice. The research has the potential to inform counselling psychologists how to work effectively with sexual difficulties related to OCD and to encourage practitioners to develop an understanding of sex and sexuality from a critical sexuality perspective. This perspective has the potential to help therapists reflect on and challenge normative judgements and stereotypes around sex and sexuality, and assist them in not further entrenching their client's experiences of sex and sexuality within dominant discourses.

Method

The current research used an online qualitative survey with responses from 134 women and one online interview to explore women's experiences of OCD, sex and sexuality. The data were analysed using thematic analysis (TA).

Theoretical Assumptions

The research is located within a critical realist ontology, which holds that there is a material reality, but this can never be fully known or accessed directly (Braun & Clarke, 2013; Burr, 2003; Madill, Jordan, & Shirley, 2000; Maxwell, 2012). Taking a critical realist perspective in this research is especially important because the study explores women's experiences of OCD, sex, and sexuality as valid and meaningful material happenings (Maxwell, 2012), whilst also acknowledging these things exist separately from our "perceptions, theories, and constructions" (Maxwell, 2012, p.5). Experience is located within specific social, political and historical contexts. These contexts influence how we experience the world, which impacts our mental health. Researchers using a critical realist ontology aim to analyse and critique the social context in which the phenomena of interest are embedded (Fletcher, 2017). Pilgrim (2015, p.5) has discussed adopting a critical realist approach to mental health

because the ‘symptoms’ people experience as a result of being depressed or anxious, for example, are subjective and based on “culturally context-bound” information.

With regards to epistemology, the present research is located within a contextualist framework. This framework does not assume there is only one reality and holds that context impacts on the development of knowledge. Although the approach still remains interested in understanding ‘truth’, and therefore does not completely reject realism, it is the context in which knowledge is produced that determines what knowledge is ‘true’ (Braun & Clarke, 2013). The current research holds that a reality exists (e.g. women’s suffering around OCD is real and this may impact on their experiences of sex and sexuality), but context and experience are important (e.g. if a woman with OCD views ‘normal’ sex as something different from what she experiences, then this will potentially create further problems when managing sex and OCD because of feelings of failure and being ‘abnormal’).

Online Qualitative Survey

Because of the sensitive nature of the research, it was important participants were given some control over their participation in the research, and a greater degree of (felt) anonymity than that provided by the face-to-face data collection, which continues to dominate qualitative research, including within counselling psychology (Braun & Clarke, 2013; Terry & Braun, 2017). Therefore, an online qualitative survey was undertaken, where participants wrote responses to a series of open-ended questions (Opperman, Braun, Clarke, & Rogers, 2014; Terry & Braun, 2017).

Because participants are not required to interact directly with a researcher, qualitative surveys are suited to sensitive topics and have been used in recent qualitative sex research – including research on orgasm and sexual pleasure (Opperman, Braun, Clarke, & Rogers, 2014) and pubic hair (Braun, Tricklebank, & Clarke, 2013). Qualitative surveys can be delivered in various formats, but online qualitative surveys offer participants the highest level of (felt) anonymity compared to hard copy and emailed surveys (Terry & Braun, 2017). In this study, using an online survey allowed me to access a geographically dispersed and hard-to-engage population. Women with OCD are hard to engage because of the shame and embarrassment they can experience from intrusive thoughts (Glazier, Wetterneck, Singh, &

Williams, 2015). The online survey facilitated disclosure as it removed the pressure associated with face-to-face interaction. Several participants explicitly commented that they would not have disclosed their experiences to a researcher in person. Data could also be collected from a large sample which is important because it provides a "wide angle" lens on the topic and allows the range and diversity of women's experiences to be examined (Toerien & Wilkinson, 2004, p. 70; see also Terry & Braun, 2017). The latter is essential when little is known about the topic and thus, the design aimed to provide both breadth and depth (Toerien & Wilkinson, 2004).

Data Collection

Survey design

The survey data was collected online using the *Qualtrics* survey software. Participants were invited to respond in their own words to ten open-ended questions (Braun & Clarke, 2013; Terry & Braun, 2017). It was important not to have too many questions in case participants experienced fatigue, which could impact the depth and richness of their responses (Terry & Braun, 2017). Questions focused on women's experience of sex and sexuality while experiencing OCD and addressed topic areas such as: the impact OCD had on their sexual experiences; managing OCD during sex; and the support they had accessed to manage any difficulties (see Appendix A for the survey questions). Because of the dearth of qualitative research around women's experiences of sexuality and OCD, the questions were developed from the limited research available and personal memoirs on people's lived experiences of OCD (e.g. Aksaray, Yelken, Kaptanoğlu, Oflu, & Özaltın, 2001; Doron, Mizrahi, Szepsenwol, & Derby, 2014; Raeisi et al., 2016; Vulink, Denys, Bus, & Westenberg, 2006) and research on women's experiences of other anxiety 'disorders', and OCD in general (e.g. Kendurkar & Kaur, 2008; Van Minnen & Kampman, 2000). The design was also influenced by the critical sexuality literature with the aim of ensuring the research was inclusive of women of all sexualities, not just heterosexual women. This required me to educate myself about heterosexist language (e.g. Committee on Lesbian and Gay Concerns, 1991; Braun, Gavey, & McPhillips, 2003; Nicolson & Burr, 2003).

To situate the sample, I collected demographic information and basic information about the women's experience of OCD (for example, the average age of onset of OCD) (Elliott, Fischer, & Rennie, 1999). I was also curious about the use of medication for treating OCD and whether women were regularly prescribed medication, what kind of medication they were prescribed and if women thought this had an impact on their interest in sex. It is well documented within the medical and quantitative literature that antidepressants can reduce sexual desire in women (Frohlich & Meston, 2002; Lorenz & Meston, 2012) and research has also suggested women are more affected by antidepressant side-effects than men (Werneke, Northey, & Bhugra, 2006).

Pilot phase

Following recommendations from the methodological literature, the survey was piloted in the UK over three months on women aged 18 and older, with either a diagnosis of OCD or who had sought therapy/treatment for OCD (Terry & Braun, 2017). The survey was completed fully by two participants, partially completed by a further two participants, and one participant completed only the demographic information. Given the very low response rate over a 3-month period, I decided to also recruit women from outside the UK. As a result of piloting the study, some changes were made to the survey, such as making it more explicit that the study was open to women of all sexualities and trans and cisgender/non-trans women. I also removed the following question: 'If you haven't been formally diagnosed, how did you decide you have OCD?', because on reflection it sounded accusatory to ask women to justify why they think they have OCD and also because it could be interpreted as implying that OCD was a choice. The full responses from two of the participants gathered from the pilot study were included in the final data set as they provided relevant data.

Online interview

I did not intend to conduct any face-to-face interviews; however, one participant emailed me to volunteer to expand her survey responses via an online interview, and I felt it appropriate to interview her because to do so was in keeping with the principles of experiential and feminist qualitative research (in terms of giving voice to women's experiences (Beckman, 2014; Clarke & Braun, in press). This allowed the participant space to

tell her story and add further context to her personal account from her survey (Beckman, 2014; Hesse-Biber, 2013).

Online interviews allow greater flexibility than face-to-face interviews (Hanna, 2012; Janghorban, Roudsari, & Taghipour, 2014). The interview was conducted using *FaceTime*, the Apple equivalent to *Skype* (Barbee, 2018). The benefits of video calling technology, such as *Skype*, to undertake qualitative interviews have been outlined by Hanna and Mwale (2017). The first of these is more convenient scheduling across different time zones (the participant was based in the US). In addition, no travel costs are incurred and thus research is inclusive of those who cannot afford to travel to the study site. Second, the researcher can gain visual feedback during the interview so rapport can be facilitated and body language utilised to aid communication (during the interview in this study, the participant became tearful, and I could adjust my response appropriately). Third, data can be captured easily through programmes such as *Audacity* (which can record the audio from calls); and last, because the participant chooses where they undertake the interview and can end it at any time, this helps to create a more equal power balance between researcher and participant. Research conducted by Jenner and Myers (2018) compared two interview projects, both using a mixture of face-to-face interviews and *Skype*. The research aimed to explore criticisms of online interviewing (such as reduced rapport building, its inappropriateness for sensitive topics, over-disclosure, shorter interview length and concerns around scheduling), to consider whether there was a difference in interview quality. The researchers concluded that *Skype* interviews were not inferior to those conducted face-to-face and could “yield a quality of data that is equal to or exceeds in-person interviews” (Jenner & Myers, 2018, p.12). This was certainly reflective of my experience of interviewing via *FaceTime*.

The qualitative interview lasted for approximately one hour. To provide consent, the participant read the following statement aloud, “I have read the informed consent form and have had the opportunity to ask questions. I understand that I can withdraw from the study at any time with no negative effects. My responses confirm my ongoing consent” (McCoyd & Kerson, 2006, p.394) (see Appendix B for the online interview participant information sheet and Appendix C for the online interview consent form). The interview was semi-

structured as I had prepared questions and prompts in advance, based on reading the participants' survey responses as well as the wider data set. During the interview, I invited the participant to expand on her responses to the online survey by asking open-ended questions and adopting an empathic and curious approach (utilising my therapeutic skills). The interview was transcribed using Braun and Clarke's (2013) system of orthographic transcription notation (see Appendix D).

Participants and recruitment

In total, 134 participants responded to the qualitative survey (following recommendations for participant numbers for online surveys in Braun and Clarke, 2013) (107 full responses and 27 partial) in addition to the single interview. A purposive sample was used, which involved recruiting participants with specific attributes and experiences (Braun & Clarke, 2013). There was no restriction on geographical area and therefore the online survey was accessible to anyone who identified as a woman, was aged eighteen or older with either a formal diagnosis of OCD or who had accessed treatment for OCD. There was no stipulation of how long participants had been experiencing OCD. The study was inclusive of all sexualities, and both trans and cisgender/non-trans women, and the women did not have to be in a sexual/partner relationship at the time of completing the survey. A very small number of the women were engaged in mental health services for other conditions and had discussed OCD with their designated mental health professional.

Online recruitment

The survey was advertised through relevant organisations and platforms, which were chosen because of their focus on OCD, sex or sexuality, and because they provided access to a wide-ranging or specific population, likely to include members of the target population. The majority of participants were recruited through *Reddit*, a social media website for posting and discussing various topics and experiences (Shatz, 2017). Users vote on posts to indicate whether they think the content is positive or negative; those with positive votes become more popular and therefore more visible (rising to the top of the user's 'feed') (Shatz, 2017). *Reddit* is made up of "subforums, called "subreddits," which cover an expansive array of topics" (Shatz, 2017, p.539). Shatz (2017, p.539) has stated that there are many benefits of using *Reddit* to gather data, as "its structure allows for free and rapid

recruitment of large samples, and for the targeting of specific groups when necessary". In order to advertise the study on *Reddit*, relevant etiquette was followed, which involved messaging the moderators of each *subreddit* to obtain permission. I was granted permission to advertise the study on twenty different *subreddits* in a range of areas, (e.g. *r/OCD*, *r/ROCD*, *r/Anxiety*, *r/sex*, *r/AllWomen*, *r/bdsm*, *r/asexuality*, *r/bisexual*) (see Appendix E for a full list of *subreddits*). Some moderators from *subreddits* required the ethical approval details of the study and one wanted verification of the study from my supervisor. The study was also advertised on the *OCD Action* website (the largest OCD charity in the UK) and shared on the discussion forum *Netmums*, which is a platform for mothers and fathers to discuss parenting.

The study and survey link were also shared through social media platforms such as *Facebook* and *Twitter*. *Facebook* pages such as *Anxiety & OCD Sufferers* (which offers a platform for those experiencing anxiety and or OCD to share their stories) and *Everything OCD* (which provides information, support and encouragement for people with OCD and those who support them) advertised the study. *London Counselling Psychologists* (a group that provides support and training for counselling psychologists during and after qualifying) also shared the study on their blog, as well as on their *Facebook* and *Twitter* pages. I contacted two well-known OCD bloggers in the UK (Taming Olivia and Ellen White) who also shared the study over social media. *Anxiety New Zealand Trust*, which is a charity helping people with anxiety, depression, OCD and phobias, shared the study within their team. I also developed a *Facebook* page to advertise the study and to post relevant articles relating to OCD to draw attention to the page and promote awareness of the impact of OCD (<https://www.facebook.com/theexperienceofsexinwomenwhohaveOCD/?ref=bookmarks>). In line with the social justice values underpinning counselling psychology, I opted to provide a summary of the research to the women in the study (an option was provided in the survey to provide an email address to send a summary to) and to those who advertised it.

Online survey completion

By clicking on the survey link, the participants were directed to the landing page, consisting of the participant information sheet (PIS) (see Appendix F), which provided details about the study and participation. Participants were only taken to the survey questions if they clicked

to give consent. Participants were asked how they would like to be referred to if they were quoted in my thesis to give them some control over how they were presented. At the end of the survey, there was a list of resources for support in countries it was anticipated that most participants would live in (such as the US, Canada, the UK, Australia or New Zealand) (see Appendix G).

Participant demographics

Of the 134 participants, 133 identified as biologically female and one participant identified as transmasculine-genderqueer. Overall the study was predominantly completed by women living in the US in their mid-twenties, who identified as white, middle class, able-bodied, and who were in a relationship and full-time employment. In some ways, the demographics of the sample represent the "usual suspects" for participants in psychological research (Braun & Clarke, 2013, p.58). This issue has previously been discussed as being problematic because research findings can only be used to know more about, or help, a very specific group of people (Henrich, Heine, & Norenzayan, 2010) (see Appendix H for further demographic information).

The majority of participants did not identify as heterosexual, but instead used a variety of labels to describe their sexualities. The proliferation of sexuality labels has been considered noteworthy by some sexuality researchers (Marinucci, 2016; McCormack, 2018; Walton, Lykins, & Bhullar, 2016). The increased use of different sexuality labels could be understood as a reaction to mainstream understandings of sexuality (that is, that sexuality can be neatly organised into specific categories and that heterosexuality is usually assumed) (Marinucci, 2016). It was an important part of data collection to obtain information from women with a variety of sexualities because of the overwhelming focus on heterosexual women within research to date examining the impact of anxiety on sex (Beaber & Werner, 2009). The average age of participants was 26; therefore, the diversity in sexuality labels and categories may reflect a cultural shift among the younger generations around defining sexuality (see Cover, 2019a; Cover, 2019b; Savin-Williams, 2014). The range of sexuality labels can be found in Appendix I and definitions in Appendix J.

The responses to questions focussed on participants' OCD and medication are highlighted in Table 1 below:

Table 1: OCD information and medication use

Age of OCD onset	Range		Mean
		2-34	
	Number		Percent
Number of women who had used medication	Yes	104	77.61
	No	30	22.39
Medication helped to reduce/manage OCD experiences	Yes	72	53.73
	No	20	14.93
	Unsure	7	5.22
	Not Stated	4	2.99
	N/A	30	22.39
	Yes for mild OCD and No for severe OCD	1	0.75
Medication reduced sexual desire	Yes	50	37.31
	No	30	22.39
	Unsure	12	8.96
	Not Stated	8	5.97
	N/A	34	25.37

The average age of OCD onset was 10. With regards to the use of medication, the majority of women (N = 104/134) had used it to manage their OCD symptoms, and of those women, the majority reported finding it useful (N = 72/104). However, of the women who took medication, a large number of them (N = 50/104) felt it had negatively impacted their interest in sex, ability to orgasm and it had increased the time it took for them to orgasm. These side-effects of medication are well documented in the research literature (see Taylor et al., 2013) (see Appendix K for a list of medications used).

Because the majority of participants lived in the US, it is important to note that direct to consumer advertising is legal in the US, and the use of antidepressants in the US has increased since 1999-2002 from 7.7% to almost 65% in recent years (Pratt, Brody, & Gu, 2017). In a survey examining antidepressant use in the US from 2011-2014, women were found to be twice as likely than men to report using antidepressants within the last month (Pratt, Brody, & Gu, 2017). Also, a study comparing the use of psychotropic and antidepressant medication in young people aged from birth to nineteen years old, found that compared to the Netherlands and Germany, the US prescribed to 19.2% of young people, which was double that in the Netherlands and three times that of Germany (Zito et al., 2008). Diagnostic information regarding medication use was not collected by the researchers. Therefore, it may be that the sexual experiences of women taking prescribed medication are different from those of women who are not taking medication.

Ethical Considerations

Ethical approval was granted by the Faculty of Health and Applied Sciences Research Ethics Committee (FREC) of the University of the West of England. The BPS (2014) Code of Human Research Ethics Guidelines was utilised when designing the study and producing the participant information sheet and debriefing information at the end of the study and shaped how consent was sought from participants. The anonymity of participants was addressed by asking participants to choose how they would like to be referred to in the thesis if their response was used. I also informed participants that if they chose to provide an email address in order to receive a copy of the research results, if it contained their name, this would reduce anonymity. Email addresses were also stored separately to participant responses. Although demographic information was requested, this could not be used to identify participants. Lastly, any identifying information in participant responses to the survey, or the interview was removed or changed so that participants could not be identified.

Regarding confidentiality, participants were informed that although the survey was anonymous, their IP addresses could be traced, but that I would not do this and more to the point did not know how. The surveys were then downloaded onto my computer from the Qualtrics online server and then would be deleted from the Qualtrics Server. The surveys

and interview were stored in a password-protected file. It was also important to inform participants about how their data would be used and stored, following the 1998 Data Protection Act.

The participants in the study were informed of the benefits and possible disadvantages and risks of taking part in the research to facilitate informed consent. Participants were also provided with information about how to withdraw from the research. In the instance that participants became distressed, information was provided about the support available. Lastly, participants had the contact details of my supervisor so that they could express any concerns or make a complaint.

Thematic Analysis

The data set was analysed using thematic analysis (TA) within a broadly experiential approach (Kitzinger & Willmott, 2002; Malik & Coulson, 2008). TA is a way of developing broad patterns within a data set (Braun & Clarke, 2006; Braun & Clarke, 2019). Experiential TA focusses on how participants experience and understand the world from their perspective (Braun & Clarke, 2013). Given the large data set, TA was an appropriate choice because it enabled me to summarise large quantities of data (Braun & Clarke, 2006). Because little is known about the topic area, a broad overview of significant themes within the data was needed, which TA enabled. TA has often been used to analyse qualitative survey data (e.g. Braun, Tricklebank, & Clarke, 2013; Clarke & Spence, 2013; Jowett & Peel, 2009). Because of the theoretical flexibility of TA, the analysis could be also informed by critical sexuality theory, which has been used by other researchers when using TA to explore sexuality related concerns (e.g. Adams, McCreanor, & Braun, 2013; Braun, 2008; Braun & Clarke, 2006; Braun & Clarke, 2012; Braun, Clarke, & Terry, 2015; Braun, Terry, Gavey, & Fenaughty, 2009; Braun, Tricklebank, & Clarke 2013; Clarke, Braun, & Hayfield, 2015; Clarke, Braun, & Wooles, 2015; Clarke & Smith, 2015; Hayfield, 2013; Opperman, Braun, Clarke, & Rogers, 2014; Terry & Braun, 2011).

Again, given TA's flexibility, it can be used across a variety of different types of data and, therefore, I coded the interview alongside the survey data set (Braun & Clarke, 2006). A primarily inductive TA approach was used in the sense that my analysis was grounded in the

women's account, but my reading of the data was also informed by feminist and critical sexuality research. Inductive TA involves using the data as a basis to produce codes and themes (Terry, Hayfield, Clarke, & Braun, 2017). The researcher is not a blank slate and contributes "their own social position and theoretical lens to the analysis" (Terry, Hayfield, Clarke, & Braun, 2017, p.22).

Recommendations by Braun and Clarke (2006; 2013) were utilised to undertake data analysis and the following process was followed:

- 1.) Familiarisation with data – this involved immersion in the data by re-reading the data set and making copious notes regarding initial thoughts, ideas and feelings (see Appendix L), both on a printout of the data and in a reflexive diary. My initial feeling after reading the data was one of sadness because of the costs of OCD for many of the women (such as avoidance of relationships or no longer engaging in sex with a partner). During this process I also looked for connecting ideas within my notes, which related to my research questions.
- 2.) Generating codes across the entire data set – codes were based on numerous readings of the data and each participant response was coded (see Appendix L). I used both semantic and researcher-derived (latent) codes (Braun & Clarke, 2013). When using semantic codes, analysis starts by describing the overall patterns in the content and those patterns are then considered in light of theory and previous literature to develop "broader meanings and implications", which then leads to a more interpretative engagement with data (Braun & Clarke, 2006, p.84). For example, instances of women struggling to label their sexuality were coded throughout the data set, which was then related to the broader issue of those with OCD not being able to tolerate uncertainty and the distress it causes. Researcher-driven codes "go beyond the explicit content of the data" and are developed based on "the researcher's conceptual and theoretical frameworks to identify *implicit* meanings within the data" (Braun & Clarke, 2013, p.207). An example of going beyond a surface level reading of the data would be considering gendered norms implicitly referenced by the women (for instance, women engaging in sex to meet their partner's needs). Therefore, after coding, I returned to the feminist and critical

sex literature to familiarise myself with the material to ensure that I was confident in the researcher-driven codes relating to these areas.

- 3.) The next phase involved constructing themes based on the codes and producing a summary of what the theme captured about the data. Developing themes involved re-reading the data set and further coding to make sure that I had applied the codes consistently across the data set. I produced a visual map of the data, which involved arranging printed quotations for each theme on a wall to consider the story of the themes (see Appendix M).
- 4.) Reviewing potential themes resulted in the development of sub-themes within two candidate themes ('OCD as Fake News' and 'OCD as Sex Killjoy') and collapsing a candidate theme into a sub-theme ('OCD is a Real Bastard') under the candidate theme 'OCD as Fake News'.
- 5.) Defining and naming themes to capture the main idea within each theme.
- 6.) Producing the report/analysis.

I invite readers to first read the pre data analysis reflexivity in Appendix N. This information is presented in an appendix because of its sensitive and deeply personal content and the requirement to deposit theses in UWE's open access research repository.

Results

An overview of the results is provided in Table 2 below. The first theme, 'OCD as Fake News', reflects the way the women experienced their OCD related sexual thoughts as a distortion of reality. This theme also captures the behaviours/compulsions the thoughts led to (in some instances, women putting themselves into risky sexual situations). OCD is then considered as a 'sex killjoy' in the second theme - women predominantly managed their OCD/intrusive thoughts by avoiding sex as much as possible (and in some cases avoiding sex altogether). The third theme considers how the 'fake news' from OCD thoughts, documented in the first theme, shaped the women's thoughts about how their experience of sexual activity compares to women without OCD. The final theme captures the women's positive and negative experiences of accessing support through therapy for OCD and sexual issues. The majority of women experienced difficulties with sex and/or sexuality at the time

of completing the survey, but there were a small number who felt that OCD had not impacted their sex or sexuality experiences or that their OCD no longer impacted them in these areas.

Table 2: List of themes and sub-themes

Theme	Sub-theme
1.) OCD as Fake News	a.) Will My 'Real' Sexuality Please Stand Up b.) Look What You Made Me Do c.) OCD is a Real Bastard
2.) OCD as Sex Killjoy	a.) Need to Avoid Getting Down b.) One Dead Bedroom
3.) What is 'Normal Sex'?	
4.) To Share or Not to Share?	a.) I'm Scared and You're Not Helping b.) Therapy with Benefits

Theme 1: OCD as Fake News – Difficulties Distinguishing Between an OCD Intrusive Sexual Thought and a 'Real' Sexual Thought

This theme captures how women tried to determine the difference between a 'real' sexual thought and an intrusive OCD sexual thought. A 'real' thought was constituted as a thought expressing a 'true' want or desire and was part of who they were as a person or a true reflection of their identity. By contrast, an intrusive sexual thought was one they could not control and was experienced as ego-dystonic. Research has suggested that those with OCD can become confused about what counts as reality, as a result of believing the content of intrusive thoughts (see Aardema & O'Connor, 2003; Aardema & O'Connor, 2007; Moulding, Aardema, & Connor, 2014). A key feature of this theme was that the women's accounts, unsurprisingly given the nature of dominant discourses around sex (Hite, 1976; Kinsey, Pomeroy, & Martin, 1953; Masters & Johnson, 1966; Nagoski, 2015), were underpinned by essentialist notions of a one 'true' sexuality that could be accessed if it was not for the uncertainty caused by intrusive sexual thoughts. Consequently, when women were not able

to determine their one 'true' sexual identity or sexual orientation, this resulted in identity confusion, which KU (27, Queer, White) summarised succinctly, "OCD tricks your brain into thinking that you actually think/feel one way, even though you don't. It is a very insidious disease that way." Here, KU captures the deceptive nature that the women attributed to OCD in preventing access to their 'true' self as well as the medicalised way in which they spoke about OCD as an 'illness', which implied it could be treated and 'cured', reflecting mainstream sense-making around OCD (Ahmari & Dougherty, 2015; Cogle & Lee, 2014; Markarian et al., 2010).

Women also treated OCD as an entity in itself and something separate from them. They described sexuality as an unchanging entity that resided within the individual rather than being fluid (Diamond, 2009; Jacklin, 1993; Katz-Wise, Reisner, Hughto, & Keo-Meier, 2016; Vance, 1984). This conceptualisation of sexuality is nicely captured by Samantha (27, Mostly Straight, White) who stated that: "During times of major OCD crisis, sex was nearly impossible and felt like a task. I was separated from my sexuality because [of] the OCD." Katie (23, Straight, White) also commented: "I feel like my sexuality is in a box"; this was because of the "rules" she experienced around sex as a result of OCD.

This theme contains three sub-themes, the first sub-theme – 'Will My 'Real' Sexuality, Please Stand Up' – captures how the women felt OCD impacted their ability to confidently label their sexual identity (e.g. as heterosexual, bisexual, asexual). It was important for the women to identify their sexuality and very distressing not to know what label to assign to themselves. The second sub-theme – 'Look What You Made Me Do' – highlights the impact on women when they could not distinguish between a thought that was 'real' and not real, which resulted in them putting themselves in vulnerable situations. Some women reported they engaged in sexual activity because of a compulsion, based on an intrusive thought(s). The woman in these instances did not engage in sex with another person because they necessarily wanted to, but because they felt they 'had' to, to stop something 'bad' from happening or to achieve certainty about their 'sexual orientation'.

Engaging in sex because of OCD raises broader questions about sexual consent – the women were not engaging in sex with others based on full 'enthusiastic' consent (Barker & Hancock, 2017; Fahs & Gonzales, 2014; Fahs & McClelland, 2016), but because they felt coerced by

the content of their intrusive thoughts (e.g. a family member might die if they did not engage in sex with another person). The last sub-theme – ‘OCD is a Real Bastard’ – captured the way OCD made sex terrifying through the content of intrusive thoughts and panic attacks. All sub-themes highlight the way intrusive thoughts distorted the women’s lives, impacting on both sexual identity and the way they engaged in sex (both alone and with a partner).

Will my ‘real’ sexuality please stand up – OCD experiences can result in uncertainty around sexual identity

This sub-theme captures the distress a large number of women reported regarding not being able to confidently or definitively identify their ‘true’ sexual identity. As previously noted, the women's accounts reflected mainstream discourses of sexuality, and were underpinned by the assumption of a ‘sexual essence’ – there would be an answer if they could only work out how to find it. EB (18, Homosexual, White) stated that OCD “... caused me to have a lot of doubts over my sexuality. Whether or not it was my OCD talking or whether it was genuinely my preference. It was very confusing.” Throughout her responses to the survey, EB wrote about OCD as though it was a live entity and therefore had an agency of its own, which communicated a sense of helplessness on her part. The feeling of helplessness was also evident in Isabel’s response (26, Heterosexual, White British): “OCD is trying to convince me I am a lesbian - which would be fine if it were true - but I just doubt myself so much and cannot trust how I feel because I don't know what's true.” Isabel described her OCD as a bully who was trying to alter both her perception of reality and her sexual identity. Being stuck within the uncertainty of never knowing what was true felt anxiety-provoking, scary and oppressive. Isabel later went on to state that when she was aged ten, she spent the “... summer picturing naked women and examining my thoughts trying to determine what my sexuality was, and it caused a lot of anxiety and exhaustion.”

Throughout the data, women either specifically spoke about their anxiety around their sexuality or this was implicit in their responses. Morgan (23, Heterosexual, White) (the sole interviewee), stated in her survey response that:

'I still to this day am nervous to kiss guys sober because I am scared I will not enjoy it, and if I don't enjoy it, my OCD brain will tell me that I'm not straight...even though I know this is completely illogical. So, it's basically it made me worry about anything and everything related to my sexuality. Am I straight, am I bi? What if I'm asexual? How does someone know if they are or if they aren't? What if I'm heteromantic or biromantic and asexual? HOW DO I KNOW WHAT I AM?'

There is a sense of building anxiety and urgency throughout Morgan's response around needing a definitive answer to whether she was heterosexual or not. Morgan's response also highlighted the proliferation of sexual identities in the wider society, which she felt added to her distress. Morgan questions which labels could be used to most accurately describe her sexuality, and she alluded to not being able to trust her mind about what her body experienced, which resulted in her avoiding her feelings and being left in limbo about her sexual identity. Morgan's response also highlighted that sexual fluidity and uncertainty were intolerable to her and reflected a broader societal view of needing to categorise people's sexualities (Nicolson & Burr, 2003). If sexuality can be labelled, it creates certainty and therefore reduces anxiety. In Morgan's interview, she further discussed the importance of having certainty around labelling her sexuality:

'Like you don't know, or even the questions 'am I lesbian' that's a real question that somebody wants to know about themselves, so it's not like 'oh did I just run over that speed bump and kill someone' it's like a real identity question you know or 'am I getting married' that's a real question too and you wanna know the answer to it so it's really hard to know like 'is this something that I should spend my time focussing on or is this something I should just let go', it's hard'.

Morgan legitimised the compulsion (reassurance seeking) to find her 'true' sexual identity through framing it as a 'real', reasonable and meaningful question – a question others ask of their sexuality; it is something everybody wants to know, and therefore it seemed appropriate to focus on finding an answer. Because of this framing, it becomes difficult to recognise questions around sexuality as being intrusive thoughts because those types of questions are socially normative. Morgan's response highlights the difficulty of having OCD

intrusive thoughts that relate to socially normative concerns, because while "it's a real identity question", the constant questioning causes distress. Morgan reported that she would spend hours on the internet researching around how somebody would know the truth of their sexual identity and seeking reassurance from people in OCD forums on the social media platform, *Reddit*. Morgan commented that "... reassurance I think is probably one of the er biggest compulsions that people don't realise that they're engaging in". At the time, Morgan did not know she had OCD and consequently did not know she was compulsively seeking reassurance. Morgan's responses also highlighted something that many women in the study experienced – a difficulty ascertaining whether a thought was just a thought.

For some of the women, uncertainty about their sexual identity could result in avoiding sexual contact:

'I identify as bisexual and am 35 and only talked about it in therapy for the first time at 32 and am still not out at all about same sex attraction. I am scared to date women because I am scared that I am "wrong" and would be leading them on if I somehow decided I was actually straight. I am super supportive of the LGBT community and accepting of anyone else's choices but the lack of certainty associated with OCD has not allowed me to be ok with my own sexuality.' (Jennifer, 35, Bisexual, White)

Jennifer articulated a fear of getting her sexuality 'wrong' and elsewhere described feeling "... tortured by needing certainty and a concrete answer about sexual orientation...". Jennifer's fear reflects an intolerance of uncertainty, which is core to the experience of OCD. Jennifer's response suggested a lack of control over her sexuality as she could change her mind at any time about whether she identified as 'bisexual' or not. The experience of OCD then impacts on Jennifer's ability to explore her sexuality with confidence. Jennifer's reluctance to explore her sexuality in case she is 'wrong' and then 'leads someone on' also reflects OCD thoughts and compulsions around preventing harm to others. It is possible that Jennifer is alluding to the issue of straight people 'experimenting' with gay people without considering the emotional impact this may have (Fahs, 2009).

Women's uncertainty around their sexuality also caused distress and complications in their relationships. Isabel (26, Heterosexual, White British) experienced this distress, which resulted in her not wanting "... to be a sexual person at all." KU (27, Queer, White) more explicitly stated that her intrusive thoughts sabotaged her relationship with a female partner, even though part of her knew she wanted the relationship, she still questioned her reality:

'It made me very uncertain as to what my sexual orientation is. I would obsess about whether or not I was actually straight and would therefore find having a relationship with a woman as dissatisfying even though that is what I wanted. I did not want to be straight, so the obsessions disturbed me.'

KU'S extract echoed other participants' struggles with thoughts and feelings that were dissonant; these women could not reconcile their intrusive thoughts and feelings (anxiety) about their sexuality with being in a relationship that contradicted these thoughts. However, Samantha (27, Mostly Straight, White) commented that: "When obsessing about not ever knowing my "true" sexuality, I was forced to consider that sexuality is far more fluid than society portrays it and have chosen to define myself as mostly straight." Rather than Samantha's sexuality being in doubt as a result of intrusive thoughts, she found relief through questioning societal norms around sexuality. Although Samantha acknowledged that sexuality was "more fluid than society portrays it", she still felt the need to choose a label but experienced some agency in making this choice.

Finally, for some women, their intrusive thoughts escalated to focus on criminal sexual behaviours, such as paedophilia or incest, which caused them a great deal of distress. Bella (25, Bisexual, White British) wrote at length within the survey of her experiences with thoughts about paedophilia, and the following extract captured the escalation of her thoughts:

'It made me question my sexuality to both extremes, constantly worrying that I was exclusively attracted to females and then when I was convinced I was bisexual my OCD would delightfully inform me I was in fact straight and lying about being bisexual for

attention. At times convincing me if I was bisexual then I could also easily be a paedophile and that's really what I was and then that I was also incestuous. I also developed groinal responses to seeing children and was constantly body checking which caused even more anxiety and heightened sensitivity.'

This extract from Bella creates a chaotic image of not being able to hold on to her (authentic) sexual identity. OCD is framed as a separate entity – something that took 'delight' in tormenting her. Bella experienced being forced by this OCD entity to think about taboo and criminal sexual behaviours such as paedophilia and incest and questioned whether she was also 'deviant'. For Bella, her "whole world collapsed" when she disclosed her intrusive thoughts about paedophilia to her therapist. The therapist's clinical supervisor decided Bella's thoughts were a safeguarding issue because Bella worked with children and Bella was informed by her therapist that her manager would need to be informed about her intrusive thoughts. Fortunately for Bella, her manager was extremely understanding and offered support in finding a suitable OCD therapist. Bella had previously tried to access support but had received judgemental responses from online counsellors, because she worked in the medical profession. When she disclosed her distress around paedophilia-themed intrusive thoughts, the counsellors also questioned whether she was a paedophile.

Furthermore, for Bella not only was 'OCD as Fake News' experienced in terms of intrusive thoughts about sexuality but also manifested in bodily responses, such as "groinal responses" to children. Bella adopts the mainstream language of diagnosis through using the term 'groinal response', which is described in the mainstream OCD diagnostic literature as "physical sensations" including "lubrication" of the vagina in women (Bruce, Ching, & Williams, 2018, p. 396). The use of a mainstream term, 'groinal response', positions arousal as involuntary and creates a distinction between OCD related and 'normal' sexual responses (see Chivers, Seto, & Blanchard, 2007; Chivers, 2010; Spurgas, 2013). The term is able to provide relief because it distinguishes between reality and fake news for women. Emily (33, Heterosexual, White British) reported dealing with her genital response through clenching her pelvic floor muscles:

'Due to contamination OCD I would not sit down on toilets properly, and due to paedophile obsessions I would clench my pelvic floor muscles to prevent any perceived arousal. As a result of both of these compulsions, I now have over tense pelvic floor muscles which creates sexual problems (pain etc).'

Emily's experience also showed how compulsions could be used to provide reassurance that a person does not have sexual feelings. She used the word "perceived", which suggests a subjective interpretation of her bodily sensations rather than these responses being 'real'. Morgan (23, Heterosexual, White) also echoed this in her interview when she explained that genital responses were "terrifying" because of what they implied about her sexuality (for example, whether she could be attracted to women even though she considered herself heterosexual):

'...erm I used to get really bad groinal [genital] response too which is terrifying for somebody with OCD erm and that's definitely not talked about either my friends would take their shirts off when we're changing to go out for a night out and I would get a groinal response from it aka in my head me being turned on from it erm and that would be terrifying ...'

Morgan's response conveys a sense of being overwhelmed and controlled by the intrusive thoughts and not being able to make the distinction between a 'real' thought and what is not 'real'. Morgan felt that the presence of a bodily sensation must mean something 'bad'.

This sub-theme has explored how distressing it is for women with OCD to not be able to distinguish between a 'real' thought and an 'OCD' thought and the serious implications this can have for the women's experience of their sexual identity. The next sub-theme takes things a step further by examining how the consequences of engaging in compulsions to alleviate anxiety can play out in women's lives.

Look what you made me do – The impact OCD can have on sexual vulnerability

The central aspect of this second subtheme is the sexual vulnerability some women with OCD can experience as a result of their OCD thoughts. The personification of OCD is even more evident in this sub-theme as reflected in the title (the 'you' is OCD). Throughout the data, many women used the words 'made me' when writing about OCD to reflect their lack of agency concerning their thoughts or actions. Some of the women reported that their inability to draw a distinction between intrusive and real thoughts resulted in them putting themselves into vulnerable sexual situations: "[t]here is a potential for self-destructive behaviour in women with OCD that relates to sex..." (Samantha, 29, Pansexual, Native American). Mira (22, Heterosexual, Arab/Mixed) provides an example of this:

'I overthink everything. My sexual obsessions led me to be sexually assaulted while on a date with a man (who I only dated because my obsession had me feeling that I was attracted to women and I was trying to see if my attraction to men was real). I thought my gut feelings about him being too controlling and weirding me were OCD thoughts. Basically, I couldn't trust anything I felt because the fake thoughts were mixing with the real ones.'

Mira touched on something fundamental to the experience of OCD for the women in this study – that they cannot trust or believe their thoughts because of the way OCD distorts reality. When this inability to distinguish between what is 'real' and 'unreal' concerns sex, women are potentially vulnerable to sexual violence and abuse. Mira states that the person she was with seemed "controlling", but she ignored the feeling and attributed it to her OCD. This self-doubt is not specific to women with OCD but could be considered a normative element of female sexuality in a patriarchal society (Vance, 1984) and thus the experiences of women with OCD are perhaps different in degree but not kind from those of women without OCD. Many women in the study experienced their OCD as sabotaging and constraining their sexuality.

OCD served to sabotage Emma's (19, Bisexual, White) experience of sexuality through having "... intrusive thoughts about not being "bisexual enough" and overcompensate[ing]

by going on dozens of dates with people of all genders just so I could feel like I was "really" bisexual'." Emma's experience highlights the way in which reassurance seeking can incorporate societal messages about sexuality. Emma attempted to establish her identity as bisexual in a context in which "bisexual identity [is] being experienced as a constant battleground for recognition or validation" (Hayfield, Campbell, & Reed, 2018, p.2). Not only does Emma have to manage her OCD, which she experiences as informing her she is not "bisexual enough", but also the normative messages from society feeding into this and therefore potentially exacerbating her OCD. Given dominant notions that bisexual people are 'confused' about their sexuality and need to 'pick a side', Emma's compulsions drew her into the stereotypical notion of the 'confused' bisexual (see Alarie & Gaudet, 2013; Burke & LaFrance, 2016; Dodge et al., 2016; Eliason, 1997; Hertlein, Hartwell, & Munns, 2016; Mohr & Rochlen, 1999; Rust, 1993; Yost & Thomas, 2012; Zivony & Saguy, 2018). C (29, Hetero, White Irish) described how her intrusive thoughts about sexuality led to her attending a "lesbian sex party":

'Yes, ocd sense of not sure I'm straight. Asking lesbian friends to bring me out to hook up with someone. Intrusive homo thoughts. Feeling the pressure of having to go to a lesbian sex party in a mansion in London to find out if I am (compulsion then ruminating about it). I know it's ridiculous and entertaining.'

C alludes to the pressure she feels, articulated by many women in the study, to find a definitive answer to the OCD fuelled uncertainty about her sexual identity. C makes a pre-emptive comment that the reader may find her story "ridiculous and entertaining", which deflects from the seriousness of OCD and perhaps reflects a self-deprecating judgement, not uncommon within the data set.

Janet (18, Bisexual, White) explained how she would put herself in situations where she was potentially vulnerable as a result of the content of her intrusive thoughts:

'I put myself in sexual situations with people much older than me at young ages, because my intrusive thoughts would be of them hurting or rewarding me if I had sex with them. My intrusive thoughts also told me that I was made for sex and nothing

more. I have compulsively had sexual contact with people who I did not want to have sexual contact with.'

Janet's experience of OCD is embedded within societal discourses of women as 'sex objects' (Fredrickson & Roberts, 1997) and also reflects the dichotomy of praise and punishment that men direct towards women within a patriarchal society (Bay-Cheng, Maguin, & Bruns, 2018; Budgeon, 2014). The women experienced vulnerability when they tried to force themselves to act in a way that was dissonant with their intrusive thoughts. Importantly, Janet's extract describes a difficulty some women in the study experienced around consenting to sex. Janet described compulsively having "sexual contact with people who I did not want to have sexual contact with", meaning that the intrusive thoughts she experienced interfered with her ability to give enthusiastic consent. Janet also stated that:

'I'll sometimes see sex as something I have to do, even if I do not want to. I'll have sex even if I do not want to. I feel like sex is a way to connect with someone but also that it is a way to degrade myself'.

Janet describes sex as though it is a chore and also a means to punish herself ("it is a way to degrade myself"). However, Janet is not consenting to being punished; her engagement in sex is driven by her intrusive thoughts. Also, for Janet, the 'just right' feeling that accompanies OCD also affected whether she could fully consent to sex: "I have been confused on my attraction to girls or guys because of OCD, because I will obey anyone until it feels right."

Testing the 'truthfulness' of intrusive thoughts, through compulsions to remove thoughts, could also be considered an aspect of 'fake news' through believing something will 'fix' the issue:

'I had tried one night stands to force myself to "get over" my issues. Those didn't really work out so well as I would go home and have a panic attack before chastising myself for being a sissy cry-baby who should just "get over it".' (Courtnee, 30, Straight, White)

Courtnee forced herself to have one-night stands to stop her intrusive thoughts but was self-critical when this did not work. Courtnee's extract reflects a broader trend in the data, which is of the women being very self-critical. This means that even when intrusive thoughts are not distorting reality and making things more difficult for them, their reality then becomes very punishing as a result of the women berating themselves for having OCD in the first place.

The women would also enter into distressing sexual situations with their partners based on an OCD compulsion:

'I would sometimes get into an awful state of mind where I was compelled to have sex with my partner because it was my way of checking if our relationship was okay. If the partner I was with didn't want to have sex, I would have a meltdown because I wasn't capable of believing that we were going to be fine without "checking". I would feel like a monster for days for feeling like I couldn't take "no" for an answer, which made me worry I was a rapist.' (Charlotte, 32, Bisexual, White)

There is a sense of panic felt within Charlotte's response as a result of her being torn between her OCD compulsions, intrusive thoughts and authentic desires. There is also a lack of agency within her response because her behaviour is driven by anxiety. Charlotte positions herself as passive compared to OCD, which she describes as compelling her. Charlotte's labelling of herself as a potential 'rapist' is an example of how the women in the study consistently tried to label their sexual behaviour and to ruminate over what that label meant about their sexual identity and the type of person they were. There is also a sense of shame in Charlotte's response, this being something women frequently experienced as a result of their compulsions or the content of their intrusive thoughts. It is also interesting to consider Charlotte's response in terms of gender discourses, as her role within the sexual encounter she described was the stereotypically male role of initiator, pressuring her partner to have sex to meet her needs (Hollway, 1984). However, Charlotte is still left in a submissive and powerless position, because seeking to initiate sex with her partner was not the result of authentic desire but intrusive thoughts that she felt compelled to test out.

This sub-theme has explored how OCD can make women vulnerable in their sexual encounters and raised questions about whether women with OCD can ever fully consent to sex because of the ways in which OCD shapes and compels their sexual thoughts and behaviours. The last sub-theme will explore further the women's perceptions of the abusive nature of OCD, which could make sex terrifying as a result of the content of intrusive thoughts.

OCD is a real bastard – The experience of fear around sex as a result of intrusive thoughts

The third sub-theme captures women's experiences of sex (broadly defined as encompassing masturbation, sexual thoughts and sexual activity with a partner) as terrifying or scary as a result of the content of their intrusive thoughts. The women experienced these thoughts as sabotaging their sexual experiences by preventing enjoyment of sex and or contributing to feeling isolated, both in partner relationships and as a result of *avoiding* partner relationships. For some women, the terror and anxiety generated by intrusive thoughts during sex (and what the thoughts might mean about them as a person and their sexual feelings and desires) sometimes resulted in a panic attack. Some of the women's intrusive thoughts centred around social taboos and sexual practices widely considered immoral and criminal (such as paedophilia and incest) as previously mentioned, and for others, around infidelity, contamination or pregnancy, all of which contributed to feelings of shame.

Socially taboo intrusive thoughts were experienced by many women as distressing, shameful and stigmatising:

'I have a recurring intrusive, anxiety-producing thought about seducing (as an adult) or being sexually abused (as a child) by my father. It is hard to even put into words because the stigma and shame is so overwhelming, but I realize most of the time when this thought occurs that it is an OCD symptom and can manage it as such. Still, this is a thought that I have not shared with my therapist, partner, or even acknowledged myself much of the time.' (Isabel, 27, Heterosexual, White and White-Jewish)

The socially taboo content of a number of the women's intrusive thoughts appeared to be related to increased feelings of anxiety and the need to block out or not even acknowledge the thoughts. Numerous women reported not sharing the content of their intrusive thoughts with their therapist because the content was too shameful. Women reported experiencing themselves as socially abhorrent. As Anonymous (34, Straight, White) noted, "Intrusive thoughts can make you feel like a sexual monster, like there's something wrong with you." The phrase "sexual monster" implied the intrusive thoughts were not something Anonymous could control, which reflected how OCD was often spoken about as something possessing and controlling. These thoughts could be viewed as sabotaging sex, in the sense that sex was associated with unpleasant thoughts and images and engaging in sexual activity risked triggering such thoughts.

Jane (28, Bisexual, White British) also wrote about the experience of incestuous intrusive thoughts impacting on her experience of masturbation:

'I had a LOT of intrusive thoughts around sexuality and sex as a teenager. I got hung up on really unpleasant ideas and scenarios that rationally I knew were not true but I found really distressing nevertheless (for example, for a few months after I had one of those gross dreams about having sex with your family members I had constant intrusive thoughts reminding me of that dream and I found it really upsetting to the point I stopped masturbating all together because inevitably it'd creep into my thoughts while I was doing it and then I'd just feel icky and have to stop). This is much less of an issue for me nowadays, but back during my early to mid-teen years it was very common, and very upsetting.'

Although Jane acknowledged the intrusive thoughts as un-true, this did not stop her from finding them distressing. Her response created the image of somebody experiencing flashbacks, not unlike people who have experienced trauma (see Gordon, 2002; O'Connor, Fell, & Fuller, 2010). Jane described her OCD as creeping into her thoughts, as though it was a being preying on her vulnerability and using her thoughts against her to cause distress. This is reminiscent of a horror film trope in which young women are depicted as both sexual

and vulnerable, and OCD was a monster lying in wait for its next victim. Intrusive thoughts and sexual activity combined to make Jane "...feel icky...", which suggests she felt she was doing something wrong and was contaminated in some way.

Furthermore, women were concerned about what sex with a partner may reveal about them (and, for example, their sexual desires and fantasies) because of the difficulty of distinguishing between real and intrusive thoughts:

'Well, I'm terrified of sex. I'm terrified that sex will reveal something awful about me, or that I'll realize that I have sexual desires that cannot be fulfilled in my relationship or that need to be met through something I don't want to do (like have BDSM sex with men). I have honestly always had anxiety about sex, but OCD makes it so much worse.'

(Cynthia R., 27, Bisexual, White)

Cynthia R stated that for her sex was "...terrifying..." because of not knowing what "...sexual desires..." she had and the fact they would "...reveal something awful about..." her as a person. She suggests that there are parts of ourselves that are only ever fully known through sex; that somewhere in the recesses of our minds there lie desires that cannot be accessed during everyday experiences. The idea that Cynthia R may need more from her sexual relationships than what is considered 'appropriate' or 'normal' sex in wider society caused her fear. She also worried about having to do something she did not want to do in order to fulfil her desires, as though the desires were a separate, uncontrollable entity.

Most of the women assumed that women without OCD would be able to 'let go' during sex. Losing control during sex for women with OCD was considered dangerous. Cynthia R's intrusive thoughts sabotaged her experience of sex, as she stated "[w]hen I start worrying, it's game over, and I can't have sex with my partner..." Cynthia R's account reflected a general issue for the women – that there was no room for 'deviant' intrusive thoughts because the women would consider themselves 'deviant' too.

Some women experienced panic attacks as a result of engaging in sexual activity. For C (29, Hetero, White Irish) the consequence of having sex was an extreme form of anxiety:

'Intrusive thoughts when having sex - can be harrowing and mind and body closes down and get an internal/depersonalisation attack which is scary and impacts on my life significantly [...] Depersonalisation attacks during foreplay/sex which is distressing and damaging to relationships'.

C experienced what she described as an "internal/depersonalisation attack" during sex. Depersonalisation is a mind and body separation related to panic attacks (Hunter, Charlton, & David, 2017). C wrote that her anxiety is triggered by a number of different fears such as the side effects of hormonal contraception (the pill), the risk of contracting STIs, relationship intimacy, and further states that "... maybe I don't love my partner enough but I am staying with them and might be harming (emotionally) them if I stay. I'm immoral and cruel if I stay...". Bella (25, Bisexual, White British) commented that she felt "... like sex would be less interrupted by becoming tearful during sex, or panicky or anxious..." if she did not have OCD. HL09 (28, Lesbian, White) experienced panic during sex, which ended the sexual contact:

'Sometimes during sex I get bad thoughts enter my head, like "you're not enjoying sex with your wife, you're enjoying this because you're thinking of someone else". This makes me panic and put a stop to any further physical contact.'

HL09 created a distinction between 'good' and 'bad' thoughts, and because some thoughts were 'bad' it meant the sex with HL09's partner had to end because of what the thoughts might mean. As is common in people with OCD, HL09 treated intrusive thoughts as factual rather than a fleeting thought with no meaning. As a result of OCD, KU (27, Queer, White) also experienced panic around sexual experiences:

'They have led me to have panic attacks during and after sex, especially after the first times with my partners. I would feel very sick, and would be close to non-functional as a result of my doubts and whether or not I could enjoy the experience.'

The worry and not knowing became so distressing that it resulted in a physical manifestation of being “...close to non-functional...”, creating the image of being paralysed by fear.

Women also experienced a fear of sex as a result of intrusive thoughts focussed on contamination issues. M (20, Queer, White) illustrated this issue:

‘My intense fear of infection means I'm terrified of contracting an STI, so I am hyper vigilant about who I have sex with, and who they've had sex with. Casual dating is really difficult for me since I have so many rituals and compulsions. When having heterosexual sex, as well, I always use a condom because the idea of someone else's semen inside of me is horrifying, even beyond the risk of STIs or infection. Part of that is my germaphobia, but another part of it is more psychological, though it's hard to describe. With someone else's bodily fluids inside of me, I get this irrational fear that I am somehow less myself, that it could change me. I know it doesn't make a lot of sense, but then what about this disorder does?’

M expressed difficulty in trying to explain her fears because she experienced them as senseless, irrational and illogical. For many women in the study when OCD was spoken about in relation to sex, it was more about a *‘feeling’* of something not being ‘right’, usually as a result of intrusive thoughts, rather than logic or facts. It is important to note how M writes about bodily fluids triggering a “fear that I am somehow less myself, that it could change me”, which could be considered ‘transformation OCD’. Transformation OCD is a term used by people with OCD to capture a “fear of turning into someone else or another object or acquiring unwanted characteristics” (Volz & Heyman, 2007, p.766). However, research on this aspect of OCD is lacking, with existing studies seemingly only of children (see Monzani et al. 2015; Volz & Heyman, 2007).

The women could not escape from the fear triggered by intrusive thoughts, and Morgan (23, Heterosexual, White) described the experience as follows: "I just sit in hell and rot because I don't know how to get out of it". M, like a lot of the women in the study, positioned OCD within the discourse of the medical model, considering it to be a ‘disorder’. Although some

women had a framework in which to explain their intrusive thoughts, it did not make their experiences of sex any less frightening. Many women echoed M's account of her hypervigilance during sex, and this hypervigilance sabotaged the pleasure they might have experienced. The sabotaging extended to not only pleasure but to having an identity as a sexual person, which was expressed by EB (18, Homosexual, White): “[i]t has pretty much prevented me from being a sexual person at all and that's not because I genuinely don't want to be”. This was further highlighted by Rose (23, Queer, White):

‘My disorder often manifests as a terror of having anything penetrate my body in any way (imagine bumps on my skin as parasites, needles, splinters), so it took time after I became sexually active with my partner for penetrative sex to physically work for us. I enjoy sex, and want to be more carefree about it than I am - but it is still very weird and scary sometimes, and that can become a barrier.’

The way Rose positioned sex as something terrifying, “...weird and scary...” creates the image of sex as an ‘unnatural act’ (Tiefer, 2004). She compared being penetrated during sex to the skin being penetrated by something sharp and painful or by a foreign object, which could also cause disease or infection. Rose's concerns also reflected many women's fears in the study around PIVI sex due to the risks that it carried around STIs, but particularly the risk of pregnancy.

Overall, the theme of ‘OCD as Fake News’ captures the complexity of the intrusive thoughts experienced by the women. Some of the women reported that they could not distinguish between an intrusive thought and a ‘real’ thought. As a result, the women often struggled to develop a strong and certain sense of sexual identity. This was the cause of significant distress, which then led some women to inadvertently put themselves into vulnerable situations. The combination of intrusive thoughts, compulsions and gender power dynamics served to make navigating sexual consent extremely complicated. Some women experienced distress in relation to intrusive sexual thoughts about paedophilia and incest, which resulted in ‘groinal responses.’ The women drew upon mainstream societal ideas of sex to interpret their bodily sensations, which meant they interpreted them as evidence of sexual attraction. Women who described socially taboo intrusive thoughts experienced

shame as a result of thinking they may be sexually deviant, which impacted on their experiences of sex and caused them further distress. This theme also explored how the women experienced sex as something to be feared as a result of intrusive thoughts, resulting in feelings of shame and even panic attacks. Women wrote about OCD as though it was a separate entity controlling them and this personification was reflected in the name of the sub-theme 'OCD is a Real Bastard'.

In conclusion, this theme captures what it is like for some women with OCD to not feel in control of their mind and bodies, because they lack a clear sense of sexual identity and agency. This data poses the question of how we can really know our sexual identities? Uncertainty around sexuality was a frequently reported experience with many examples of women analysing intrusive thoughts to the extent that they deconstructed the concept of sexuality (for example, what does it mean to the person to be a specific sexual orientation and how is that sexual orientation expressed). The women in this study show that identifying our sexuality is simply not a case of correctly labelling one's sexuality, but of questioning what those labels mean and how we *'feel'* them to be true.

Theme 2: OCD as Sex Killjoy – Avoiding Sex to Avoid Intrusive Thoughts

The theme of 'OCD as Sex Killjoy' explores how the women managed their intrusive thoughts by avoiding sex and relationships whenever it felt possible to do so, or by avoiding them altogether.

This theme consists of two sub-themes – 'Need to Avoid Getting Down' reflects the women's avoidance of sex with a partner, driven by a need to avoid intrusive thoughts and subsequent distress, and because of fears around pregnancy and STIs. However, it appeared that total avoidance of sex was not possible for some women when taking into consideration their partner's needs and they reported engaging in sex for the benefit of their partner (the latter is explored further in the theme of 'What is Normal Sex?'). The avoidance of sex in relationships also caused difficulties with partners and at times resulted in relationship breakdown.

A second sub-theme of 'One Dead Bedroom' highlights how some women completely avoided sex and partner relationships as a way of managing the distress created by their intrusive thoughts. This sub-theme considers how these women conceptualised their sexual identity when not having sex with a partner – some described themselves as 'asexual'. However, there was some uncertainty around whether this was a 'true' sexual identity or the result of the impact of OCD.

Need to avoid getting down: Avoiding sexual activity to manage the distress caused by intrusive thoughts

The women in the study predominantly managed intrusive thoughts by avoiding sex:

'OCD has made me want to avoid sex because of uncomfortable thoughts and images experienced or the fear of experiencing uncomfortable thoughts and images.'

(Michaela, 22, Straight, White)

Michaela's extract highlighted that sex triggered intrusive thoughts and just the prospect of experiencing intrusive thoughts was enough for her to want to avoid sex. Isabel (26, Heterosexual, White British) further expanded on the use of avoidance, more specifically because of not wanting to experience intrusive thoughts about socially taboo content and because of pregnancy and STI related 'contamination' fears. Engaging in sex was no longer pleasurable for Isabel, and this lack of pleasure provided a rationale for avoiding it:

'Anxiety about being a paedophile/pervert/lesbian has made me quite scared of having sex in case I have intrusive thoughts about children or women. So it is more anxiety provoking than pleasurable so I avoid it as much as possible [...] I try not to have sex so that I can avoid intrusive thoughts and images. I also have thoughts that my partner has ejaculated into me and impregnated me so feel quite on edge and convinced I am pregnant or have an STI until I start my next period. I become hyper vigilant about any symptoms of pregnancy.'

Isabel's statement that she avoided sex "as much as possible" suggests that her desire to avoid sex clashed with her felt obligations to her male partner to have sex. Isabel's fears of becoming pregnant and contracting an STI reflected the accounts of other women.

Courtnee (30, Straight, White), for example, reported that:

'On bad days, I can't have sex with anyone because the thought of bodily fluids is disgusting to me. On really bad days that sneak up on me, I will start having sex with my partner and have a panic attack because I don't want to get pregnant through the contraceptives and even though my partner has gone through radiation and can't have children. Or because the bodily fluids (saliva, pre-ejaculate, etc.) are never going to wash off my body. Or because we may have caught an STD/STI from somewhere else (like sitting on a park bench) and passed it to the other and now we're going to die [...] I thought I was going to get pregnant my first time having sex. I was on birth control, used condoms and still had to get plan B. Yet, despite all that, I thought I was still going to get pregnant. It stressed me out so much, I didn't have my period for a year which fuelled the whole "I'm pregnant" thing.'

The anxiety experienced by both Isabel and Courtnee expanded beyond the instances of sexual activity and could last for several weeks or even months. Other women reported that they felt compelled to take numerous pregnancy tests in order to check they were not pregnant after having PIVI. Some women did not want to take the contraceptive pill because of the side effects and therefore relied on other forms of contraception such as condoms. Courtnee's experiences of not having a menstrual cycle for twelve months highlights the material, bodily implications of intrusive thoughts.

Isabel and Courtnee also echoed other women's worries about contamination, which included contracting an STI, even when in a long-term relationship. This could be considered as reflective of ordinary relationship issues, as people assume their long-term partners are faithful and therefore stop using barrier contraceptives (Braun, 2013; Lowe, 2005). Sex, particularly unprotected PIVI and other sexual acts where there is risk of STI transmission, requires a certain degree of trust in a sexual partner. For Chloe (21, Heterosexual, White/Māori/Croatian) this was a reason to avoid sex with a partner: "I think I avoid sex

with others more due to my need for control, hence my stronger desire to masturbate.” Chloe highlighted that not all women completely avoided anything sexual, and there were advantages to solo masturbation (such as no risk of pregnancy or STI, and not having to be vulnerable with another person). Not all women were able to engage in masturbation, however, because of their intrusive thoughts. For example, Nicole (26, Heteromantic/Bisexual, White) explained that although she and her partner had agreed to have sex infrequently, in order to manage her intrusive thoughts, she did not engage in masturbation at all:

‘I feel like I cannot be a sexual person. I suffer most of my intrusive thoughts either during sex or in a sexual setting and it has turned me off to sex almost completely. My partner and I rarely have sex anyway by choice, but I do not often masturbate because I am fearful I will have distressing thoughts.’

However, for Bella (25, Bisexual, White British), masturbating seemed a way of still being able to engage in sexual activity with somewhat less anxiety: “[i]t made me want to have sex alone more to avoid/reduce anxiety and sexual intrusions seemed to be less alone than with a partner”.

Having ‘rules’ around having sex with a partner was one way for the women to manage their OCD and meant that even when they wanted sex, they were not able to engage in it as much as they would have liked, and in some instances, relationships would end.

Furthermore, for Anonymous (21, Heterosexual, White), her OCD caused embarrassment as a result of having “... to explain the "rules" of my OCD to my partner”. Although Isabel (26, Heterosexual, White British) earlier alluded to not always being able to avoid sex with her partner, a different Anonymous (22, Lesbian, White) reported that not engaging in sex “... put a strain on [her] relationships...”. Such consequences were further elaborated on by Amanda (22, Bisexual, White):

‘I don't have sex as much as I want to due to my strict rules with sexual partners [...] I have a lot of rules for other people and myself when I get into a relationship, either I

or my partner will get overwhelmed and drop the relationship. I just think too much when I'm in a relationship.'

There is a feeling of loss and frustration within Amanda's response, and there is a lack of agency, as though enforcing the 'rules' of OCD was not considered a choice. This response also reflected the contradictory nature of OCD, in that the 'rules' were enforced to reduce the feeling of being overwhelmed or things being out of control, yet these rules produced the overwhelming feelings. Even when relationships did not end, feelings of frustration were experienced in other ways, such as waiting a long time after a relationship started to engage in sex, which for C (29, Hetero, White Irish) was two years and for Katie (24, Heterosexual, White), four years.

"One dead bedroom": Avoiding sex and partner relationships altogether to manage the distress of intrusive thoughts

For some women in the study, it was deemed a necessity to avoid sex or partner relationships altogether to avoid enduring the distress of intrusive thoughts. Complete avoidance was captured in Kandice's (39, Normal, White) description of the impact of OCD on her sexual relationships, which forms the title of this sub-theme – "One Dead Bedroom". Similarly, Jennifer (35, Bisexual, White) stated: "I avoid romantic relationships totally at this point and haven't had sex in 8 years." When women wrote about no longer engaging in sex, they often used personifying language to describe OCD, as shown in the following examples:

'Everyone gets mad at me because my OCD won't even let me kiss a person let alone sleep with them.' (Brianna, 21, Bisexual, White)

'It [OCD] makes me avoid it.' (Alice, 21, Straight, White)

The avoidance of sex for both women (which also involved avoiding kissing for Brianna), was not described as a choice, but something that the OCD entity did to them, creating the image of OCD as an emotionally abusive partner. Even if some of the women wanted to be in a relationship, it was not something they felt able to pursue:

'Despite wanting to be in a relationship, I avoid them due to OCD.' (Anonymous, 18, Bisexual, White)

'I have yet to allow myself to be in a relationship - it scares me and I often abandon anyone who attempts to facilitate one with me. Even if deep down I want it too... This may have been linked to the trauma associated with the development of my OCD and also having my social interactions growing up hindered by my personal OCD and mental health struggles too.' (EB, 18, Homosexual, White)

There is a sense of sadness in the women's responses, many clearly felt they had to choose between having sexual experiences or managing their OCD. OCD was part of the women's identities, and because of it, there are other parts of themselves they were not permitted to experience such as their sexual self, which felt restricting and confining. Also, for some women in the study, an avoidance of relationships was driven by fear, triggered by either the content of intrusive thoughts or the possibility of experiencing intrusive thoughts at all, overriding any desire for sexual contact. This was described by Katie (24, Heterosexual, White):

'I avoided sex entirely and was afraid of it even though I would say I had a high sex drive and wanted physical contact.'

Finally, some of the women described their sexuality as asexual, and some of the women wondered if they were truly asexual:

'I'm probably asexual, and it's possible that developing OCD prior to puberty somehow affected this. I know that some people are asexual as a genuine sexual orientation and not as the result of physical or mental illness, but I don't know whether or not that's the case with me, because of my history of mental health problems and some traumatic experiences (my first real knowledge of sex came from slowly understanding that I'd saw a parent being raped).' (Cara, 24, Not sure - but not straight, White)

'I would not class myself as a sexual person at all. I do believe that my OCD has put me in the category of asexual. Although I am in a relationship, I have no desire to have sex due to how uncomfortable it makes me feel. It seems easier and less threatening to see myself as non-sexual being.' (Meghan, 40, Gay, White)

It is as though Cara's experience of asexuality was not valid because her experiences of OCD had distorted her 'real' sexuality; she suggested that the label of asexual was a way to manage her feelings rather than an authentic expression of herself. Meghan draws on the personifying language evident throughout the data to note that OCD had classified her sexuality without her active involvement. Meghan reflected on how it was easier for her to avoid herself as a sexual person, as though that part of her was closed off.

Overall, the theme of 'OCD as Sex Killjoy' explored how the experiences of intrusive thoughts led the majority of women in the study to utilise the avoidance of sex as a coping strategy for managing their intrusive thoughts. The sub-theme 'Need to Avoid Getting Down' explored how avoidance resulted in having less sex than was preferable, or conversely, engaging in unwanted sex with a partner. The second subtheme, 'One Dead Bedroom' highlighted that some women completely avoided both sex with a partner and masturbation. Overall, there was a sense of frustration and sadness within the women's accounts of avoiding sex, as it impacted on their sense of sexual identity, and led some women to wonder whether they were 'asexual'. Throughout the data, the women expressed conflicting thoughts and feelings – they wanted to engage in sex but at the same time deemed it too risky because of experiencing intrusive thoughts, and fears of pregnancy and contamination.

Theme 3: What is 'Normal' Sex? – How Normative Discourses of Sex Interact and Exacerbate Women's Experiences of OCD, Sex and Sexuality

The theme of 'What is 'Normal' Sex?' poses the question of how women with OCD described sexual activity and particularly how they implicitly and explicitly compared their experiences of sex with those of 'normal' women (without OCD) as well as how this

impacted on their sexual identity. Although the theme reflects a question within the survey ('Please tell me how you think your experience of sex compares to someone who doesn't have OCD'), it captures data from all survey questions and responses. This theme examines the gendered nature of sex through exploring the ways in which women within heterosexual relationships attempted to please their partner (for example, through engaging in obligatory receptive anal intercourse) and the emotional labour involved in sex for women, such as prioritising the needs and pleasure of men (Elliott & Umberson, 2008; Fahs & Swank, 2016; Hochschild, 2012). A strong message throughout the data set was that women with OCD thought that women without OCD had more desire for sex, were having more frequent sex, and that sex was more enjoyable and happened more spontaneously for them. Therefore, the theme title reflects the general anxiety that all people, not just those with OCD, experience around sex, a common question being 'am I normal?' (Barker, 2011; Nicolson & Burr, 2003; Paine, Umberson, & Reczek, 2019). Consequently, it is unhelpful when women with OCD compare their sex life with women without it as it serves to exacerbate their anxiety and OCD experiences.

Katie (23, Straight, White) highlighted some concerns around sex that were common for women throughout the data set, such as the infrequency of sex within their relationship and not feeling 'normal':

'... I feel that I am completely abnormal from others and I am not a sexual being in the way that others are. I look at my partner after sex and he is completely relaxed and at ease and is not bothered by anything that bothers me. I wonder what it's like to be relaxed like that. When people talk or joke about sex I stay quiet because I know I'm not normal and nobody would understand. Honestly, I really feel that I have improved and healed from a lot of obsessions and compulsions that I used to have, but sex is that final frontier, it's like something I just can't cope with. I don't really know why this is the case, but it really bothers me'.

Katie responded as though she is a failure when it comes to sex and this is in stark contrast to her perception of her male partner's feelings of relaxation and comfort with sex, which makes her feel even worse about herself. Katie's metaphor of sex as the 'final frontier'

creates the impression of sex as something alien, scary, unknown or a final obstacle to overcome. This could reflect a problem for women, especially heterosexual women, of lacking awareness about how other women actually experience sex and only having messages from the media to draw upon regarding what they 'should' feel and experience (Barker, Gill, & Harvey, 2018). Fahs (2011a, pp.15-16) has stated that "[w]e know very little about women's subjective sensibilities about sex" to the point that women lack a shared "common language about [their] sexuality." A lack of language available to discuss female sexuality (Fahs, 2011a) and OCD experiences (Friedrich, 2015) combined creates a toxic, scary and isolating environment, both externally (socially and relationally) and internally (mentally and physically).

Furthermore, Meghan (40, Gay, White) explicitly stated that social representations of sex make her "feel quite inadequate" and this was something echoed by Anonymous (36, Heterosexual, White British) who stated, "It's very easy to consider yourself a failure when you really struggle to do something that according to the press and media, everyone else loves." Meghan also expressed feeling different to her friends because she was not able to openly talk about sex like they could:

'The majority of my friends love sex and talk very openly about how much they enjoy it. I cannot connect to this narrative at all and find myself feeling isolated, like there is something really wrong with me. I feel able to talk about sex openly and I am quite frank about my dislike of it, this normally causes the usual jokes from friends and in some cases disbelief as some think 'I must be lying'.'

Meghan's response suggests there is a way women are 'supposed' to feel about sex and that other ways of experiencing sex are unacceptable, such as not enjoying it, which makes her an 'outsider' to other women. The feeling of being an 'outsider' only serves to reinforce feelings of 'otherness'. With regards to a 'normal' sex life, spontaneity was frequently mentioned: "My guess is it happens more often, more spontaneously, and it's more enjoyable for others without this problem" (Julie, 34, Straight, Caucasian). Likewise, they assumed that 'normal' women were able to be more present during sex with a partner:

'I think I am not as mindful/present as others are able to be. I am not enjoying it, relaxing etc. as I am worrying.' (Maisy, 20, Bisexual, White)

'[...] Maybe it's more enjoyable for someone free of OCD because they are able to focus solely on being in the moment.' (HL09, 28, Lesbian, White)

Many of the women within the study spoke about not being able to enjoy sex, and as a consequence, it meant they often engaged in sex for the sake of their partner. Katie (23, Straight, White) engaged in PIV and oral sex for her partner, but found it distressing to do so:

'... I struggle with the smell of the condom and bodily fluids, and the feeling of bodily fluids on my thighs. I often get very agitated or anxious immediately after sex and sometimes I cry. Sometimes I am more or less okay, but other times I have to get in the shower right after. I am really not able to receive oral because of this. I have been with my boyfriend for 7 years and he has only given me oral 3 times because I usually just can't even take the idea of it. I am also not able to give him oral. The only way I can give him a blowjob is if we take a shower and I wash him and then give him oral in the shower. Again I struggle with the bodily fluids so he cums somewhere in the shower instead of in my mouth. Overall I feel very inhibited and there are so many "rules" I have to follow to have sex. My boyfriend is very understanding but it makes me self-conscious and I often don't want to bother with sex at all.'

Katie struggled with the sensory aspect of sex, and there was no space within her relationship to negotiate sex that worked for her. Katie's response suggested that sex worked for her partner and she engaged in it to meet his needs. Katie referred to the "rules" she had to follow if she wanted to engage in sex, which interfered with 'normal' sex rules (e.g. she should be able to give her partner oral sex and swallow his semen). For Katy, it was OCD that sabotaged her experience of sex rather than prescriptive social scripts around 'normal' heterosexual sex (Braun, Gavey, & McPhillips, 2003; Holland, Ramazanoglu, Sharpe, & Thomson, 2004; Hollway, 1984; McPhillips, Braun, & Gavey, 2001; Wilkinson & Kitzinger,

1993). Anonymous (36, Heterosexual, White British) was more explicit in stating that she did not engage in sex for her own pleasure:

'[...] I'm pretty sure I dread it more than others and struggle a whole heap more to complete the act itself. I'm not adventurous and very much have the lie back and think of England mindset. I do it for my husband, not for me.'

Anonymous highlights how some women in the study engaged in unwanted sex with a male partner (which was also discussed in the theme 'OCD as Fake News' in relation to women putting themselves into vulnerable situations). Engaging in unwanted sex is something women generally have been consistently found to do (Bay-Cheng & Eliseo- Arras, 2008; O'Sullivan & Allgeier, 1998; Vannier & O'Sullivan, 2010); sexual compliance has been defined as "unwanted yet consensual acquiescence to sex" (Katz & Schneider, 2015, p.451). Braksmajer (2017, p.2092) coined the term 'sexual care work' to capture when "women fulfil what they see as their inherent sexual 'obligations' or 'duties'." This was reflected predominantly within heterosexual relationships. Annie (32, Heterosexual, Half White/Half Asian) offers an insight into just how far she would go to engage in anal sex for her male partner:

'My contamination obsessions make it difficult to engage in certain sex acts. For example: I have severe contamination obsessions about faecal matter. I wear latex gloves while defecating (a compulsion), and then I wash my hands for 6 minutes after that (another compulsion), and then I shower (compulsion). At this point, I cannot defecate without doing the glove-hand wash-shower procedure. I do those compulsions in order to limit my contamination by faecal matter. So as you can imagine, engaging in anal sex is difficult for me to do because of this faecal matter obsession. My partner enjoys anal sex almost more than vaginal sex, so I try to "handle the obsession" and engage in it for his benefit. However, the drastic OCD-related anal-cleansing procedure I do prior to anal sex -- and the lengthy hand washing (and body washing) cleansing procedure I do after it -- does cause me considerable mental discomfort, and it makes the entire anal sex experience extremely unpleasant for me. (Of course I do not tell my partner this.) But the truth is: I do dread anal sex

because of the OCD. (If I did not have OCD, I probably would still only tolerate -- not enjoy -- anal sex because I find it physically uncomfortable, but the OCD causes me to dread it, obsess about it in a negative way, and avoid it as much as possible.)

Another example is fellatio. Fellatio used to be extremely difficult for me to do because of my contamination obsession. I used to feel that the penis was horribly contaminated by faecal bacteria and other bacteria. (While trying to perform fellatio, my mind would bombard me with obsessions about my partner's hand touching the public bathroom doorknobs, then touching his penis at the urinal -- which makes the penis feel contaminated to me.) I do actually enjoy giving my partner fellatio, so I have done ERP exposures (didn't tell my therapist about these exposures -- too embarrassing) to help myself habituate to the high SUDS¹ that I used to get while doing fellatio. Since I have done these exposures, it is now easier (but not totally free of SUDS) to perform fellatio. However, on days that I forget to take my NAC² dose, or on days that the OCD feels worse (or when I know my partner has defecated that day without showering after), it is still very challenging for me to perform fellatio on him. The obsessions just make me have so much anxiety.'

Consistent with research on women's experiences of anal sex, Annie engaged in the act solely for her male partner's benefit and pleasure and also experienced discomfort in the process (Fahs & Gonzalez, 2014; Maynard, Carballo-Diéguez, Ventuneac, Exner, & Mayer, 2009; McBride, 2019; Reynolds, Fisher, & Rogala, 2015). It is striking that Annie commented, "Of course I do not tell my partner this", highlighting how Annie performs a certain role for her partner, which takes priority over honest and open communication. Open communication feels impossible for Annie and for women more generally, because of prioritising men's needs above their own. This obligatory sex contrasts with more progressive and reciprocal models of sexual practices in which partners openly negotiate their desires and boundaries, and all involved parties experience sexual satisfaction (see

¹ The subjective units of distress scale is used to measure the level of distress before and after completing exposure and response prevention (ERP) for OCD.

² N-acetyl cysteine is medication used in the treatment of OCD (see Oliver et al., 2015).

Braun, Gavey, & McPhillips, 2003). Annie described her preparation for anal sex as "drastic" and "lengthy", implying a serious amount of commitment and determination to engage in anal sex. Within Annie's response it seems that she cannot negotiate what she wants from sex as her partner's needs take priority. Experiencing OCD means that engaging in anal sex "causes" her to "dread it, obsess about it negatively, and avoid it as much as possible."

Annie appeared to lack agency in her engagement with anal sex as she positioned her OCD as an entity in itself, which made anal sex worse for her (although acknowledging that even without OCD she would not enjoy it), both through the intrusive thoughts and "drastic OCD-related anal-cleansing procedure". The only way Annie could negotiate any agency was to avoid anal sex "as much as possible", although she did not detail how this was negotiated.

Annie draws on gendered sexual scripts, which define what is culturally expected of women during sexual experiences and in Annie's case, the script she is drawing from is women's sexual needs being subservient to those of men (Frith & Kitzinger, 2001; Gagnon & Simon, 1973; Masters, Casey, Wells, & Morrison, 2013). Annie goes to great lengths to perform the kind of sex her partner wants and even uses the words "perform" and "give" in relation to providing oral sex to her partner, which suggests she is playing a role for her partner rather than expressing her authentic sexual desires. Even more striking here is that anal sex now appears to be part of the sexual scripts for heterosexual sex (Shah-Beckley, Clarke, & Thomas, 2018).

Related to women pleasing their partner during sex was the importance of getting sex 'right' and the importance placed on sex within a relationship:

'OCD makes me feel worthless. It makes me so tired and frustrated. I always feel I'm not performing good enough and it really impacts my confidence and body image. It destroys my mind. When I feel like this, sex is the last thing I want. I feel if I don't do well enough in having sex, I've let my husband down and then bad things will happen.'

(Eems, 22, Heterosexual, White)

Engaging in sex places Eems into a double-bind (Bateson, Jackson, Haley, & Weakland, 1956) – she did not want to engage in sex because of her OCD, which made her feel low. However, when she engaged in sex, she also felt low from feeling as though she was not doing it ‘properly’ and consequently letting down her husband. Eems implied that providing good sex is her responsibility and there is a certain standard of sex she is expected to provide. This resulted in further intrusive thoughts, and whatever she did, she could not escape her OCD.

Throughout the data, the women indicated that engaging in sex was important in order to feel ‘normal’ and avoid feelings of shame. Anon (28, Straight, White) expressed the lengths she would go to engage in sex with her male partner and how PIVI seemed the only option for ‘real’ sex (Gavey, McPhillips, & Braun, 1999). Absent from her response was any reference to negotiating other ways to have sex that worked for her:

‘I actually have problems with the skin around my vagina, which was originally misdiagnosed as psychological and vaginismus. It took years to get the right diagnosis. Recently I got an appointment with a specialist in vulval skin and she thinks that the fact that I dry myself extensively whenever I do a wee is likely to be contributing to the problem. So that is a way that OCD directly affects sex for me - I have never been able to have penis in vagina sex without pain. At the moment it is too painful even to get my partner's penis in, despite lots of lubricant and some local anaesthetic. Frequency of sex is very low because of the pain and the feelings of shame [...] The sexual part of me is unclean and needs to be suppressed - and I suppress it very well, I don't want to but it is stuck. Makes me feel that sex/lust is shameful.’

Anon highlighted her attempts to engage in sex (to the extent of using a local anaesthetic to dull the pain) while also feeling that sex and desire were shameful (a feeling evident throughout the data). Anon's engagement in sex reflects the coital imperative discourse (Nicolson, 1993), which serves to maintain the notion that ‘normal’ sex is between a man and women and involves PIVI. There is also evidence of Anon's sexual partner being positioned as the subject in the male sexual drive discourse (Hollway, 1984), which maintains the status quo of men ‘requiring’ sex, whatever the cost. Also, with regard to

sexual pain, it is well documented that women without OCD will engage in sex for the benefit of men even when it is painful (Braksmajer, 2017; Hinchliff, Gott, & Wylie, 2012). Anon also writes about the sexual part of her being separate from the rest of her, as though it was something that she tried to get rid of but was aware on some level that this was not possible and therefore she was 'stuck' with this part of herself.

In conclusion, this theme has captured how the women imagined that other women were having more frequent and enjoyable, spontaneous, 'in the moment' sex. However, the women's experiences of sex shared much in common with the experiences of women in general, as documented in the critical sexuality literature (e.g. Fahs, 2011a; Fahs & Plante, 2017; Hills, 2015; Hinchliff, Gott, & Wylie, 2009; Kaschak & Tiefer, 2001; Perel, 2007). For example, women in heterosexual relationships would 'perform' sex for their male partner, out of a sense of duty or obligation rather than desire (Braksmajer, 2017; Darden, Ehman, Lair, & Gross, 2019; Katz & Tirone, 2009; Vannier & O'Sullivan, 2010). Women would engage in both oral and anal sex solely to satisfy their partner (see Bay-Cheng & Eliseo-Arras, 2008; Burns, Futch, & Toman, 2011; Fahs & Gonzalez, 2014; Fahs, Swank, & Clevenger, 2015; Jozkowski & Peterson, 2013; Lewis & Marston, 2016; Marston & Lewis, 2014; Reynolds, Fisher, & Rogala, 2015; Sovetkina, Weiss, & Verplanken, 2017; Stadler, Delany, & Mntambo, 2007). Thus, women with OCD are impacted by societal norms around sex in the same way that all women are (Braun, Gavey, & McPhillips, 2003; Fahs, 2011a; Fahs & Plante, 2017; Nicolson & Burr, 2003). To conclude, the experiences of sex for women with OCD are embedded within social norms and the discourses around sex for women, which only serves to make sex even more challenging for women with OCD.

Theme 4: To Share or Not to Share? – The Dilemma of Talking About OCD and Sex/Sexuality

This theme addresses the difficulties women reported in being open with therapists about the impact OCD had on their sexual experiences. Many women either implied or explicitly stated that they felt there were risks attached to sharing information about sex and sexuality in therapy. They feared being judged and experiencing feelings of shame and embarrassment. Although most of the participants had accessed therapy for their OCD, they

reported that they rarely discussed the impact of OCD on sex/sexuality. It should also be acknowledged that the theme reflects a question within the survey (Please tell me about any experiences of seeking help for OCD and sexual issues. This support could be formal (therapy) or informal (chatroom/forums), but it also captures information in the responses to other survey questions.

Two sub-themes were developed to highlight the positive and negative aspects of women's experiences. Firstly, the aspects of therapy that made it challenging to share intimate details of their sexual experiences and feelings ('I'm scared and You're Not Helping'), and secondly, positive experiences of talking about sex in therapy ('Therapy with Benefits'). The features of therapy that created barriers to sharing including therapists' lack of training in sexual issues and therapists being judgemental. The features of therapy that enabled sharing included the therapeutic modality (the following modalities were defined as beneficial - mindfulness, dialectical behaviour therapy (DBT) and ERP³), the therapeutic relationship and therapists providing empathy, unconditional positive regard and validation of the women's experiences.

I'm scared and you're not helping – The shame of sharing intrusive thoughts and the unhelpfulness of therapy

When women were in therapy, there was a fear around sharing information about intrusive thoughts because of what the thoughts may mean:

'verbalizing your obsessions is so hard. It makes them "real" and it's always terrifying that you'll be told your fears are well-founded and that you're right to be afraid. In the first few sessions with my therapist I could not bring myself to say my real obsessions. I think that many therapists don't realize how frightening it is to share this.' (Leyla, 30, Bisexual, Greek-Jewish-American)

³ Exposure and response prevention (ERP) involves the person with OCD approaching what they are afraid of without engaging in compulsions to neutralise the anxiety.

Leyla's response showed how powerful words can be for women with OCD and the way that language played a pivotal role in their experiences, so much so that speaking words aloud had the power to make something 'true' or 'real'. Leyla also captured the 'in-between' space of uncertainty, between disclosing and not disclosing and how scary that could be. She also highlighted how women could feel frightened in their therapy sessions and how therapists could be presumably unaware of this.

When women were asked about their experiences of seeking help, shame and embarrassment were often mentioned in relation to intrusive thoughts: "... there was a lot of shame associated with them even though I knew I didn't like or want the thoughts, so it was hard for me to talk to my therapist about that specifically" (Jane, 28, Bisexual, White British). Similarly, Alex (26, Gay, White) wrote: "I've been too ashamed to talk about it or really seek help. I'm worried about what a therapist might think". Likewise, Emma (19, Bisexual, White) stated: "I have been in therapy for OCD and anxiety for the past 2-3 years but have always felt too anxious to talk about sexual issues." These extracts highlight that many women were not talking about their distress around sexual experiences in therapy and therefore not receiving the support they needed.

The lack of therapists' education in OCD also contributed to the women's shame, embarrassment and distress in therapy, because the women found that some therapists were not able to identify taboo thoughts as OCD (see Glazier, Calixte, Rothschild, & Pinto, 2013). Mira reported that (22, Heterosexual, Arab/Mixed):

'Went to see a therapist for the sexual assault and she told me I was gay because of the OCD thoughts. It sent me into a mental breakdown where I felt I couldn't trust myself. It took 2 years to be diagnosed and properly medicated. But until then, I dealt with having my own therapist doubting my thoughts and preferences as well as me.'

OCD has been called "the doubting disease" because those with the condition doubt their thoughts and experiences (Gordon, 2002, p.348). In Mira's case, not only did she doubt her sexuality, but her therapist contributed to these doubts by telling her she was gay. This further exacerbated her OCD experience. There were other instances throughout the data

set of women reporting experiences with therapists who were not sufficiently educated about OCD:

'I am unfortunately a bit embarrassed to talk about sex in therapy, but sometimes we do. She has had implied that my intrusive thoughts about sex with men (that include my close family) are real, while informally and through books I've discovered that they are ego dystonic.' (R.S., 20, Lesbian, White)

'The therapists who had less knowledge about OCD were more likely to try to analyse my thoughts and the relationship instead of focusing on the anxiety, which was helpful to an extent but largely encouraged me to ruminate more.' (Cynthia R., 27, Bisexual, White)

From the women's accounts, it seemed many of the therapists they had worked with also lacked education in critical sex literature, which is not unsurprising given the lack of focus on sex in therapeutic training (see Hicks, 2010; Hicks & Milton, 2010; Hill, 2013; Milton, Coyle, & Legg, 2002; Moon, 2010; Roughley & Morrison, 2013; Shah-Beckley, Clarke, & Thomas, 2018; Smith, Shin, & Officer, 2012; Spinelli, 1997). For Bella (25, Bisexual, White British), this resulted in her therapist giving her deeply problematic, sexist advice that reflects dominant heteronormative discourses around women's sexual passivity, women's obligation to 'have and hold' their male partners and to put their male partner's needs before their own (Fahs & Plante, 2017; Hollway, 1984; Nicolson, 1993). Bella also commented that the advice of the counsellor was offered in a reassuring and kindly manner, which makes the dominant patriarchal discourses she drew on all the more insidious:

'One person suggested I have face to face counselling so I searched for a non NHS charity organisation and saw one person who was a lot older than me and new to counselling and was clearly quite shocked at Polyamory, I chose not to see her again and met with a new counsellor who was lovely and I initially felt a reduction in anxiety being able to talk through my difficulties but after a few sessions it became clear that talking was just reinforcing my OCD and the counsellor was offering "reassuring" and well-meant comments like a lot of women feel like "lie back and think of other things"

when having sex which just wasn't helpful because I don't think sex should be endured.'

However, rather than Bella accepting her counsellor's advice, she challenged their views by stating that their approach was unhelpful, and that sex should not be "endured."

There were women who also experienced judgement from their therapist concerning their OCD and sexuality, and Amanda offered advice to therapists regarding not stereotyping sexualities:

'The online counselling helped a little at times but the professionals often changed and some were quite judgmental that I was a nurse and I should seek help if I tell other people too... it may not have been that harshly worded but at the time it felt like it [...] The most invalidating thing was when people questioned if I was really a paedophile [...]' (Bella, 25, Bisexual, White British)

'Don't stereotype, my therapist assumes that I have a crush on everyone because I'm bi (we've talked about that and it's cool now). Take some sort of ally training, even if you're queer, it's a dope training all around.' (Amanda, 22, Bisexual, White)

Bella was met with the judgement that as a nurse she should not talk to others about her distress. Her therapist assumed that somehow Bella had 'failed' and needed to keep her difficulties to herself, as though she should be ashamed of her OCD. There was also the judgement about Bella potentially being a paedophile, which only served to highlight how some therapists lack information about OCD and therefore how easily they can jump to unhelpful and damaging conclusions. Past research has found that inappropriate and detailed risk assessments could be very damaging to people with OCD, by worsening their intrusive thoughts and compulsions (Veale, Freeston, Krebs, Hyman, & Salkovkis, 2009). In Amanda's case, her experience of therapy highlighted how stereotypes about sexuality, taken into the therapy room, could be damaging to the therapeutic relationship. However, although Amanda dealt with her therapists' prejudice positively by educating her, other

participants were unable to do this, and it is questionable whether they should have to (see Richards, 2018).

Therapy with benefits – The positive aspects of therapy

I will now turn to the positive experiences of therapy, which were only reported by only a small number of women. Some of these women reported they had found particular therapeutic modalities helpful – Morgan (23, Heterosexual, White) expressed how she felt about ERP, which she thought had: “... changed my life! That's pretty much all I have to say about OCD treatment...ERP really works especially when combined with medication.” Mindfulness was also mentioned by some participants as being a useful technique because it helped with difficulties around ‘staying in the moment’. Utilising mindfulness when having sex with a partner and when masturbating was described by some participants. Charlotte (32, Bisexual, White) mentioned both mindfulness and the usefulness of DBT. The latter aims to move people past feeling stuck between two opposing thoughts, through utilising emotional regulation strategies and problem-solving skills (for a brief overview see Calvert, 2012):

‘Mindfulness therapy was also invaluable. I could not enjoy sex as I do today if I hadn't learned how to keep myself in the moment, focus on feeling physical existence and sensations, and to "notice" I am feeling an emotion (as opposed to having it consume me). DBT goes hand-in-hand with this.’

Charlotte touches on something vital – that many women described feeling consumed by OCD and related anxiety, and therefore it was necessary for therapy to provide them with the tools to manage this. Charlotte (32, Bisexual, White) also went on to state that she found DBT more useful than CBT:

‘I did about two years of therapy with one therapist. I found DBT to be more helpful than CBT. Understanding my emotions, learning how to tolerate them as opposed to frantically trying not to feel them, and learning how to focus on the moment vs. the past/the future were the keys to my recovery. CBT made me feel anxious over the

disparity in rational thought vs. the way that I thought. I felt like it simply highlighted how disordered I was without giving me the tools to deal with how that made me feel about myself.'

It has been well documented in the therapeutic literature that the therapeutic relationship is the most essential ingredient of effective therapy and the factor most likely to produce change in a client's thoughts, feelings and behaviour (Cameron, Rodgers, & Dagnan, 2018; Falkenström, Granström, & Holmqvist, 2014; Flückiger, Del Re, Wampold, & Horvath, 2018; Rogers, 1957). A good therapeutic relationship was very important for women within the study:

'Having found a great therapist myself, I think developing trust is very important. Sexuality is a very intimate topic but easier to discuss if you feel a connection with your therapist.' (Elizabeth, 61, Heterosexual, White)

Elizabeth highlighted that a client was unlikely to talk about something as intimate as sex unless there was a good relationship with their therapist. For the women, having their experiences validated was part of a good therapeutic relationship:

'Honestly just be really validating. One of the things that makes a huge difference for me with my current therapist is when she validates my feelings on things and makes me not feel like a crazy person. She does mention that things are just intrusive thoughts, but at the same time she knows they are real to me and is considerate of that. I think talking about sex and sexuality makes people feel very vulnerable, so extra care should be taken.' (Cheyanne, 26, Pansexual, White)

'Be as educated you can be on the issues of sexuality and OCD and the obsessive thoughts that relate to sex that someone may struggle with. The best thing a therapist can be is an open and non-judgmental sounding board for someone plagued by these thoughts. Being able to tell a therapist and having them understand is the most relieving feeling for a patient and can really help boost their confidence in therapy.' (Anonymous, 34, Straight, White)

Cheyenne and Anonymous both highlighted that having somebody validate their feelings and take them seriously reduced their anxiety. Cheyenne acknowledged that having OCD made her feel as though she was "crazy" and Anonymous used the word "plagued", which creates an image of intrusive thoughts consuming the mind. Acceptance reduced anxiety around potential judgement and made the women less afraid to talk about sex.

Not only was education around OCD considered important for therapists but it was equally important for therapists to pass on that knowledge to clients:

‘During my first session with my psychologist he diagnosed me pretty quickly. It gave me a new framework to view things and as we spoke more, a lot of my issues made better sense. It was a big relief.’ (Elizabeth, 61, Heterosexual, White)

‘For me, understanding the problem and what was ocd vs "normal" thinking really helped me address the ocd aspects. Often I just wasn't aware.’ (Elena, 36, Bisexual, White)

Elizabeth and Elena both found that having an explanation for their intrusive thoughts allowed them to view things differently and to recognise the difference between OCD thoughts and ‘real’ thoughts.

Lastly, the women needed to know that they had permission to talk about sex in therapy and that it was also acceptable to do so:

‘It might be helpful if you are as open and understanding as possible about issues related to sex (don't shy away from these topics), and also, it would be helpful if you initiate conversations about sex. I say this because my current therapist *never* mentions the topic, and even when I have tried to broach the subject with her, she seems to shy away from it. (It has almost seemed like she didn't want to engage in discussion about the topic, so I just stopped talking about it.) It would be really helpful to me if my current therapist could be completely un-judgmental about topics related

to sex and not shy about it. (For all I know, she *might* be un-judgmental about sex-related topics, but because she has never expressed that, I just don't know if that is the case. So maybe it would be good if you told your patients -- and remind them every so often -- that anything sex-related is open for discussion and that nothing the patient says will disgust you or cause you to see them negatively.)' (Annie, 32, Heterosexual, Half-white/Half-Asian)

The theme of 'To Share or Not to Share?' has highlighted the need for therapists to utilise the core conditions of unconditional positive regard, empathy and congruence (Rogers, 1957), especially with those women for whom OCD impacts on their experiences of sex. Women faced a dilemma when accessing therapy as to whether to disclose the impact of OCD on their sex lives. This was because of a fear of being judged or fears that their intrusive thoughts would be treated as real and responded to accordingly (which some women experienced). It was important to the women that their therapists had training in specific models of therapy that were known to help within the OCD literature, such as ERP (Hansen, Kvale, Hagen, Havnen, & Öst, 2019). A strong message throughout the data was that women in therapy should be treated as individuals rather than receiving a 'one size fits all' approach.

Discussion

This research aimed to explore the 'lived' experiences of women with OCD in relation to sex and sexuality, particularly the strategies women used to manage their OCD thoughts and compulsions around sex and their experiences of seeking help. This chapter provides an overview of the main findings, a discussion around core issues within the data, such as sexual consent and women comparing their experiences of sex against (perceived) societal norms. The ethics of interviewing women with OCD are considered and the importance of having diverse sexualities within the sample discussed. The importance of leadership in counselling psychology around sex and sexuality will be addressed, recommendations for practice will be made, the study will be evaluated and areas for further research will be identified.

Overview of Main Findings

The study generated four overarching themes, which highlighted the distress OCD caused the women and the impact of OCD on their experiences of sex and sexuality. Throughout the study, women described feelings of shame, embarrassment, fear and isolation. Distress was caused through not being able to establish their 'true' sexual identity. This sits in stark contrast to the findings of research on women without OCD, which has found that women can experience sexuality as complex and fluid, and thus are able to tolerate uncertainty (Bellamy, Gott, Hinchliff, & Nicolson, 2011). Generally, the women did not share how OCD impacted their experiences of and feelings about sex with their therapist or sexual partners, which left them managing their intrusive thoughts and compulsions alone. Women predominantly managed their OCD through avoiding sex, which is a coping strategy more widely used by women to manage a range of sexual and related difficulties, such as sexual pain, body image and childhood sexual abuse (see Hinchliff, Gott, & Wylie, 2012; La Rocque & Cioe, 2011; Vaillancourt-Morel et al., 2015). The analysis showed that women's distress around sex and sexuality was complicated by dominant heteronormative discourses around 'normal' sex and gendered power dynamics in heterosexual sex (Frith & Kitzinger, 2001; Gagnon & Simon, 1973; Masters, Casey, Wells, & Morrison, 2013). This was highlighted through the women describing finding themselves in risky sexual situations and engaging in sex to meet their partner's needs. Lastly, women predominantly did not find therapy beneficial and some experienced judgmental and sexist advice from therapists.

The 'Messy' Nature of Sexual Consent and OCD

Consent was a consistent theme throughout the data, with some women engaging in PIV sex to please their partner, even when sex was painful, or intrusive thoughts caused a lack of pleasure. It has to be questioned whether women who put themselves in risky sexual situations to 'prove' their OCD wrong (for example, having sex to prove that they were attracted to men) or because they felt compelled to have sex because of intrusive thoughts (for instance, to stop something bad from happening) were actually fully and meaningfully consenting to sex, as it was not a choice born of sexual desire or interest but an act driven by a need to reduce anxiety.

The experience of OCD could result in the women having less control over the choices they made when engaging in sex. The philosophy literature has discussed the concept of control in OCD and whether compulsions are acted on from a place of agency or lack of freewill. Meynen (2012) and Stein (2012) both suggest OCD is an experience of lack of control, with the former author stating OCD "... is a lack of control disguised as an increase of control" (Meynen, 2012, p.329).

Szalai (2016) alternatively stated that people with OCD choose to act on their compulsions, but the author failed to address how anxiety might impact agency. When anxiety reaches a certain threshold, the person is no longer able to carry out the decision-making processes to choose not to engage in a compulsion (for a discussion of cognitive performance differences in those with OCD, see Ouimet, Ashbaugh, & Radomsky, 2019).

It is important to consider the agency of some women in the study when engaging in sex. Some women did not describe engaging in sex as a choice, because this was a compulsion driven by an intrusive thought. The women felt a responsibility to be certain about their sexual identity or to prevent a loved one from dying through having sex. Furthermore, it is important to consider how dominant discourses around sexuality and gender create pressure and expectations for these women (as they do for all women). It is debatable how much free choice women really have not to engage in sex with their (male) partner, when women (and men) have been taught that men have a right to sex. Fahs and McClelland (2016, p.399-400) considered this issue when they posed the question – how can women fully and freely consent to sex when women are socially conditioned "to please others, to prioritize others' emotional needs, and to engage in emotion work around sex" at the expense of their own needs, wants and desires?

OCD and Being 'Normal'

Women within the study were no different from women without OCD in that the patriarchal messages women received around sex were predominantly not acknowledged as contributing to their experiences of sex, and their sexual difficulties. Instead women in the study internalised their sexual difficulties, feeling they were 'lacking' as sexual partners or had to engage in sex to make sure their partners' sexual needs were fulfilled. Through using

a critical realist ontology, within the study, I was able to capture the women's material, embodied distress, but locate those experiences within a social context. Societal messages regarding gendered norms around sex, communicated through dominant discourses, had real consequences for the women in the study and contributed to their experiences of distress when trying to navigate sexual relationships.

Fahs (2011b) has discussed female desire as a commodity, by considering the lack of agency women have over their bodies and sex, as a result of being bombarded with messages from society about the ways they 'should' think, feel, and behave. An example of current societal norms around a particular sexual act would be those around the conceptualisation of anal sex. Pornography, and increasingly, wider culture, normalises anal sex as part of 'normal' heterosexual sex, and something men are entitled to (see Fahs & Gonzalez, 2014). Fahs (2011b, p. 180) described women's bodies as both a literal and metaphorical embodiment of the imbalance of power between men and women, especially in the way "women's sexuality is disciplined, constructed, controlled, and regulated." Therefore, women with OCD and mental health conditions could be thought of as 'soiled goods'; less valuable as a commodity compared with other women, and less wanted by others. Consequently, women with OCD may have a greater need to live up to expectations around sex within the wider society. The need to conform could be internalised as more important in order to draw attention away from thoughts and behaviours, and parts of the self, that are shameful and embarrassing. Fahs (2011b) suggested that women have to prioritise men's sexual desire over their own, which results in their own desires being 'othered' or unexplored. Related to this is the notion that for women wanting sex is less important than the 'performance' of wanting it (Fahs, 2011b).

Women blamed their sexual difficulties on their intrusive thoughts, which were considered by most women to be 'abnormal', further implying that part of them was not conforming to society's view of 'normal'. For some women in the study, diagnostic information was useful to provide a framework in which to understand their OCD and relief that they were not going 'crazy'.

The Ethics of Interviewing People With OCD

In her interview, Morgan (23, Heterosexual, White) commented that previously (before some degree of recovery) she would have been very triggered by the content of the interview, but I would not have known that and would have potentially caused her distress. This led to a great deal of reflection on my part regarding the ethics of interviewing participants with OCD. As a therapist, I would know about a client's coping strategies through obtaining the information during assessment. At the end of the interview with Morgan (23, Heterosexual, White), I wanted to ask what coping strategies she would utilise if she found her OCD had been triggered. However, I was stopped by the thought that I was not Morgan's therapist and therefore if she were to ask me what I would recommend, I would not have felt comfortable providing information without knowing more about Morgan and her experience of OCD, to ensure that the strategies I provided were appropriate. There is also the potential problem for those with OCD that any conversation can be triggering. It may be something said by the other person, or a memory returns from a previous obsession. The interview process itself may function as a compulsion for obtaining reassurance. Therefore, the question is raised how one best conducts ethical interviews with those experiencing OCD, because to the best of my knowledge, there is no research or guidance regarding this.

The interview with Morgan involved not one but two people with OCD, and I was aware of being anxious about conducting my first online interview and the potential for technical problems. Part of my own OCD manifests in perfectionism and some of my anxiety revolved around being the best interviewer I could be, rather than just 'good enough'. I also worried that I might be positioned as 'expert', but equally, my OCD would lead me to question 'what if I did not present as knowledgeable?' – would this make my research less legitimate? Particularly given that I identified as an 'insider-researcher' (see Kanuha 2000; Kitzinger & Wilkinson, 1997). On the other hand, what did it mean if I was positioned as 'expert', and the power imbalance with the participant meant there was the expectation for my participant to give the responses she thought I wanted?

Revealing myself as an 'insider-researcher' also felt different when interviewing than it did for the survey. The survey not only allowed anonymity for participants but also some degree

of anonymity for me. Interviewing virtually face-to-face made me feel vulnerable because I had revealed my 'mental health' status to a specific person. How would my OCD compare to the participant's OCD? This was something the participant asked about; did I experience the same things as she did? I had already self-disclosed as 'having' OCD, but how much did I want to disclose as a professional and where would that information go? The participant was not bound to keep what I said confidential (the same applies to a client in a therapy session), but on the other hand, it seemed problematic not to offer anything of myself and such withholding was not in the spirit of both qualitative and feminist research (Daly, 1992; Oakley, 1981; Reinharz, 1992). Therefore, I disclosed that I could relate to what the participant had said; this was also evident to her by my vigorous head nodding in response to some of her answers to my questions.

Dickson-Swift, James, Kippen and Liamputtong (2007) interviewed qualitative health researchers about their experiences of undertaking qualitative interviews, and a number of similar areas were commented on. The authors found that it was important for researchers to consider the impact of researching sensitive topics on both the participants and themselves, and to think about self-disclosure before interviewing. Milling-Kinard (1996) commented that there is not enough research into researchers' experiences of the research process, and this still appears to be the case.

When reflecting on the process of gathering data via the *FaceTime* interview, I reflected that there were many issues that could potentially raise ethical concerns when interviewing participants with OCD. The dual role of trainee counselling psychologist and researcher needs to be considered, because although the aim of both roles is to obtain information, it is for very different reasons. Therapy is for the benefit of the client and research is predominantly for the benefit of the researcher, although it is hoped that research is disseminated to facilitate change. Certain information should perhaps be gathered by researchers from participants with OCD to assess their suitability to participate before undertaking qualitative interviews. Gathering information prior to interviewing would help to answer questions such as: What are the expectations of the participant that has elected to be interviewed? How far along in their OCD journey are they in terms of how they manage their intrusive thoughts and compulsions and recognising these as such? Will the

person have a good understanding of how their OCD impacts them and what their triggers are? It is not always easy for those with OCD to know something as OCD when they experience it, which is reflected in the 'OCD as Fake News' theme and therefore, what are their motives for being interviewed? Does the participant want to seek reassurance? Even though it is not their overt intention to seek reassurance, could this inadvertently happen during the interview and would the interviewer be aware of this? If not, they would be contributing to exacerbating the participants' OCD.

The ethics around 'do no harm' are very important both as a therapist and psychological researcher (see Health and Care Professions Council, 2016; The British Psychological Society, 2017; The British Psychological Society, 2018). If a participant does try to obtain reassurance how is that going to be managed – is it agreed at the outset in the participant information form through a protocol? However, there is also the risk of adopting a paternalistic approach to participants. One of the BPS (2014, p.9) core ethical principles is respecting autonomy, which involves a reasonable balance “between protecting participants and recognising their agency and capacity.” Within the same document minimising the risks of research participation is also discussed, which is considered a priority, but also considered in relation to the benefits to society the research provides. It could be argued that if participants are made aware of the risks of being interviewed and because of the need for more research in the area of OCD to further help women with OCD, then the method of interviewing could be justified. However, the reason participants self-select for research may be to talk about their experiences because they do not have anybody else to talk to about them (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991). Therefore, the researcher needs to consider how to reduce the chances of triggering somebody's obsessions or compulsions during an interview. Lastly, the need to confess thoughts or compulsions is an element of OCD and it would be difficult for a researcher to ascertain whether this is the participants motivation for engaging in the research. Overall, more consideration needs to be given to make sure informed consent is obtained from participants with OCD to take into account the aforementioned issues.

Why a Sexually Diverse Participant Sample Was Important

It was critical that the study did not just focus on heterosexual women and therefore I posted widely on various *subreddits* aimed at the LGBTQ community. I was aware that the majority of quantitative sex research that included women (e.g. Abbey, Clopton, & Humphreys, 2007; Aksoy, Aksoy, Maner, Gokalp, & Yanik, 2012; Doron, Mizrahi, Szepeswol, & Derby, 2014; Fontenelle, et al., 2007; Ghassemzadeh et al., 2017; Kendurkar & Kaur, 2008) predominantly recruited heterosexual women and therefore there was a significant gap in the diversity of women's voices when it came to sexualities and sex research (Wolf, 2012). One of the participants, Cynthia R. (27, Bisexual, White), commented (in response to the question 'What advice would you give me, as a trainee counselling psychologist, to help me work more effectively with women whose OCD impacts on their experiences of sex and sexuality?'):

'Please don't focus just on straight women! Lesbian, bisexual, queer, and asexual women can and often do have OCD themed around sex and sexuality. LGBTQ people are still a uniquely vulnerable group, and we do not have enough well-informed therapists to turn to. The terminology and politics are changing all the time, but if a therapist has a core of compassion and understanding toward LGBTQ people and a willingness to learn more, that means a lot and can be very effective.'

It is important to note that thirty-one participants in the study were bisexual, and as Barker et al. (2012, p.3) have stated, "[b]isexual populations have significantly higher levels of distress and mental health difficulties than equivalent heterosexual or lesbian/gay populations," which includes "depression, anxiety, self-harm and suicidality" (p.4), both in the UK and internationally. Bisexuality has been described as "an 'invisible', 'excluded' or 'silent' sexuality within several domains including mainstream media, lesbian and gay communities, sex research, psychology and psychotherapy and policy and legislation" (Barker et al., 2012, p.4). The lack of bisexual visibility has been identified as a core barrier for bisexual people accessing support services (Barker et al., 2012). Negative judgments around bisexuality are still very much alive today (Burke & LaFrance, 2016; Dodge et al., 2016; Zivony & Saguy, 2018) and one of the participants in the study, Amanda (22, Bisexual, White), experienced her therapist assuming "... that I have a crush on everyone because I'm

bi...". Therefore, it seems extremely important that the needs of those who identify as bisexual are met in the therapy room. This is particularly so when women are experiencing OCD in relation to sex and/or their sexuality, as the invisibility of bisexuality could contribute to worsening mental health for women with OCD.

Lastly, when considering the sample as a whole, there were similarities in the impact of OCD on sex and sexuality regardless of the women's sexual identity, such as fears of contamination from sexual fluids, fears around actually being a different sexual orientation than the participant identified with (one participant identifying as asexual worried she was a lesbian), or avoiding sex and relationships as a coping strategy. Cultural norms around sex also impacted all women, for example, that there was a 'right' way to 'perform' sex. However, women who had sex with men described feeling obligated to have sex with their partner or implied that they should put their partner's sexual needs before their own. They also described more conflict in relationships around sex. These experiences were different from those of women in same-sex relationships who rarely experienced the same pressures and obligations to prioritise their partner's needs and engage in unwanted sexual activity.

Leadership in Counselling Psychology

Leadership is part of being a counselling psychologist. However, this topic is acknowledged as one that is scarcely explored in the counselling psychology research literature (Fassinger, Buki, & Shullman, 2017). Richards (2018) has discussed the role of leadership in counselling psychology in relation to sexuality and gender and argued that counselling psychologists should assist those who are marginalised through speaking up and creating space for those voices. I hope to foster this approach of leadership in the area of mental health, sex and sexuality, and support and encourage those with mental health conditions to speak about these issues. It is hoped that this thesis will help to educate counselling psychologists in the area of OCD, sex, sexuality and gender through drawing on feminist and critical sex research, so that, as Richards (2018, p.19) states, those attending therapy "should not be called upon to provide CPD for free, or even asked to pay for the privilege. The client is there to receive a service, not to provide one."

Although there is some discussion in the literature around physical health conditions and sex, this remains limited (see Barker & Iantaffi, 2015). There is an even greater lack of discussion around the experience of sex for those with a mental health condition.

Therefore, it is hoped that this research highlights the need for counselling psychologists and other therapists to talk to clients about sex and sexuality, to signal their comfort and willingness to talk about sexual matters, and to challenge normative and dominant discourses of sexuality that entrench clients' distress (Hare-Mustin, 1994).

Practice Implications and Recommendations for Therapists Working With Women, OCD, Sex and Sexuality

Within this section, I consider how therapists can improve their practice with clients, through being as educated as possible in the areas of sex, sexuality and OCD. I strongly encourage practitioners to engage in training to become more comfortable talking about sex with clients. I also ask practitioners to consider undertaking risk assessments for women engaging in sex as a compulsion.

Treating clients as individuals and with empathy

Women strongly expressed wanting their therapist to treat them as an individual rather than using a 'one size fits all' approach, especially because of the felt individuality of OCD experiences (see Hoffer, Knowles, Bower, Lovell, & Bee, 2016; Kohler, Coetzee, & Lochner, 2018; Lee & Rees, 2011). Neal-Barnett and Mendelson (2003, p.175) have stated that "each woman with OCD has her own "prescription" for her OCD, her own rules and rituals." Being treated as an individual in therapy has also been identified as important for other mental health conditions such as bipolar disorder (Joyce, Tai, Gebbia, & Mansell, 2017) and depression (Barnes et al., 2013). Of equal importance was to treat the women with empathy and make no judgement about their intrusive thoughts, compulsions or sexuality. Research by Steinberg and Wetterneck (2017) found that clinicians held stigmatising views of OCD, particularly of those with contamination, sexual and violent intrusive thoughts. However, the stigmatisation of OCD reduced with the amount of education and training the clinician received.

Vuong, Gellatly, Lovell and Bee (2016) have also explored the help-seeking experience of those with OCD in the United Kingdom using an online survey comprised of multiple-choice questions and some open-ended questions. The majority of participants were female and the mean age was thirty-three. Participants predominantly did not seek help due to shame and embarrassment and participants “repeatedly reported a lack of understanding by health professionals, particularly their GP, the public and family” (p.7). Interestingly, contamination concerns were not the primary issue, rather aggressive concerns (fear around harming the self or others) and sexual concerns were participant’s primary concern, which participants felt there was less information about generally. The authors considered whether the high number of participants with aggressive and sexual concerns was related to people with OCD becoming more confident to report them or a result of shifts in the wider cultural context and particularly social media campaigns that had raised awareness of sexual assault and harassment (e.g. #MeToo campaign and The Times’s Up Movement) (see also Friedrich, 2015).

Therapists’ educating themselves about different sexualities and including sexuality and sex in OCD assessments

It was important to the participants in this study that asexuality was not ‘medicalised’ and treated as a sexual problem to be solved or ‘cured’, because they did not feel there was something ‘wrong’ with them (although some wondered if asexuality was their authentic sexuality). Participants felt therapists should learn about different sexualities to reduce judgements and stereotypes about marginalised sexualities. Some women felt it was important for therapists to ask women with OCD if their sexuality or experience of sex was impacted during their assessment session, because otherwise, they may be unable to introduce these topics themselves because of feelings of shame, embarrassment or fear (something also advocated by Williams, Crozier, & Powers, 2011). One participant reported that therapists should normalise women’s experiences and feelings about sex, sexuality and OCD, through providing examples of other women experiencing similar difficulties, in order to reduce feelings of isolation.

Therapists' approach to dealing with sex

The impact of mental health on experiences of sex is something not generally discussed in wider society or even within the mental health profession and no doubt this silence contributed to some women not expressing their distress to others, including partners and therapists (Urry & Chur-Hansen, 2018). Therapists should make it clear they are open to talking about sex and sexuality, so clients know that discussion of this topic is permitted. However, research has found that therapists are reluctant to initiate or talk about sex in therapy sessions, which suggests that they are not comfortable with the topic and are therefore perhaps unable to help clients with sexual problems (see Cruz, Greenwald, & Sandil, 2017; Dermer & Bachenberg, 2015; Hill, 2013; Miller & Byers, 2009; Reissing & Giulio, 2010).

Research has consistently found that therapists do not receive enough training around sex in order to confidently and competently work with clients (see Mollen, Burnes Lee, & Abbott, 2018). Furthermore, in a story completion study by Shah-Beckley, Clarke and Thomas (2018) it was found that when both therapists and non-therapists completed a story around either a male or female character suggesting 'trying something new' to their sexual partner, therapists were just as likely to draw on heteronormative discourses as non-therapists. The authors concluded that therapists lacked a critical perspective on sex, which contributed to their predominantly heteronormative way of making sense of sex and thus perpetuated gendered power dynamics.

Therapists' need for training and professional development around OCD, and sex and sexuality

Participants felt it was imperative for therapists to be educated in types of therapy recommended for OCD (e.g. CBT, ERP). Some women had experienced well-meaning therapists who exacerbated their intrusive thoughts and compulsions by engaging with the intrusive thoughts through offering reassurance or a place to ruminate to get to the 'root cause' of the intrusive thoughts. Importantly, as already stated, therapists should develop their knowledge of feminist and critical approaches to sex and sexuality to challenge unhelpful and dangerous stereotypes that further contribute to women's distress (books such as Fahs, 2011a and Tiefer, 2004 are a good place to start). For example, heterosexual

women need to know there is not one way of 'doing' sex, such as PIV1, and there may be other activities that they enjoy. They also need to know that not everybody is having more frequent, spontaneous and enjoyable sex than they are (Barker, Gill, & Harvey, 2018; Fahs, 2011a; Fahs & Plante, 2017; Hills, 2015; Kaschak & Tiefer, 2001; Perel, 2007). Feminist therapy advocates for an equal relationship between client and therapist and "that each participant is an expert, bringing particular sets of skills and knowledge to the collaboration, with no one set more highly valued than another," and crucially, that the therapist continuously aims to empower the client (Brown, 2009, p. 38). Given the gendered power dynamics that women experience in their sexual relationships, it is important for women to experience an equal relationship in the therapy room, as this could provide role modelling that could be applied to other areas of the women's lives. Also, therapists should provide psycho-education around sex where appropriate, so that women have a better understanding of their sexual desires and preferences.

I hope to develop a workshop for therapists drawing on my findings in order to disseminate the results and inform practice. Through providing education to therapists it could help to reduce the stigma of talking about sex in the therapy room, reduce the potential for making heteronormative assumptions, and increase clinicians' confidence in asking clients questions about sex.

Therapeutic modalities

A relational and integrative approach to helping women with OCD, sex and sexuality issues may be useful, to provide a safe base for facilitating the disclosure of intrusive thoughts and compulsions. The aforementioned approach would combine the core conditions (Rogers, 1957), emotional regulation techniques such as grounding in DBT (Linehan, 2015), mindfulness and CBT techniques (Hershfield, 2019; Hershfield & Corboy, 2017).

OCD is about narrative and language, the stories we tell ourselves, which can be scary and frightening for people with OCD because of the content of intrusive thoughts. However, women need a therapist willing to go on a narrative journey with them, so they can re-narrate their lives without feeling 'bullied' by OCD. Hopefully at the end of therapy, women will have a new narrative they can draw upon to form a more coherent identity.

Assessing risk

Lastly, therapists should be aware that some women with OCD may place themselves in risky sexual situations and should enquire as to whether they ever engage in sex as a compulsion to obtain reassurance. Sexual compulsions may be part of 'relationship-OCD' and testing out whether they really find their partner attractive, or 'sexual-orientation OCD', where women want certainty that they really are straight, gay or bisexual. Helping women to develop alternative ways of managing these types of compulsions should be developed between therapist and client.

Evaluation of The Research

The use of online qualitative surveys to gather data is still in its infancy and is yet to be more widely adopted. However, to conduct explorative research, it was a highly effective technique for obtaining an extensive data set from across the world (views were not limited to one area of the country or even one country) (Braun & Clarke, 2013). However, it should be noted that the data set was predominantly obtained from the US and the UK and therefore the results reflected Western ideas around sex, sexuality and gender. Differences have been acknowledged between people who do and do not volunteer for sex research (Boynton, 2003; Opperman, Braun, Clarke, & Rogers, 2014; Saunders, Fisher, Hewitt, & Clayton, 1985), which may impact the conclusions that can be drawn from the sample. A study by Wiederman (1999) explored differences between people who agreed or declined to participate in three different types of sex research: an anonymous questionnaire study, a one-to-one interview study and a laboratory study that involved watching videos of explicit sexual content. It was found more women than men would participate in the one-to-one interview and more men than women would watch the sexually explicit video. Furthermore, it was more likely that participants would undertake the questionnaire than the other two studies. Overall, "volunteers were more likely to have had sexual intercourse, have performed oral sex, have greater tendencies toward self-monitoring and interpersonal exploitation, indicate greater sexual esteem and sexual sensations seeking, and report less traditional sexual attitudes" (p. 63). These differences were the same across genders. The implications being that participants in my study may be more likely to engage in sex and to discuss their sexual experiences with others than women who chose not to volunteer.

However, it is hoped that the use of an online survey encouraged more women to participate than would have been the case if I had used face-to-face interviews.

The study was only advertised across social media, which meant the sample was predominantly middle class, as not everybody has access to a computer or mobile device or has the skills to use them (Braun & Clarke, 2013). In a recent survey, it was found that 57.3% of households across the globe had access to the internet (Internet World Stats, 2019), which meant there is a large portion of the population who were excluded from the study. Most participants (77.61%) were white women, and on reflection, I should have made the study more accessible to women of other races and ethnicities. I could have done this by stating my race/ethnicity in the participant information sheet and by spending more time building a relationship with moderators on *Reddit* who managed *subreddits* focussing on race and ethnicity and the concerns of people of colour. The majority of participants were recruited from the social media platform *Reddit*. A study by Barthel, Stocking, Holcomb and Mitchell (2016) reported that 63% of the US population on *Reddit* were white. There is no equivalent data regarding race and ethnicity for *Reddit* users in the UK (Sattelberg, 2019). In not stating my whiteness on the participant information form I implicitly communicated my whiteness to participants of colour. This may have contributed to reticence about completing the survey for some because of a concern about how I would represent their experiences.

It is important to acknowledge that many women were excluded from the current study through the inclusion criteria. The inclusion criteria required that women either had a diagnosis of OCD or had accessed or were accessing therapy for OCD. Many women across the globe do not have access to therapy, whether due to issues of cost, limited access to a health care system or because of patriarchal systems, which deny them access to medical practitioners or psychologists (Williams, Chapman, Simms & Tellawi, 2017).

Mona Eltahawy (2015) discusses the extent to which the patriarchy governs women in the Middle East and North Africa under the guise of religion. The consequence has been physical and sexual violence against women and control over their lives (e.g. sexuality, access to education and employment). Due to the high level of sexual violence towards

women, completing research about OCD sex and sexuality, would not be just about mental health, but also potentially trauma. It may be that women not participating in research of this kind are exercising self-care, as taking part could be re-traumatising (see Ellard-Gray, Jeffrey, Choubak & Crann, 2015). Some participants took part in the study whose OCD had been triggered or exacerbated by traumatic events.

Importantly, some women would not have had access to computers to complete the survey, especially in more rural areas of the world or women in abusive relationships. It might be risky for women to engage in research if partners were to find out about their participation (see Ellard-Gray, Jeffrey, Choubak & Crann, 2015).

My experience of living as a white woman within the West, and the biomedical model being the dominant model, provides me with a lens through which I experience my OCD and view others' experiences. Consequently, the way I analysed the data was also embedded in these experiences and views. The impact was that other stories of OCD were missed or misinterpreted, or women did not provide their accounts at all because they may not consider their experiences as OCD in the first instance. Although OCD presents across ethnicities, it is essential to acknowledge that culture impacts on the way OCD manifests (Nedeljkovic, Moulding, Foroughi, Kyrios & Doron, 2012; Williams, Chapman, Simms & Tellawi, 2017), and that experiences of racism impact on OCD severity (Williams et al., 2017). Furthermore, Nedeljkovic, Moulding, Foroughi, Kyrios and Doron (2012) have commented on the need for culturally and linguistically appropriate assessment measures for OCD, because the measures have been developed predominantly in the US and UK. The authors reference a Puerto Rican study, which found that the lifetime prevalence rate for OCD was 3%, but reduced to 1.1% when a measure was adapted to account for both cultural and linguistic factors (Canino et al., 1987).

The impact of language should not be underestimated as the current study was written in English and would have excluded a number of women across the globe. Overall, there is a bias for research to be written in English and therefore excluding a large number of people from the majority of research projects (Nielsen, Haun, Kärtner & Legare, 2017; Rad, Martingano & Ginges, 2018).

Older people (Gott & Hinchliff, 2003, used the term 'older' adult to refer to participants between the ages of 50-92) are an often neglected cohort in sex research (Hinchliff & Gott, 2004; Lyons et al., 2017). Through using an online tool to gather my data, I will have missed out on other stories around sex, sexuality and OCD in this population that do not access the internet or use computers. It is useful to consider the data from the Office for National Statistics (2019), which considers internet use in the UK, to put into perspective the digital exclusion, more specifically, of older women. More than half of people who had never accessed the internet were seventy-five years old or older. Forty-one per cent of women aged seventy-five and over were not recent internet users, compared to fifty-four per cent of men the same age. Overall, the proportion of women (8.7%), having never used the internet was higher than that of men (6.3%). I am thus highlighting how older women in this age group are disproportionately absent from the online world compared to men and speaks to the wider inequality of opportunities between genders. However, there has been an increase in internet use in ages sixty-five to seventy-four when comparing statistics from 2011 (52%) to 2019 (83%). Also, of note is that within the age group of sixty-five to seventy-four, more men (84%) than women (82%) had accessed the internet recently.

It is also important to note that there was also a lower proportion of disabled, recent internet users (78%) compared to people without a disability (95%). People in the survey self-identified as having a disability. The survey results do not distinguish between the number of users for gender and then again for age. Still, it is conceivable that a higher number of women identifying as disabled and over the age of seventy-five would be non-internet users.

Face-to-face interviews may have made the study more accessible for older women who wanted to take part but did not want to use the internet to do so. Interviews would also have been a more appropriate method of gathering data from women who experienced difficulties with literacy. I could also have advertised the study in other locations, as I did this solely through the internet, but instead through organisations that target an older population (e.g. Age UK, Age International) (see Lyons et al., 2017). In other studies which focussed on sex and were inclusive of older women, participants have been sought from psychosexual clinics and general practice surgeries (Bellamy, Gott, Hinchliff & Nicolson,

2011; Gott & Hinchliff, 2003; Hinchliff & Gott, 2004). Therefore, in limiting my participant pool of women, I also limited the stories that could be shared about experiencing OCD.

Another important element about the design of the demographic questions centred on the wording of a question about sex/gender. One participant commented:

‘In my experience, most trans women do not like to be referred to as "transwomen" or set aside from cis (not trans) women as if they were a separate gender. If I had designed this survey, I would have asked participants if they were cis(gender) or trans(gender).’ (Cynthia R., 27, Bisexual, White)

Although it was stated in the participant information sheet that the survey was open to women of all sexualities and trans or cisgender/non-trans women, the tick box options of either woman or trans woman to describe gender may have felt ‘othering’ for those women who identified as trans. There was also a question from a person on *Reddit* who saw the study advertised about the exclusion of trans men and whether sex and gender had been confused, because of the inclusion of trans women who are biologically male. These comments highlight the tensions around terminology and the difficulties of not alienating some potential participants with the terminology chosen (e.g. the term ‘cisgender’ has become increasingly contentious with some non-trans women rejecting it as a label to describe themselves for various reasons) (Mackay, 2015). On reflection, a more inclusive and somewhat less contentious option would have been an open-ended question inviting women to identify their ‘sex/gender’. I argue it is important that counselling psychologists adopt an inclusive approach in their research and think carefully about the terminology they use.

Due to the sensitive nature of the study topic, it may have been difficult to recruit participants for face-to-face interviews and the amount of specific detail about sex provided by participants may have been limited in an interview study. Comparing the interview and the survey responses (as previously noted, I only conducted one interview at a participant’s request), more detail was obtained from the surveys regarding the specific details of sex and intrusive thoughts. During the interview, it was difficult to ascertain where the ‘line was

drawn' between being curious from a research perspective and asking for too much personal information and making the participant uncomfortable. Although the participant could have refused to respond to a question or easily leave the interview because it was online, a power imbalance existed between researcher and participant. The participant may have felt obliged to answer questions and give more information than they wanted to, which then complicates the issue of whether the participant is giving their full consent. There were times when I wanted to ask for more detail regarding the mentioned sexual experiences, but I was conscious of not pushing too much as the participant did become teary at one point during the interview.

It should be acknowledged that I invited women in the study to actively reflect on how they felt their sexual experiences were different from women without OCD. In the study, this was found to be a cause of distress. However, the flexibility of the survey meant that participants could refuse to answer questions, or if distress had been caused, contact details were provided for services that offered support. Again, this reflects BPS (2014) principles around participant autonomy. It felt important to ask the question because no other known research has considered the impact of societal norms around sex for women with OCD.

Overall, the women who completed the survey were generous in the amount of information they provided, and some women gave very detailed responses. It should be acknowledged that compared to interviews, surveys do not have the flexibility to request further information or for responses to be clarified (Braun & Clarke, 2013). However, an online survey had the significant benefit of a high level of (felt) anonymity; this was something the women commented on as being important:

'I have a recurring intrusive, anxiety-producing thought about seducing (as an adult) or being sexually abused (as a child) by my father. It is hard to even put into words because the stigma and shame are so overwhelming, but I realise most of the time when this thought occurs that it is an OCD symptom and can manage it as such. Still, this is a thought that I have not shared with my therapist, partner, or even acknowledged myself much of the time.' (Isabel, 27, Heterosexual, White and White-Jewish)

'[...] And, unless they pressured me, I probably wouldn't admit how completely non-existent my sex life is to someone in a non-anonymous setting [...]' (Daisy, 31, Asexual...Pansexual?, White)

Furthermore, some commented that the act of writing or participating in the research itself felt therapeutic (see also Dickson-Swift, James, Kippen, & Liamputtong, 2007):

'I have found writing out my experiences knowing they will be read by somebody who has a passion and understanding of OCD especially in this domain very therapeutic and I'm so pleased that this area of OCD is being looked into more. I think a lot of people can feel isolated and alone in their experiences.' (Bella, 25, Bisexual, White British)

Some women also thanked me for carrying out the research and commented on the subject area being under-researched:

'Really pleased to see some research being done on such an untalked about topic. A great deal of people do not understand the amount of facets of someone's life that is affected by OCD. As I always say it's not all hand washing and lined up tins in cupboards, it's so much more than that.' (Meghan, 40, Gay, White)

'Just to urge you to go as far as you can in this, if you want to. Both OCD and sexual issues are neglected areas [...]' (Anon, 28, Straight, White)

Anon (28, Straight, White) also thanked me for asking the following question: 'What advice would you give me, as a trainee counselling psychologist, to help me work more effectively with women whose OCD impacts on their experiences of sex and sexuality?' The question led Anon to express the following:

'Thank you for asking this question! I would advise you to learn as much as you can about religion and the shame that is involved in some interpretations of religion. Also

to be aware that people with OCD can take relatively subtle messages and take them totally on board - there was not a lot of overt anti-sex messaging at the churches I went to, but being in that culture was enough for me to develop huge issues around it. And be aware that OCD often begins early, so people may have trouble identifying what healthy sexuality is because it has always been through the lens of OCD.'

This question was necessary to ask for a number of reasons. First, I wanted to make clear that I was not positioning myself as the 'expert' on the topic area. Second, the 'non-expert' stance fits with the values and principles of both counselling psychology and qualitative research (Braun & Clarke, 2013), and last, I believe therapy is not something 'done' to a client but a collaborative process between therapist and client.

Recommendations for Further Research

Because this is the first qualitative study of women with OCD and their experiences of sex and sexuality, it has identified many areas that warrant further exploration. A number of women reported obsessing about becoming pregnant, and therefore they experienced compulsions around contraceptives (e.g. using multiple methods of contraception such as condoms and the pill). This raises the question of whether OCD impacts women's reproductive decision-making, and to the best of my knowledge there is no research on this.

A crucial issue raised by Morgan (23, Heterosexual, White) in her interview revolved around her fear of visiting her gynaecologist in case she perceived genital sexual sensations during examinations. Therefore, it is important to explore whether women with OCD do not attend routine medical appointments such as smears and breast screenings because of fears and anxiety around OCD (for example, 'am I sexually attracted to the female doctor, but I'm heterosexual, what does that mean?'). Because there is no research in this area, women's experiences of screening should be ascertained. It needs to be established how OCD impacts on women's experiences of screening and willingness to participate, and for the results of this research to be considered in screening campaigns.

The average age of onset of OCD for the women in this study was 10.43 years, which means that many girls go through puberty with OCD and it is important to consider how that

impacts on their developing sexuality and early sexual experiences. de la Cruz et al. (2013) also found, in questionnaire research on the outcomes of therapy for children with OCD, that children aged eight to seventeen experience sexual obsessions. Further research is needed to explore the experiences of young girls with OCD, with results informing sex education in schools and other settings. One participant commented they had noticed an increase in online forums of people with OCD considering whether they identified as transgender. As OCD attaches to contemporary social concerns (Friedrich, 2015; Vuong, Gellatly, Lovell, & Bee, 2016), further research is needed to explore experiences of gender identity related obsessions and compulsions, with the ultimate aim of informing therapeutic interventions for those experiencing intrusive thoughts and compulsions around gender identity.

OCD experiences could be considered an embodied problem of language; intrusive thoughts are analysed and ruminated about through language, which then trigger compulsions. The body then becomes the means through which OCD can be acted out and is used as a litmus test of whether things are 'okay' or not, through a feeling of things being 'just right.' However, there are no objective tests of certainty for concepts such as sex, sexuality and gender. The body seems to be an important element missing from the research on OCD to date; it is a vessel which people experiencing OCD try to protect the boundaries of (for instance, through keeping clean), or they inadvertently push the boundaries by trying to challenge it (having sex to 'prove' their sexuality). Through cleanliness obsessions, people with OCD attempt to make the body and or mind 'pure' and will go to great lengths to do this, even crossing the line into self-harm, for example, through lengthy anal cleansing procedures. Harm becomes directed at the body/mind but not at other people, and this is something future research should explore further.

CBT is the recommended treatment for OCD; however, there is very little research exploring other types of therapy (see Dembo, 2014; Murphy & Perera-Delcourt, 2014). A (28, Pansexual, White) stated that CBT exacerbated her OCD because the focus was on her thoughts, which she already obsessed about. Future research needs to examine integrative therapy for women with OCD, such as combining techniques from DBT, CBT and knowledge around attachment (Bowlby, 1988; Cozolino, 2016; Wallin, 2007), and the core conditions of

person-centred therapy (Rogers, 1957). This would help meet women's need for individualised therapy and provide them with a safe and accepting space to discuss their experiences of sex and sexuality. This would allow them to form a coherent sense of identity, which can become fragmented with OCD (Bhattacharya & Singh, 2015; Pedley, Bee, Wearden, & Berry, 2019).

Lastly, there needs to be more research into how ethical ERP can be carried out with women experiencing intrusive thoughts around paedophilia ('P-OCD') and incest so as not to cause further distress. ERP involves the person with OCD using a variety of "therapeutic techniques aimed at teaching an individual to approach, rather than avoid, fear-producing stimuli (exposure)" without engaging in compulsions to neutralise the anxiety ("response prevention") (Himle & Franklin, 2009, p.29). It should be questioned whether ERP exercises, such as writing imaginal exposure scripts about becoming a paedophile, would be reasonably expected to be undertaken by people without OCD (see Bruce, Ching, & Williams, 2018). Given what is known about OCD, avoidance of the feared thought or situation perpetuates anxiety and exacerbates the OCD. There are clear lines to be drawn when challenging OCD in the realm of sex because it would be unethical to do things such as encourage engaging in anal sex to challenge OCD intrusive thoughts around contamination.

Please refer to Appendix O for post data analysis reflexivity. As previously noted, this information is presented in an appendix because of its sensitive and deeply personal content and the requirement to deposit theses in UWE's open access research repository.

Conclusion

To summarise, the women in this study felt a deep sense of shame around intrusive sexual thoughts and compulsions, which resulted in feelings of isolation as they avoided sex and, in some cases, partner relationships, and did not share their experiences with their partners or therapists. Compulsions resulted in women putting themselves into risky situations, which could result in sexual assault, and a lack of certainty around sexuality caused a great deal of distress. Lastly, women strongly expressed a need for acceptance rather than judgement from therapists, as they were already highly judgmental about themselves. Ultimately women needed compassion from therapists for the never-ending inner turmoil they

experienced, which was something they felt they could not obtain from society or from ill-informed and insensitive therapists.

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Appendices

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Appendix A – List of qualitative survey questions

- 1.) Please tell me about any ways in which (if any) having OCD has impacted on how you think and feel about sex.
- 2.) Please tell me how (if at all) having OCD has impacted on how you feel about yourself as a sexual person.
- 3.) Please tell me about how any obsessions and/or compulsions impact on your sexual experiences.
- 4.) Please tell how you think your experience of sex compares to someone who doesn't have OCD (I'm interested in things like frequency of sex, using sex toys, contraception for birth control and /or STI protection).
- 5.) If you developed OCD symptoms early in life, please tell me about any impact (if any) this had on your developing sexuality and early sexual experiences.
- 6.) Please tell me about any impact (if any) OCD has had on your sexual partners and/or relationships.
- 7.) Please can you tell me about any impact (if any) OCD has had on your thoughts/feelings about your sexuality (sexual orientation/preference).
- 8.) Please tell me about any experiences of seeking help for OCD and sexual issues. This could be formal (therapy) or informal (chat rooms/forums).
- 9.) What advice would you give me, as a trainee counselling psychologist, to help me work more effectively with women whose OCD impacts on their experiences of sex and sexuality?
- 10.) Is there anything else that you would like to add about your experience of sex and sexuality? Anything not covered by your answers to the previous questions?



**The experience of sex and sexuality for women with Obsessive Compulsive Disorder (OCD)
Participant Information Sheet**

You are being invited to take part in a research study. Before you decide to take part it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully and discuss it with others if you wish. If anything is not clear or you would like more information, please contact me (my email address is below). Thank you for taking the time to read this.

Who are the researchers?

My name is Elicia Boulton and I am completing a Professional Doctorate in Counselling Psychology in the Department of Health and Social Sciences at the University of the West of England, Bristol. I am undertaking this research for the research thesis that forms part of my doctoral training. My research is supervised by Dr Victoria Clarke, an Associate Professor in Qualitative and Critical Psychology in the Department of Health and Social Sciences, and Liz Maliphant, a Senior Lecturer in Counselling Psychology in the same department.

What is the research about?

Research exploring people's experiences of living with OCD, and especially research focused on women, is very limited. Nonetheless, there is some indication that women with OCD can experience difficulties with sex and sexuality. The aim of this project is to listen to women's voices and understand their experiences of sex and sexuality when they have been diagnosed with and/or undergone therapy for Obsessive Compulsive Disorder (OCD). The project will explore how women deal with any sexual difficulties when having OCD, the impact OCD has on their sexual partners and relationships, and how therapy has helped or not helped with their sexual difficulties. The research has the potential to help therapists understand how to work with women who develop sexual difficulties related to OCD. I also have a personal interest in this study, as I am also a woman with OCD.

What does participation involve?

You are invited to participate in a qualitative interview – a qualitative interview is a 'conversation with a purpose'; you will be asked to answer questions in your own words. The questions will ask you to elaborate on the responses you gave in the qualitative survey you have already completed. The interview will take place via telephone or *Skype*, depending on your preference, and audio recorded. 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 this to me. 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?

You are eligible to participate if you:

- Are female
- Aged 18 or over
- Have either been diagnosed with OCD or received therapy/treatment for it

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.

The personal information collected in this research project (e.g., the interview audio recording and transcript, and the demographic form) will be processed by the University in accordance with the terms and conditions of the 1998 Data Protection Act. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. Your personal information will be used/processed as described on this participant information sheet.

What are the benefits of taking part?

You would be helping to provide information about an area we do not know much about. You would be helping to develop a better picture of how women experience sex and sexuality when they have OCD. The information you provide could be used to help therapists to develop their knowledge of how to work more effectively with women with OCD in relation to sexual matters. You would be helping other women with OCD to appreciate that women with OCD have sexual problems and they are not alone.

How do I withdraw from the research?

If you decide you want to withdraw from the research please contact me via email [Elicia2.Boulton@live.uwe.ac.uk]. 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 information about some of the different resources which are available to you.

UK:

Ocdaction is a national charity providing education and support around OCD:

<http://www.ocdaction.org.uk> You can phone their helpline (0845 390 6232) or email them: support@ocdaction.org.uk

OCD UK (<http://www.ocduk.org/adviceline>) offers OCD specific support via their telephone advice line (usually open Monday to Friday from 9am to 5pm subject to volunteer availability, on 0845 120 3778). You can also email them using the following address: support@ocduk.org

The **British Psychological Society** can help you to find an accredited psychologist located in your area: <http://www.bps.org.uk/bpslegacy/dcp>.

The **British Association for Counselling & Psychotherapy** (<http://www.bacp.co.uk/>) It's Good to Talk website enables you to search for an accredited counsellor or psychotherapist in your area: <http://www.itsgoodtotalk.org.uk/>

The **Samaritans** (<http://www.samaritans.org>) are open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and/or self-harm. Contact them via telephone on: 116 123.

SANE (<http://www.sane.org.uk/home>) offers an out-of-hours helpline for emotional support and information from 4.30pm-10.30pm, 365 days a year. Their national number is 0300 304 7000.

MIND (<http://www.mind.org.uk>) are situated throughout the UK and their services include talking therapies and you can contact them on: 0300 123 3393.

Pink Therapy provides an online directory of therapists who work with gender and sexually diverse clients across the LGBTIQ spectrum from a non-judgmental standpoint: <http://pinktherapy.mobi/>

You can also contact your **GP** for a referral to NHS provided therapy.

United States:

The website of the **American Psychological Association** enables you to search for an accredited psychologist in your area: <http://www.apa.org/topics/therapy/>

The website of the **American Counseling Association** enables you to search for an accredited counselor in your area: <https://www.counseling.org/>

The **Samaritans** (<http://www.samaritansusa.org/index.php>) are open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and/or self-harm. Contact them via telephone on: 1 (800) 273-TALK.

Australia:

The **Australian Psychological Society (APS)** provides a database to help you find a psychologist in your area to suit your needs. They provide an online search, a telephone service and an email referral service to the general public who are seeking the advice and assistance of a qualified and suitable APS psychologist in private practice. Their website can be accessed at: <http://www.believeinchange.com/Home/Become-the-Change/Find-A-Psychologist>

The website of **beyondblue** provides support with mental health issues and can be accessed at: <https://www.beyondblue.org.au/get-support/national-help-lines-and-websites>

- 24/7 call line 1300 22 4636
- Online chat from 3.00pm-12am 7 days per week
- Email and receive a response within 24 hours
- Online forums can be accessed 24/7

The **SANE** help centre is a registered charity, which provides information and guidance regarding referrals needed to manage mental health concerns. Their help page, containing various ways of getting in touch, can be found at: <https://www.sane.org/get-help>

- Helpline with access to a mental health professional (Weekdays 9am-5pm, AEST)
- Online chat helpline (9am-5pm)
- Email via helpline@sane.org
- Online forums for information and support (anonymous and moderated 24/7)

Lifeline is a national charity, which provides Australians experiencing personal crisis with 24-hour access to crisis support (Tel: 13 11 14) and suicide prevention services. Their website can be accessed at: <https://www.lifeline.org.au>

Suicide Call Back Service offers free counselling seven days per week across Australia and has the option to phone them 24/7 (Tel: 1300 659 467), chat online or video chat. Their web address is: <https://www.suicidecallbackservice.org.au>

The **Samaritans** offer non-judgemental support for anybody in emotional distress and is available 24/7: 135 247

Canada:

The **Canadian Psychological Association (CPA)** provides information about services who can provide psychological support: <http://www.cpa.ca/public/findingapsychologist/>

The **Canadian Mental Health Association (CMHA)** is a charity, which has branches across Canada providing services and support to people who are experiencing mental illness and their families. These services are tailored to the needs and resources of the communities where they are based: <http://www.cmha.ca>

The **Canada Counseling Directory** helps people to find therapists and counsellors in your area: <http://www.goodtherapy.org/therapists/canada>

Revivre is an organisation that provides information about anxiety and mood disorders. They can be contacted Monday to Friday (9.00am-5.00pm) on 1 866 REVIVRE (738-4873). Their website is www.revivre.org/en/

New Zealand:

Anxiety New Zealand Trust is a charity that offers support with anxiety. They can be contacted 24/7 on: 0800 269 4389 and their website is <http://www.anxiety.org.nz>

Depression.org offer support with anxiety and depression and offer a free 24/7 helpline (0800 111 757) and can be texted (4202). Their website is: <https://depression.org.nz>

Healthpages is a leading online reference resource for all New Zealanders. The site features a comprehensive directory of health and well-being services: <https://healthpages.co.nz/mental-health-neurology-3/>

PsychDirect helps people to find a psychologist and who are registered with the New Zealand Psychologists Board, have a current Annual Practising Certificate and are members of the New Zealand Psychological Society (NZPS): <http://www.psychology.org.nz/community-resources/find-a-psychologist/#cid=884&did=1>

Supporting Families NZ has a network of branches throughout the country that provide information, education, support and training to the families and people experiencing mental illness: <http://www.supportingfamilies.org.nz/resources/mental-health-info/counselling-and-helplines.aspx> They can also be contacted by phone 06 343 9535 or 021 744 106 or email sfnatcouncil@gmail.com

The **Mental Health Foundation** provides information to help you to make your own choice about mental health support. They suggest seeing your GP in the first instance and to call the national free Healthline service on 0800 611 116: <https://www.mentalhealth.org.nz/get-help/in-crisis/find-a-gp-or-counsellor/>

The **Samaritans** offer confidential and non-judgemental support for anybody in emotional distress: 0800 726 666

If you have any questions about this research please contact my research supervisor: Dr Victoria Clarke, to express your concerns:
Address: Department of Health and Social Sciences (Psychology), Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY.
Email address: Victoria.Clarke@uwe.ac.uk
Telephone: 0117 32 82176

This research has been approved by the UWE Health and Applied Sciences Faculty Research Ethics Committee (FREC)

Appendix C – Online interview consent form



The experience of sex and sexuality for women with Obsessive Compulsive Disorder (OCD)

Consent Form

I have read and understood the project information sheet and have been given the opportunity to ask questions about the project. I agree to take part in the project and I understand that taking part will include the following: completing a telephone or *Skype* interview that will be audio recorded, that I can stop the interview at anytime with no consequences, my taking part is voluntary, I can withdraw from the study after completing the interview (within a month of the data of the interview is recommended) and I do not have to give any reasons for why I no longer want to take part. I also understand my personal details will not be revealed to people outside the project and that my words may be quoted in publications, conference presentations and other research outputs.

If my words are quoted in the project or other research outputs I would prefer to be referred to as [] for the purposes of the research.

Signature

Date

Researcher signature

Date

Appendix D – Transcription notation for the interview

Identity of the speaker	Morgan: Interviewer:
Laughing	((general laughter)) ((laughs))
Pausing	((pause))
Overlapping speech	[] which signalled that I was talking when the interviewee was talking or vice versa (e.g. Morgan: ah ha and there and it's just crazy because it's weird to me still that there's no certainty in life I just don't understand that [yeah yeah yeah – both laugh] oh I don't get that but I'm trying to think of like what else do you have any other questions?). ((overlap)) when it could not be discerned what was being said due to talking at the same time
Inaudible speech	((inaudible))
Non-verbal utterances	erm, er
Punctuation	This was used when it was clear the interviewee was asking me a direct question.
Reported speech	('')
Accents and abbreviations /vernacular usage /mispronunciation	cuz, kinda, wanna

Identifying information

The interviewee used identifying information about another person and this was changed (e.g. "... one of my friends at school has OCD (name) from Organ State had OCD...").

Appendix E - List of *subreddit* sites the study was advertised on

r/AllWomen

r/Anxiety

r/asexuality

r/bisexual

r/bdsm

r/BDSMcommunity

r/demisexuality

r/diagnosed

r/lgbt

r/lgbtsex

r/mentalhealth

r/Mommit

r/OCD

r/pansexual

r/queer

r/ROCD

r/sex

r/sexover30

r/TwoXChromosomes

r/vaginismus



The experience of sex and sexuality for women who have Obsessive Compulsive Disorder (OCD)

You are being invited to take part in a research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. If anything is not clear or you would like more information, please contact me (my email address is below). Thank you for taking the time to read this.

Who are the researchers?

My name is Elicia Boulton and I am completing a Professional Doctorate in counselling psychology in the Department of Health and Social Sciences at the University of the West of England, Bristol. I am undertaking this research for the research thesis that forms part of my doctoral training. My research is supervised by Dr Victoria Clarke, an Associate Professor in Qualitative and Critical Psychology in the Department of Health and Social Sciences and Liz Maliphant, a Senior Lecturer in counselling psychology in the same department.

What is the research about? Research exploring people's experiences of living with OCD, and especially research focused on women, is very limited. Nonetheless, there is some indication that women with OCD can experience difficulties with sex and sexuality. The aim of this project is to listen to women's voices and understand their experiences of sex and sexuality when they have been diagnosed with an /or undergone therapy for Obsessive Compulsive Disorder (OCD). The project will explore how women deal with any sexual difficulties when having OCD, the impact OCD has on their sexual partners and relationships, and how therapy has helped or not helped with their sexual difficulties. The research has the potential to help therapists understand how to work with women who develop sexual difficulties related to OCD. I also have a personal interest in this study, as I am also a woman with OCD.

Who can participate?

You are eligible to participate if you:

Are female;

Aged 18 or over; Have either been diagnosed with OCD an /or received therapy/treatment for it.

I hope to gather the views of up to one hundred women with OCD. The survey is open to women of all sexualities (women who identify as heterosexual/straight, queer, lesbian, gay or bisexual) and trans or cisgender women.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be

asked to answer a consent question. If you decide to take part you are still free to withdraw at any time during completion of the study and without giving a reason. A decision not to take part will not have any consequences for you. Also, if you submit your responses and decide you want to withdraw from the study you have one month from the date of submission of your survey to request this, by contacting the researcher and providing your participant code. Your data will then not be used and will be destroyed.

What does taking part involve?

Taking part in the study involves completing an online qualitative survey. The survey has some click box/short answer questions to help me understand something about the range of people taking part in the study (e.g. how old people are etc.) and then 10 main questions. These main questions require you to write in your own words about your experiences of sex and sexuality in relation to having OCD. You can write as much or as little as you like in response to each question, but **detailed responses are really useful for my research.**

There is no fixed length of time for completing the survey, it will depend on how detailed your responses are, but **expect to spend around 30 minutes completing the survey.**

What are the possible disadvantages and risks of taking part?

The study could cause anxiety due to thinking about possible difficulties in your life because of OCD. It may involve realising OCD has more of an impact on your life than you initially thought and this could cause distress (e.g. wanting things to be different, disappointment about how OCD has impacted your life and your view on whether it is being managed or not).

You may feel embarrassment about disclosing more information than you thought you would on reflection after completing the survey. If you do feel like this then please contact me within a month of submitting your responses, and you can request that certain information is not used in the research. You could instead provide an alternative response, which you are more comfortable with. If you'd like to do this, please contact me via email, however if you provide an email address containing your name this will reduce your anonymity.

What are the possible benefits of taking part?

The benefits of taking part include: -

- You would be helping to provide information about an area we do not know much about.
- You would be helping to develop a better picture of how women experience sex and sexuality when they have OCD.
- The information you provide could be used to help therapists to develop their knowledge of how to work more effectively with women with OCD in relation to sexual matters.
- You would be helping other women with OCD to appreciate that women with OCD have sexual problems and they are not alone.

What if something goes wrong?

If something goes wrong, such as you would like to make a complaint, then you would be invited to contact my supervisor, Dr Victoria Clarke, to express your concerns: -

Address: Department of Health and Social Sciences (Psychology), Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY.

Email address: Victoria.Clarke@uwe.ac.uk

Telephone: 0117 32 82176

Will my taking part in this study be kept confidential?

The personal information collected in this research project (i.e. the interviews and the demographic data) will be processed by the University in accordance with the terms and conditions of the 1998 Data Protection Act. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. Your personal information will be used/processed as described on this participant information sheet (see below).

When completing the online survey you will not be asked for your name, instead you'll be asked to create a unique and easy to remember participant code. At the end of the survey, there will be a question asking you to indicate whether you would be willing to participate in an online discussion group. If you are willing, you'll be asked to provide your email address so I can get in touch with you to arrange this. You'll also be asked if you would like to receive a short summary of the research findings, again you'll be asked to provide an email address if you would like to receive this information. It is important to point out that if you provide an email address that contains your name, I will know that someone with your name has participated in the study. But your email address will be stored separately from your response.

You'll also be asked to provide some information about your age, ethnicity, relationship status etc. but this won't identify you. Qualtrics guarantee that the data will be kept private and confidential. If you include any identifying information in your responses to the survey this will be removed or changed, so you can't be identified if I quote from your responses in my thesis, or in any publications or presentations reporting the findings of the research. You can opt to have your real name used or have it changed for the purposes of the research to something of your choosing.

The survey will be anonymous but the IP address could be traced, however I would not do this and more to the point I do not know how! The surveys will be downloaded from the Qualtrics online server onto my individual computer and then deleted from the Qualtrics Server. The surveys will be stored in a password-protected file.

What will happen to the results of the research study?

I will download the survey responses onto my computer. The questions about participants' age, ethnicity etc. will be compiled into a table and included in my thesis and in any publications and presentations reporting the results of the research. The responses to the main survey questions will be analysed for my research. Extracts from your responses may

be quoted in my thesis, and in any publications and presentations reporting the results of the research.

Contact for Further Information

If you would like more information then please contact me using the following email address:

Elicia2.Boulton@live.uwe.ac.uk

Alternatively, you can contact my supervisor (who oversees my research) using the contact details listed above.

Many thanks for taking the time to read this form and thank you in advance if you decide to take part in the study!

Appendix G – Survey OCD support information for different countries

Thank you!

Please click on >> to submit your responses.

If you feel you need further information or support the following can be accessed:

UK:

Ocdaction is a national charity providing education and support around OCD:

<http://www.ocdaction.org.uk>

You can phone their helpline (0845 390 6232) or email them: support@ocdaction.org.uk

OCD UK (<http://www.ocduk.org/adviceline>) offers OCD specific support via their telephone advice line (usually open Monday to Friday from 9am to 5pm subject to volunteer availability, on 0845 120 3778). You can also email them using the following address: support@ocduk.org

The **British Psychological Society** can help you to find an accredited psychologist located in your area: <http://www.bps.org.uk/bpslegacy/dcp>.

The **British Association for Counselling & Psychotherapy** (<http://www.bacp.co.uk/>) It's Good to Talk website enables you to search for an accredited counsellor or psychotherapist in your area: <http://www.itsgoodtotalk.org.uk/>

The **Samaritans** (<http://www.samaritans.org>) are open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and/or self-harm. Contact them via telephone on: 116 123.

SANE (<http://www.sane.org.uk/home>) offers an out-of-hours helpline for emotional support and information from 4.30pm-10.30pm, 365 days a year. Their national number is 0300 304 7000.

MIND (<http://www.mind.org.uk>) are situated throughout the UK and their services include talking therapies and you can contact them on: 0300 123 3393 or text 86463.

Pink Therapy provides an online directory of therapists who work with gender and sexually diverse clients across the LGBTIQ spectrum from a non-judgmental standpoint: <http://pinktherapy.mobi/>

You can also contact your **GP** for a referral to NHS provided therapy.

United States:

The website of the **American Psychological Association** enables you to search for an accredited psychologist in your area: <http://www.apa.org/topics/therapy/>

The website of the **American Psychotherapy Association** enables you to search for an accredited therapist in your area: <http://www.americanpsychotherapy.com/>

The website of the **American Counseling Association** enables you to search for an accredited counselor in your area: <https://www.counseling.org/>

The **Samaritans** (<http://www.samaritansusa.org/index.php>) are open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and/or self-harm. Contact them via telephone on: 1 (800) 273-TALK.

Australia:

The **Australian Psychological Society (APS)** provides a database to help you find a psychologist in your area to suit your needs. They provide an online search, a telephone service and an email referral service to the general public who are seeking the advice and assistance of a qualified and suitable APS psychologist in private practice. Their website can be accessed at: <http://www.believeinchange.com/Home/Become-the-Change/Find-A-Psychologist>

The website of **beyondblue** provides support with mental health issues and can be accessed at: <https://www.beyondblue.org.au/get-support/national-help-lines-and-websites>

- 24/7 call line 1300 22 4636
- Online chat from 3.00pm-12am 7 days per week
- Email and receive a response within 24 hours
- Online forums can be accessed 24/7
- The **SANE** help centre is a registered charity, which provides information and guidance regarding referrals needed to manage mental health concerns. Their help page, containing various ways of getting in touch, can be found at: <https://www.sane.org/get-help>
- Helpline (1800 18 7263) with access to a mental health professional (Weekdays 9am-5pm, AEST)
- Online chat helpline (Weekdays 9am-5pm)
- Email via helpline@sane.org
- Online forums for information and support (anonymous and moderated 24/7)

Lifeline is a national charity, which provides Australians experiencing personal crisis with 24 hour access to crisis support (Tel: 13 11 14) and suicide prevention services. They also offer a nightly online chat helpline, seven days per week. Their website can be accessed at: <https://www.lifeline.org.au>

Suicide Call Back Service offers free counselling seven days per week across Australia and has the option to phone them 24/7 (Tel: 1300 659 467), chat online or video chat. Their web address is: <https://www.suicidecallbackservice.org.au>

The **Samaritans** offer non-judgemental support for anybody in emotional distress and is available 24/7: 135 247

Canada:

The **Canadian Psychological Association** (CPA) provides information about services who can provide psychological support: <http://www.cpa.ca/public/findingapsychologist/>

The **Canadian Mental Health Association** (CMHA) is a charity, which has branches across Canada providing services and support to people who are experiencing mental illness and their families. These services are tailored to the needs and resources of the communities where they are based: <http://www.cmha.ca>

The **Canada Counseling Directory** helps people to find therapists and counsellors in your area: <http://www.goodtherapy.org/therapists/canada>

Revivre is an organisation that provides information about anxiety and mood disorders. They can be contacted Monday to Friday (9.00am-5.00pm) on 1 866 REVIVRE (738-4873). Their website is www.revivre.org/en/

New Zealand:

Anxiety New Zealand Trust is a charity that offers support with anxiety. They can be contacted 24/7 on: 0800 269 4389 and their website is <http://www.anxiety.org.nz>

Depression.org offer support with anxiety and depression and offer a free 24/7 helpline (0800 111 757) and can be texted (4202). Their website is: <https://depression.org.nz>

Healthpages is a leading online reference resource for all New Zealanders. The site features a comprehensive directory of health and well-being services: <https://healthpages.co.nz/mental-health-neurology-3/>

PsychDirect helps people to find a psychologist and who are registered with the New Zealand Psychologists Board, have a current Annual Practising Certificate and are members of the New Zealand Psychological Society (NZPS): <http://www.psychology.org.nz/community-resources/find-a-psychologist/#cid=884&did=1>

Supporting Families NZ has a network of branches throughout the country that provide information, education, support and training to the families and people experiencing mental illness: <http://www.supportingfamilies.org.nz/resources/mental-health-info/counselling-and-helplines.aspx> They can also be contacted by phone 06 343 9535 or 021 744 106 or email sfnatcouncil@gmail.com

The **Mental Health Foundation** provides information to help you to make your own choice about mental health support. They suggest seeing your GP in the first instance and to call the national free Healthline service on 0800 611 116: <https://www.mentalhealth.org.nz/get-help/in-crisis/find-a-gp-or-counsellor/>

The **Samaritans** offer confidential and non-judgemental support for anybody in emotional distress: 0800 726 666

Appendix H – Further demographic information

Age		Range	Mean
		18-61	26.13
		Number	Percent
Race/Ethnicity	Arab	1	0.75
	Arab, Mixed	1	0.75
	Biracial, Mexican & Caucasian	1	0.75
	Black	1	0.75
	Black British	1	0.75
	Greek-Jewish-American	1	0.75
	Half White, Half Asian	1	0.75
	Hispanic Mixed	1	0.75
	Indian American	1	0.75
	Mixed White Chinese (British)	1	0.75
	Mixed, White & Black Caribbean	1	0.75
	Mixed (White & Hispanic)	1	0.75
	Native American	1	0.75
	NZ Euro	1	0.75
	Puerto Rican	1	0.75
	Scottish	1	0.75
	Welsh Roma	1	0.75
	White, White British	104	77.61
	White Irish	1	0.75
	White Jewish	3	2.24
White Australian	1	0.75	

	White & Canadian Aboriginal	1	0.75
	White European	1	0.75
	White German	1	0.75
	White Hispanic	1	0.75
	White & Indigenous American	1	0.75
	White, MÃ©tis, Croatian	1	0.75
	White, Middle Eastern	1	0.75
	White other	1	0.75
Country	Australia	1	0.75
	Brazil	1	0.75
	Canada	17	12.69
	France	1	0.75
	Germany	3	2.24
	New Zealand	1	0.75
	Norway	3	2.24
	Not Stated	1	0.75
	UK	31	23.13
	US	75	55.97
Relationship Status	Relationship	86	64.18
	Single	47	35.07
	Not Stated	1	0.75
Social Class	Middle	85	63.43
	Working	24	17.91
	Lower	1	0.75
	Professional	9	6.72
	Military	1	0.75
	White Collar	1	0.75

	Blue Collar	1	0.75
	Not Stated	12	8.96
Work Status	Full Time	66	49.25
	Part Time	34	25.37
	Unemployed	34	25.37
Disabled	Yes	26	19.40
	No	107	79.85
	Not Stated	1	0.75
OCD Considered a Disability or Part of Disability	Yes	15	62.50

Appendix I - Participant sexuality labels

Sexuality Label	Total Number	Percentage of Participants
Bisexual	31	23.13%
Heterosexual	31	23.13%
Straight	30	22.39%
Queer	6	4.48%
Pansexual	6	4.48%
Lesbian	4	2.99%
Bisexual/Pansexual	3	2.24%
Asexual	3	2.24%
Unsure	2	1.49%
Gay	2	1.49%
Normal	2	1.49%
Bisexual/Grey Ace	1	0.75%
Heteromantic/Bisexual	1	0.75%
Relaxed	1	0.75%
Heteroflexible	1	0.75%
Very Heterosexual	1	0.75%
Lesbian/Queer Woman	1	0.75%
Bisexual/Kinky	1	0.75%
Mostly Straight	1	0.75%
Sexual	1	0.75%
Demi	1	0.75%
Asexual/Pansexual	1	0.75%
Ok	1	0.75%
Homosexual	1	0.75%
Open	1	0.75%

Appendix J - Table of sexuality definitions

Asexual	“A sexual orientation generally characterized by not feeling sexual attraction or a desire for partnered sexuality. Asexuality is distinct from celibacy, which is the deliberate abstention from sexual activity. Some asexual people do have sex. There are many diverse ways of being asexual” (LGBTQIA, 2019, para. 11).
Bisexual	“Bi is an umbrella term used to describe a romantic and/or sexual orientation towards more than one gender” (Stonewall, 2017, para. 4).
Demi-sexual	“Someone who can only experience sexual attraction or desire after an emotional bond has been formed (or the adjective describing a person as such). This is different from the choice to abstain from sex until certain criteria are met” (The Asexual Visibility & Education Network, n.d., para. 5).
Gay	“A sexual and affectional orientation toward people of the same gender” (LGBTQIA, 2019, para. 35).
Grey Ace	<p>“Gray-asexual (gray-a) or gray-sexual: Someone who identifies with the area between asexuality and sexuality (or the adjective describing a person as such). For example, they may experience sexual attraction very rarely, only under specific circumstances, or of an intensity so low that is ignorable and not a necessity in relationships. (Note: the spelling of gray/grey may vary by country)” (The Asexual Visibility & Education Network, n.d., para. 6).</p> <p>Ace “An informal label for asexuals or people under the asexual umbrella” (The Asexual Visibility & Education Network, n.d., para. 17).</p>
Heteroflexible	“Individuals who are primarily attracted to people of a different sex and who typically identify as heterosexual, but who may engage in same-sex sexual activity in certain situations. As it is defined by the Urban Dictionary, “I’m straight but shit happens” (Beemyn & Martin, 2016, p. 8).
Heteroromantic	“Individuals who are romantically, but not necessarily sexually, attracted to people of a gender different from themselves” (Beemyn & Martin, 2016, p. 8).
Heterosexual	“Refers to a man who has an emotional, romantic and/or sexual orientation towards women or to a woman who has an emotional, romantic and/or sexual orientation towards men” (Stonewall, 2017, para. 21).

Homosexual	“This might be considered a more medical term used to describe someone who has an emotional romantic and/or sexual orientation towards someone of the same gender. The term ‘gay’ is now more generally used” (Stonewall, 2017, para. 22).
Kinky	“General term for BDSM, fetish or non- ‘vanilla’ sexual behaviour or people engaging in this” (Richards & Barker, 2013, p.226).
Lesbian	“Refers to a woman who has a romantic and/or sexual orientation towards women” (Stonewall, 2017, para. 28).
Mostly Straight	Mostly heterosexual has been described as a type of “enhanced” heterosexual “... in that they add a touch of homosexuality without losing or decreasing their heterosexuality ... mostly heterosexuals call into question the traditional three-group system of assessing sexual orientation” (Savin-Williams & Vrangalova, 2013, p.85).
Pansexual	“Refers to a person whose romantic and/or sexual attraction towards others is not limited by sex or gender” (Stonewall, 2017, para. 33).
Queer	“[I]n the past a derogatory term for LGBT individuals. The term has now been reclaimed by LGBT young people in particular who don’t identify with traditional categories around gender identity and sexual orientation but is still viewed to be derogatory by some” (Stonewall, 2016, para. 29).
Straight	“Being sexually attracted to people in a different gender than oneself” (Richards & Barker, 2013, p.231).

Appendix K - List of medications women used to manage their OCD

Abilify - Antipsychotic

Acamprosate - Used in alcohol addiction

Acetylcysteine (NAC) - Used to treat paracetamol overdoses and cystic fibrosis

Adderall - Stimulant

Alprazolam (Xanax) - Benzodiazepine class

Ambien - Sleep medication

Belsomra - Sleep medication

Bupropion (Wellbutrin, Zyban) - SSRI - Antidepressant

Buspar - Anxiolytic drug

Carbamazepine - Anticonvulsant

Citalopram (Celexa) - SSRI - Antidepressant

Clomipramine - TCA - Antidepressant

Clonidine - To treat high blood pressure

Cymbalta - Antidepressant

Depakote - Mood stabiliser

Desvenlafaxine (Pristiq) (SNRI) - Antidepressant

Diazepam (Valium) - Benzodiazepine class

Escitalopram (Cipralex, Lexapro) - SSRI - Antidepressant

Fluoxetine (Prozac, Oxactin) - SSRI - Antidepressant

Fluvoxamine (Luvox) - SSRI - Antidepressant

Gabapentin - Painkiller

Hormonal birth control

Hydroxyzine – Antihistamine

Klonopin (Clonazepam) - Benzodiazepine class

Lamictal - Anticonvulsant

Lamotrigine - Anticonvulsant

Lipitor - Statin

Lithium - Mood stabiliser

Lorazepam (Ativan) - Benzodiazepine class

Medical Marijuana

Mirtazapine (Remeron) - Antidepressant
Nortriptyline - TCA - Antidepressant
Olanzapine (Zyprexa) - Antipsychotic
Oxcarbazepine - Anticonvulsant
Paroxetine (Paxil, Paxil CR) - SSRI - Antidepressant
Pregabalin – Stops the brain releasing anxiety chemicals
Propranolol - Beta blocker
Propranolol (Slow release) - Beta blocker
Quetiapine (Seroquel) - Antipsychotic
Rexulti - Antipsychotic
Risperdal - Antipsychotic
Risperidone - Antipsychotic
Sertraline (Zoloft) - SRI – Antidepressant
Sobril - Benzodiazepine class
Suboxone - Opioid
Topiramate - Anticonvulsant
Trazodone - Antidepressant
Velija – Balances serotonin and norepinephrine levels
Venlafaxine (Effexor, Effexor XR) SNRI - Antidepressant
Viibryd - SSRI - Antidepressant
Vortioxetine (Trintellix) - Antidepressant
Vyvance – Stimulant
Ziprasidone - Antipsychotic
Zopiclone - Cyclopyrrolone (Treatment for insomnia)

Appendix L - Example of raw data and the process of data analysis

Stage 1: Familiarisation with data

Participant Identifier	Participant Data	Initial Thoughts and Ideas
Maria (22, Bisexual, White)	OCD made me feeling incredibly guilty about sex in the past. I still struggle in overcoming this shame, though I have made great strides. I used to feel scared to touch my vulva because I perceived it as dirty.	Disconnected from parts of the body (object relations theory). Genitals as dirty and 'other'.
Isabel (27, Heterosexual, White/White-Jewish)	Besides the AIDS concerns (which, in the grand scheme, felt minor and even rational), I was obsessed with the idea that I could be a lesbian when I was about 10. I did not have any negative connotations of gay or lesbian people, and I felt bad about my obsession because I knew it was ok to be gay, but I spent a summer picturing naked women and examining my thoughts trying to determine what my sexuality was, and it caused a lot of anxiety and exhaustion.	There must be a 'truth'. Thoughts must mean something. Punishing self? Guilt Physical impact of OCD stress.
Brianna (21, Bisexual, White)	Everyone gets mad at me because my OCD wont even let me kiss a person let alone sleep with them.	Others get mad due to their needs not met – something about body as property – expectations.
Annie (32, Heterosexual, Half White/Half Asian)	Things have only gotten worse now that I have this cheating obsession. I constantly think (and see "evidence") that he has cheated or will cheat, so I constantly ask him for reassurance... and that compulsion, too, is causing problems.	OCD = being trapped OCD takes on a life of its own and shape shifts into different obsessions. OCD is never satisfied and is insatiable.
Lily (28, Straight, White)	Oops, I already talked a bit about this earlier! I'll restate quickly, though: OCD has caused me to go through periods of extreme anxiety about my sexual orientation, and it's also caused me to be much less comfortable with	OCD can dis-integrate sexual identity even when it is established. 'It' (being OCD) takes something fundamental to a

	aspects of my sexuality (fantasies, tastes, etc.) that I'd previously seen as totally integrated into my identity as a straight woman.	person and begins to dismantle it and take it apart until it becomes something 'other' or unknown to the person.
Rae (20, Straight, White)	As my adult experience with OCD has been about fearing that inappropriate photos will be uploaded to social media, I often feel quite scared about being naked, especially around technology.	OCD can latch onto bit themes within an era (e.g. health, morality, religion). Perhaps we are moving into an era of OCD focussing around technology.

After reading the data set and making initial notes next to the data set, I then made copious notes regarding thoughts about the data, some examples are provided below:

Need confirmation about relationships (certainty)
Less sex
Easier to be single
Avoid relationships
Trying to share OCD and its impact on the person in the relationship
Need to give self permission to be in a relationship
Relationships are scary
OCD is a burden to partner
OCD as a secret
Spontaneity out the window
Needed a lot of reassurance in relationship before knowing about OCD
Impact of not knowing what OCD is
Knowing that ignoring the thoughts of OCD is an option feels very IMPORTANT
Sex/intimacy expected in relationships!
Poses question of how mental health issues are negotiated in relationships
People don't know how to handle mental health
Exposure work not working – when women force themselves to do things they don't want to do sexually – issues around OCD and consent to sex
Understanding partner = more sex
Sex not as satisfying with OCD
Partner feels rejected
Women have a right to their body
Boundaries of space
Society views/stereotypes can cause sexual 'dysfunction' between couples
Get it over with approach
Huge impact on relationship
Strain on relationship
Whether to disclose OCD thoughts or not about sex
Isolated due to anxiety
Partners turned off by unease of women
OCD as a secret

OCD identified by therapist
 More OCD awareness needed
 Only have one-night stands
 Partner feeling rejected
 OCD has the potential to end relationships
 Comfortable after OCD routine
 OCD changes the way sex is done/negotiated
 The unspoken messages picked up about sexuality and gender as a child
 OCD stops exploration of self as a sexual person
 Afraid of sex
 Sex organs – medical/ ‘other’
 Regret not exploring when younger
 Lack of information around female masturbation when growing up
 What is normal/appropriate for females?
 Intoxication to have sex
 Sex can feel comfortable with the right partner
 Not thinking but feeling
 Communication

Stage 2: Generating codes across the entire data set

Participant Identifier	Participant Data with codes in brackets (e.g. N, A, B)	Codes and explanation of codes, with thoughts and ideas
Cathy (31, Heterosexual, White other)	I have put off being intimate with partners in the past <u>because I've felt uncomfortable about the current state of my body hair.</u> (N) <u>I've turned down sexual advances for this reason.</u> (A) Similarly <u>I've felt frustrated when I've spent hours plucking out hair</u> (B) and then there's been no sexual encounter, as I know that if we put it off until the following day or later that week, I know I probably won't feel comfortable unless I've had a chance to go through the entire routine again.	N ('What is normal sex?') Body hair and societal values and judgements. A ('Need to Avoid Getting Down') Cathy avoids sex if she is not comfortable with her body hair. B ('OCD is a Real Bastard') As a consequence of OCD Cathy has the compulsion to pluck out her hair which feels punitive.

Appendix M – Visual mapping of themes



The themes in the visual map are in the following order from left to right: ‘OCD as Fake News’, ‘OCD is a Real Bastard’, ‘OCD as Sex Killjoy’, ‘What is ‘Normal’ Sex?’ and ‘To Share or Not to Share?’. However, the candidate theme ‘OCD is a real bastard’ was later collapsed into a sub-theme under the candidate theme ‘OCD as Fake News’.

The following quotes are those used within each theme of the visual map and are taken from the survey and single interview.

OCD as Fake News

Participant Identifier	Quote
Morgan (23, Heterosexual, White) (Interview)	<p>Morgan: Which will be very exciting because I have not had any like sexual experiences, I say sober sexual experiences</p> <p>Interviewer: Right yeah</p> <p>Morgan: Because I’m too scared because then I could find out that I don’t like it and then I could find out that I’m lesbian or something to that extent which obviously is very</p>

	<p>OCD and very not logical I realise that now but (laughs) erm but you know when I'm in the moment I don't really realise it</p> <p>Interviewer: Yeah, yeah and I think yeah getting kinda caught up in it in that</p> <p>Morgan: Mmm</p> <p>Interviewer: Kinda like you say the compulsion and the intrusive thought and</p>
Jane (18, Bisexual, White)	I put myself in sexual situations with people much older than me at young ages, because my intrusive thoughts would be of them hurting or rewarding me if I had sex with them. My intrusive thoughts also told me that I was made for sex and nothing more. I have compulsively had sexual contact with people who I did not want to have sexual contact with.
Annabelle (38, Bisexual, White)	When I was young I used to have to make sure none of my male stuffed toys or dolls could see me masturbate, if they "saw" me I could somehow get pregnant.
Isabel (27, Heterosexual, White and White-Jewish)	I have worried that if I don't have sex with my partner right before he leaves for a few days or more, that it will put him in danger or that he will forget me. I worry that if I don't have sex with my partner enough, I am a bad person. This makes it difficult for me to distinguish when I actually want to have sex versus when I feel like I should want to.
Mira (22, Heterosexual, Arab/Mixed)	I overthink everything. My sexual obsessions led me to be sexually assaulted while on a date with a man (who I only dated because my obsession had me feeling that I was attracted to women and I was trying to see if my attraction to men was real). I thought my gut feelings about him being too controlling and weirding me were OCD thoughts. Basically, I couldn't trust anything I felt because the fake thoughts were mixing with the real ones.
Morgan (23, Heterosexual, White) (Interview)	Erm yeah and I have a really hard time deciphering between OCD and anxiety [yeah] it's still really hard for me to tell because I think a majority of my days are spent are OCD but I also don't know the difference so erm but it's very hard to be in the moment erm I've been trying to do that though I've definitely been trying to do erm be I try to stick my hand outside of the window sometimes and feel the fresh

	<p>air on it (laughs) on my hand or I'll do the five or I'll do the five senses erm I will do some deep breathing app I have a deep breathing app on my phone that I use sometimes erm or sometimes (inaudible) I just sit in hell and rot because I don't know how to get out of it (laughs) [yeah yeah yeah] yeah [yeah] but, any other questions?</p>
C (29, Hetero, White Irish)	<p>Yes, ocd sense of not sure I'm straight. Asking lesbian friends to bring me out to hook up with someone. Intrusive homo thoughts. Feeling the pressure of having to go to a lesbian sex party in a mansion in London to find out if i am (compulsion then ruminating about it). I know it's ridiculous and entertaining.</p>
Morgan (23, Heterosexual, White) (Interview)	<p>And it's it's hard to because it's always in the back of your mind [yeah mm] it's always in the back of your mind and then sometimes I'll even now I'll even with other OCD themes that I obsess over I will kind of have an internal battle is this my OCD or is this my real thought [yeah yeah] so even you know and someone's sexuality first of all that's a very important thing (laughs) to someone erm and so the little thoughts you have you really latch on to because they're really important to you so you know am I attracted to his abs oh my God I didn't get attracted to his abs all of these other girls are saying that he has a really hot body but I don't think he does should I think he does [yeah yeah] what if I don't think he does that mean that I'm yeah</p>
Emma (19, Bisexual, White)	<p>There have been several occasions where I have had intrusive thoughts about not being "bisexual enough" and overcompensated by going on dozens of dates with people of all genders just so I could feel like I was "really" bisexual</p>
Samantha (29, Pansexual, Native American)	<p>I certainly believe that it is a dialogue that should be opened between a psychologist and their patient, probably during initial screenings and meetings. There is a potential for self destructive behavior in women with OCD that relates to sex that should be spoken about along with career and other general life topics.</p>
Charlotte (32, Bisexual, White)	<p>I would sometimes get into an awful state of mind where I was compelled to have sex with my partner because it was my way of checking if our relationship was okay. If the partner I was with didn't want to have sex, I would have a meltdown because I wasn't capable of believing that we were going to be fine without "checking". I would feel like a</p>

	<p>monster for days for feeling like I couldn't take "no" for an answer, which made me worry I was a rapist.</p>
<p>Charlotte (32, Bisexual, White)</p>	<p>I struggled from my early teens till my early 20s with my sexuality-- was I gay or straight? Did it mean anything that I just checked that girl out like that? What did it mean that I checked her out when I enjoyed sex with him last night? I felt like I didn't know if I was really straight or just being straight because it was the societal norm, because I was aware that I was attracted to women.</p> <p>I eventually came to terms with my bisexuality. I slept with a couple of women in my 20s, but only ever ended up in relationships with men. I probably would have slept with a lot more women-- even dated some-- in my teens and early 20s if I hadn't been afraid of what it would mean about me.</p>
<p>Courtnee (30, Straight, White)</p>	<p>And then there was my whole rape thing when I was around 16/17 where I was terrified that if I was alone with a guy he would try to rape me. So I could not be alone in a room with any male.</p>
<p>EB (18, Homosexual, White)</p>	<p>It caused me to have a lot of doubts over my sexuality. Whether or not it was my OCD talking or whether it was genuinely my preference. It was very confusing. I am also probably very far behind with regards to sexual experiences compared to most people my age and that may have something to do with OCD. Although I'm not entirely sure.</p>
<p>Jennifer (35, Bisexual, White)</p>	<p>I am not actually sure other than I didn't have sex until age 25 but am not sure how the OCD directly led to that. I do know that I spent a lot of time questioning sexual orientation and now identify as bisexual but that was also significantly impacted by OCD because instead of just accepting that, I was quite tortured by needing certainty and a concrete answer about sexual orientation and always was so concerned about being "wrong" or leading someone on if I didn't know 100% what my orientation was.</p>
<p>Morgan (23, Heterosexual, White) (Survey)</p>	<p>I am not actually sure other than I didn't have sex until age 25 but am not sure how the OCD directly led to that. I do know that I spent a lot of time questioning sexual orientation and now identify as bisexual but that was also significantly impacted by OCD because instead of just accepting that, I was quite tortured by needing certainty and a concrete answer about sexual orientation and always</p>

	was so concerned about being "wrong" or leading someone on if I didn't know 100% what my orientation was.
Helen (22, Bisexual/ Pansexual, White British)	I thought I was asexual for a year. I thought I was broken. I also thought I was a trans man for a year too. All OCD.
Jennifer (35, Bisexual, White)	I identify as bisexual and am 35 and only talked about it in therapy for the first time at 32 and am still not out at all about same sex attraction. I am scared to date women because I am scared that I am "wrong" and would be leading them on if I somehow decided I was actually straight. I am super supportive of the LGBT community and accepting of anyone else's choices but the lack of certainty associated with OCD has not allowed me to be ok with my own sexuality.
Isabel (26, Heterosexual, White British)	I have no problems with lesbianism but I do not identify as one so when I have intrusive thoughts about having sex with women it is extremely distressing and I question my sexuality, wondering if I would prefer to be a woman and not with my male long term partner so I just don't want to be a sexual person at all.
Isabel (26, Heterosexual, White British)	OCD has convinced me that my boyfriend does not love me and that's the reason why he hasn't proposed yet. It has caused lots of distress and upset because of this and also made me question whether I love him or whether I would be happier on my own. I spend so much time thinking about it and trying to find evidence to show that I do love him or that he loves me. OCD is trying to convince me I am a lesbian - which would be fine if it were true - but I just doubt myself so much and cannot trust how I feel because I don't know what's true.
Morgan (23, Heterosexual, White) (Survey)	Oh my god I really can't even begin to explain... as I am filling out this survey, in the back of my mind I am wondering if I truly am straight or if one day I will find out I am lesbian or asexual (or some other sexual orientation) and I even am wondering if I have OCD... those are just intrusive thoughts and I have learned to let them go, but that is just a brief synopsis of how much it really has impacted me. Before treatment, I spent 3-4 hours some day researching my sexuality. I once had to leave a guys house because we were cuddling and I was shaking so intensely (I blamed this on being cold, but I have come to learn that I was so incredibly anxious and that was my body's response

	to the anxiety) There were multiple times where I would go to the bathroom after a drunken sexual experience and it felt like my body was almost convulsing because I was shaking so bad with anxiety. I thought this meant I was asexual or not attracted to men when in reality I was just so incredibly anxious around males (due to my OCD that I mentioned in previous answers)
Morgan (23, Heterosexual, White) (Interview)	Morgan: Like you don't know or even the questions am I lesbian that's a real question that somebody wants to know about themselves so it's not like oh did I just run over that speed bump and kill someone it's like a real identity question you know or am I getting married that's a real question too and you wanna know the answer to it so it's really hard to know like is this something that I should spend my time focussing on or is this something I should just let go, it's hard.
Samantha (29, Pansexual, Native American)	I developed OCD prior to my loss of virginity. I read a quote in a book that made me feel that I needed to lose my virginity as soon as possible or I wouldn't achieve the goals I wanted to (goals unrelated to sex or romance or relationships)
Isabel (27, Heterosexual, White and White-Jewish)	I have a recurring intrusive, anxiety-producing thought about seducing (as an adult) or being sexually abused (as a child) by my father. It is hard to even put into words because the stigma and shame is so overwhelming, but I realize most of the time when this thought occurs that it is an OCD symptom and can manage it as such. Still, this is a thought that I have not shared with my therapist, partner, or even acknowledged myself much of the time.
Morgan (23, Heterosexual, White) (Interview)	Morgan: Yeah cuz you're in the moment like right now when I'm not triggered I'm fine and I can say that all of that's irrational and I know that it's irrational but when I'm in the moment and I'm triggered and I have that thought it just feels so real and so I think just working through those triggers while I'm in that moment is something that will be really beneficial from treatment but I don't know do you have any questions for me?
Leyla (30, Bisexual, Greek-Jewish-American)	verbalizing your obsessions is so hard. It makes them "real" and it's always terrifying that you'll be told your fears are well-founded and that you're right to be afraid. In the first few sessions with my therapist I could not bring myself to

	say my real obsessions. I think that many therapists don't realize how frightening it is to share this.
Janet (18, Bisexual, White)	I have been confused on my attraction to girls or guys because of OCD, because I will obey anyone until it feels right.
Morgan (23, Heterosexual, White) (Interview)	Morgan: Yeah and all of a sudden I questioned if I had a crush on him which in my head that's OCD because it gave me anxiety and stuff but but normal thoughts like that they're so real and they're real questions to ask yourself.
Morgan (23, Heterosexual, White) (Interview)	Morgan: Yeah what's your anxiety [yeah] what's not what's your real thought what's not that's what that's what's hard is knowing like a real thought versus an OCD thought I think.
Sarah (23, Queer, Mixed White Chinese/British)	Obsessions about needing a certain amount of sex or sexual talk (even if it was unenjoyable) and fear of destroying a relative through not having sex

OCD is a Real Bastard

Participant Identifier	Quote
Janet (18, Bisexual, White)	OCD has concerned my fiancée after sex because I will shut down or brush my teeth for hours.
Rose (23, Queer, White)	My disorder often manifests as a terror of having anything penetrate my body in any way (imagine bumps on my skin as parasites, needles, splinters), so it took time after I became sexually active with my partner for penetrative sex to physically work for us. I enjoy sex, and want to be more carefree about it than I am - but it is still very weird and scary sometimes, and that can become a barrier.
Courtnee (30, Straight, White)	I had tried one night stands to force myself to "get over" my issues. Those didn't really work out so well as I would go home and have a panic attack before chastising myself for being a sissy crybaby who should just "get over it".
Cynthia R. (27, Bisexual, White)	Well, I'm terrified of sex. I'm terrified that sex will reveal something awful about me, or that I'll realize that I have sexual desires that cannot be fulfilled in my relationship or that need to be met through something I don't want to do (like have BDSM sex with

	men). I have honestly always had anxiety about sex, but OCD makes it so much worse.
HL09 (28, Lesbian, White)	Sometimes during sex I get bad thoughts enter my head, like "you're not enjoying sex with your wife, you're enjoying this because you're thinking of someone else". This makes me panic and put a stop to any further physical contact.
A8 (23, Normal, Hispanic Mixed)	Sometimes while having sex, the high cardio will make me feel like I'm going to throw up and then led to me having a panic attack during sex. But it's all just irrational thoughts. I feel like my obsessions around being sick effect me from being affectionate. I'm not a huggy person and I actually feel angry when hugged or cuddled without my permission or when I feel it is not the right time for me.
Bella (25, Bisexual, White British)	<p>It caused a reduction in penetrative sex due to pain that I think was caused as a psychosomatic response to the sexually intrusive thoughts and unfortunately at the same time I developed an ectropion cervix from the contraceptive pill so all combined caused a negative schema around penetration and increased a lot of anxiety.</p> <p>It made me want to have sex alone more to avoid/ reduce anxiety and sexual intrusions seemed to be less alone than with a partner.</p> <p>At the very beginning when my intrusive thoughts was at there worst I would find sex alone and with a partner a very difficult experience where I felt anxious that an intrusion would pop into my head and became tearful and upset and panicky.</p>
C (29, Hetero, White Irish)	<p>Obsessions about hormonal contraception (health anxiety so unable to take the pill etc), STI fears.</p> <p>Intrusive thoughts when having sex - can be harrowing and mind and body closes down and get an internal/depersonalisation attack which is scary and impacts on my life significantly. the not just right feeling of relationship OCD for example when kissing this doesn't feel right so maybe it's a reflection on the quality of our connection and maybe it's a sign that something is wrong. Moral ocd - then maybe I don't love my partner enough but I am staying with them and might be harming (emotionally) them if I stay. I'm immoral and cruel if I stay...</p>

<p>Jane (28, Bisexual, White British)</p>	<p>I had a LOT of intrusive thoughts around sexuality and sex as a teenager. I got hung up on really unpleasant ideas and scenarios that rationally I knew were not true but I found really distressing nevertheless (for example, for a few months after I had one of those gross dreams about having sex with your family members I had constant intrusive thoughts reminding me of that dream and I found it really upsetting to the point I stopped masturbating all together because inevitably it'd creep into my thoughts while I was doing it and then I'd just feel icky and have to stop). This is much less of an issue for me nowadays, but back during my early to mid teen years it was very common, and very upsetting.</p>
<p>Katie (23, Straight, White)</p>	<p>I have always associated sex with that "bad" "heavy" feeling. I have struggled off and on with this. Sometimes I feel close to what I think normal must be, other times I feel completely debilitated or sexually repressed and I don't even want to try. This has caused me distress throughout puberty and into adulthood. My sexual experiences have always been laced with anxiety and seriousness. I feel that my sexual potential was greatly stunted. I stated before that I don't really see why anyone would want to have sex with me. Sex shouldn't be this difficult.</p>
<p>Lisa (39, Straight, White British)</p>	<p>It frightens me as I don't like being touched and worry about pain.</p>
<p>M (20, Queer, White)</p>	<p>My intense fear of infection means I'm terrified of contracting an STI, so I am hypervigilant about who I have sex with, and who they've had sex with. Casual dating is really difficult for me since I have so many rituals and compulsions. When having heterosexual sex, as well, I always use a condom because the idea of someone else's semen inside of me is horrifying, even beyond the risk of STIs or infection. Part of that is my germaphobia, but another part of it is more psychological, though it's hard to describe. With someone else's bodily fluids inside of me, I get this irrational fear that I am somehow less myself, that it could change me. I know it doesn't make a lot of sense, but the what about this disorder does?</p>
<p>Courtnee (30, Straight, White)</p>	<p>When I have bad days, I can't touch people or even think about bodily fluid without having a panic attack. If I think about it too much, sex is completely out of the question unless I want to have sex in the midst of a panic attack. As well, there are times when sex automatically equals</p>

	<p>pregnant which causes me to panic for months after having sex.</p> <p>On bad days, I can't have sex with anyone because the thought of bodily fluids is disgusting to me. On really bad days that sneak up on me, I will start having sex with my partner and have a panic attack because I don't want to get pregnant through the contraceptives and even though my partner has gone through radiation and can't have children. Or because the bodily fluids (saliva, pre-ejaculate, etc.) are never going to wash off my body. Or because we may have caught an STD/STI from somewhere else (like sitting on a park bench) and passed it to the other and now we're going to die.</p> <p>Panic attacks + sex do not mix.</p>
<p>Jemima (29, Very heterosexual, Scottish)</p>	<p>I hated the way that (as is common for many OCD sufferers), my OCD thoughts about morality would 'latch on' to sexual themes whenever I was thinking about sex. My OCD has given me some utterly horrendous thoughts over the years. One time have be obsessive terrifying thoughts that the sperm I'd just swallowed were somehow sentient and screaming in pain at being dissolved by my stomach acid, and that I should go to the kitchen and take a knife and cut myself open to 'save' them. When I went through a phase of having religiously-themed OCD thoughts, I would experience constant intrusive thoughts that I was going to burn in hell forever for having sex, whilst I was trying to enjoy being in bed with my husband. I've also had OCD thoughts during sex like 'Why the hell do you deserve to enjoy yourself like this when there are people/animals suffering in the world right now? What kind of selfish freak are you that you're not devoting this time to saving everyone you can?'. Fortunately, however, I've never had sexually-focussed themes in OCD, like an obsessive fear of somehow being a paedophile or obsessive homosexuality fears.</p>
<p>KU (27, Queer, White)</p>	<p>They have led me to have panic attacks during and after sex, especially after the first times with my partners. I would feel very sick, and would be close to non-functional as a result of my doubts and whether or not I could enjoy the experience.</p> <p>It made me break up with my first partner multiple times, and put a strain on our relationship. My second partner was much more understanding. I also began taking sertraline somewhat early in our relationship, so it was never as</p>

	<p>affected as badly as my first relationship. However, I still obsessed about whether or not to break up with my partner, and I had panic attacks after we had sex the first time.</p>
<p>Courtnee (30, Straight, White)</p>	<p>It was terrifying.</p> <p>Kissing was out of the question because who really knows what is in the other person's saliva.</p> <p>Touching was limited. I just did not want to be touched.</p> <p>I thought I was going to get pregnant my first time having sex. I was on birth control, used condoms and still had to get plan B. Yet, despite all that, I thought I was still going to get pregnant. It stressed me out so much, I didn't have my period for a year which fuelled the whole "I'm pregnant" thing.</p> <p>And then there was my whole rape thing when I was around 16/17 where I was terrified that if I was alone with a guy he would try to rape me. So I could not be alone in a room with any male.</p>

OCD as Sex Killjoy

Participant Identifier	Quote
<p>Lisa (39, Straight, White British)</p>	<p>I don't have sex.</p>
<p>A7 (21, Heterosexual, White)</p>	<p>I feel it has limited me, I tend to avoid sex at first because I am embarrassed of having to explain the "rules" of my OCD to my partner</p>
<p>Isabel (20, Completely Straight, Biracial/Mexican and Caucasian)</p>	<p>I often have problems during self pleasure sessions, cause i will get impulses or have moments where my thoughts won't stop racing obsessively over something.</p>
<p>Kandice (39, Normal, White)</p>	<p>One dead bedroom</p>
<p>Isabel (26, Heterosexual, White British)</p>	<p>Anxiety about being a paedophile/pervert/lesbian has made me quite scared of having sex in case I have intrusive thoughts about children or women. So it is more anxiety provoking than pleasurable so I avoid it as much as possible.</p>

Katie (24, Heterosexual, White)	I avoided sex entirely and was afraid of it even though I would say I had a high sex drive and wanted physical contact.
S (37, Straight, NZ Euro)	Head in sand approach. Need to avoid getting down.
Rose (22, Pansexual, White)	I wouldn't kiss or hold hands with people because of germs for a very long time.
R.S. (20, Lesbian, White)	To this day I have only had sex with one person, and I've felt empty and dirty afterwards every time. I wanted to wash it out of me.
Sarah (23, Lesbian, White British)	I think that it has stopped me having sex with men because the thought of being pregnant every time I had sex worried me for months making me compulsions a lot more frequent and my fears harder to control
Nicole (26, Heteromantic/Bisexual, White)	I feel like I cannot be a sexual person. I suffer most of my intrusive thoughts either during sex or in a sexual setting and it has turned me off to sex almost completely. My partner and I rarely have sex anyway by choice, but I do not often masturbate because I am fearful I will have distressing thoughts.
Alice (21, Straight, White)	Decreased frequency of sex; It makes me avoid it
Anonymous (22, Lesbian, White)	It's put a strain on my relationships because I avoid sex.
Lynn (18, Bisexual, White)	My intrusive thoughts make it impossible to enjoy sexual experiences sometimes. It's very, very hard to have a sexual experience when you're stuck in your own head and obsessing over unrelated things. There are times where I've stopped masturbating because the intrusive thoughts I got during it were so consistent and bad I was too anxious to continue.
Anonymous (36, Heterosexual, White British)	I think you'd need to provide them with examples. It wasn't until I really thought about it that I realised that it was OCD affecting my sex life. Before that, it was very easy for me to just put it down to stereotypical things such as being a mum, with my partner a long time. I think avoidance will be a big thing too. Working through it and doing exposure etc, is not romantic or sexual at all so the knowledge that

	<p>treatment may involve that may put women off. Some would much rather avoid than face the treatment. i think it would also be really important to consider the self esteem of the woman. its very easy to consider yourself a failure when you really struggle to do something that according to the press and media, everyone else loves.</p>
Amanda (22, Bisexual, White)	I don't have sex as much as I want to due to my strict rules with sexual partners
Brianna (21, Bisexual, White)	Everyone gets mad at me because my OCD won't even let me kiss a person let alone sleep with them.
C (29, Hetero, White Irish)	I had ocd since about 6 years old but only diagnosed and aware i had it 23 years later (aged 29). I was phobic about hormonal contraception and sex (pregnancy fear) and moral OCD as a teenager (17 years old) with a long term boyfriend. Made my boyfriend wait 2 years to have sex as i had all these ocd scary thoughts!!!
Bella (25, Bisexual, White British)	<p>It caused a reduction in penetrative sex due to pain that I think was caused as a psychosomatic response to the sexually intrusive thoughts and unfortunately at the same time I developed an ectropion cervix from the contraceptive pill so all combined caused a negative schema around penetration and increased a lot of anxiety.</p> <p>It made me want to have sex alone more to avoid/ reduce anxiety and sexual intrusions seemed to be less alone than with a partner.</p> <p>At the very beginning when my intrusive thoughts was at there worst I would find sex alone and with a partner a very difficult experience where I felt anxious that an intrusion would pop into my head and became tearful and upset and panicky.</p>
Courtnee (30, Straight, White)	On bad days, I can't have sex with anyone because the thought of bodily fluids is disgusting to me. On really bad days that sneak up on me, I will start having sex with my partner and have a panic attack because I don't want to get pregnant through the contraceptives and even though my partner has gone through radiation and can't have children. Or because the bodily fluids (saliva, pre-ejaculate, etc.) are never going to wash off my body. Or because we may have caught an STD/STI from somewhere else (like sitting on a park bench) and passed it to the other and now we're going to die.

	<p>Panic attacks + sex do not mix.</p> <p>It was terrifying.</p> <p>Kissing was out of the question because who really knows what is in the other person's saliva.</p> <p>Touching was limited. I just did not want to be touched.</p> <p>I thought I was going to get pregnant my first time having sex. I was on birth control, used condoms and still had to get plan B. Yet, despite all that, I thought I was still going to get pregnant. It stressed me out so much, I didn't have my period for a year which fuelled the whole "I'm pregnant" thing.</p>
<p>Chloe (21, Heterosexual, White/Māori/Croatian)</p>	<p>I think I avoid sex with others more due to my need for control, hence my stronger desire to masturbate</p>
<p>Daisy (31, Asexual/Pansexual?, White)</p>	<p>I have occasional thoughts about incest or paedophilia that really freak me out, although that is not a huge part of my OCD. I do really worry about STDs and can't even masturbate without excessive handwashing before and after. I'm also not big on contact with other people, which makes intimacy required for sex very difficult. Generally, I find it easier just to not think about sex. Less anxiety and no big loss.</p> <p>Generally my relationships end when my date realizes I'm not comfortable with hand holding, kissing, and sex was definitely off the table. I've had one long term boyfriend, who was okay with the glacial pace of my comfort with intimacy. However, his patience always weirded me out a bit, because he made it obvious he was interested in sex without pressuring me. I could never figure out why he stayed with me.</p>
<p>EB (18, Homosexual, White)</p>	<p>It has pretty much prevented me from being a sexual person at all and that's not because I genuinely don't want to be.</p> <p>I have yet to allow myself to be in a relationship - it scares me and I often abandon anyone who attempts to facilitate one with me. Even if deep down I want it too.</p> <p>This may have been linked to the trauma associated with the development of my OCD and also having my social</p>

	interactions growing up hindered by my personal OCD and mental health struggles too.
Isabel (26, Heterosexual, White British)	I try not to have sex so that I can avoid intrusive thoughts and images. I also have thoughts that my partner has ejaculated into me and impregnated me so feel quite on edge and convinced I am pregnant or have an STI until I start my next period. I become hypervigilant about any symptoms of pregnancy.
Emily (33, Heterosexual, White British)	Due to contamination OCD I would not sit down on toilets properly, and due to paedophile obsessions I would clench my pelvic floor muscles to prevent any perceived arousal. As a result of both of these compulsions, I now have over tense pelvic floor muscles which creates sexual problems (pain etc)
Elizabeth (61, Heterosexual, White)	I don't know like people to touch me even casually. I couldn't tolerate a sexual experience even now with therapy and meds.
Katie (24, Heterosexual, White)	<p>I avoided having sex with a partner for four years due to overwhelming fear of pregnancy (even though I was on hormonal birth control) and vaginismus. I have overcome this fear somewhat, have overcome my vaginismus, and am with a new partner who I am more comfortable and happy with. I would anxiously await my period each month even when I was not engaging in penetrative sex or anything that would put me remotely at risk of pregnancy.</p> <p>I am much more afraid of pregnancy than any of my friends who do not have OCD, even though I take precautions. I have been so fearful of pregnancy even when I did not have penetrative sex that I made myself ill waiting for my period to come several times. I only had PIV sex once with my previous partner of 4 years. I think a combination of hormonal birth control and my feelings toward this partner made me almost asexual for a while.</p>
Jane (28, Bisexual, White British)	I had a LOT of intrusive thoughts around sexuality and sex as a teenager. I got hung up on really unpleasant ideas and scenarios that rationally I knew were not true but I found really distressing nevertheless (for example, for a few months after I had one of those gross dreams about having sex with your family members I had constant intrusive thoughts reminding me of that dream and I found it really upsetting to the point I stopped masturbating all together

	because inevitably it'd creep into my thoughts while I was doing it and then I'd just feel icky and have to stop). This is much less of an issue for me nowadays, but back during my early to mid teen years it was very common, and very upsetting.
Anonymous (22, Lesbian, White)	I've never fully gone through with having sex and am not sure if I'll ever be able to.
Leyla (30, Bisexual, Greek-Jewish-American)	My obsession with my health is almost 100% limited to sexual health and sexually transmitted infections. Before I was married it also included pregnancy. I didn't lose my virginity until I was 20 because of this fear. I knew that having sex would just make it worse. Probably around 50% of my obsessions revolves around having an undetected sexually transmitted disease, which I am afraid would cause the end of my marriage (it probably would not but OCD is not rational). I have been tested for disease multiple times but frequently worry that the testing was performed incorrectly, that lab results were misattributed to me, etc.
KF (24, Lesbian or Queer Woman, White)	I have a hard time with bodily fluids on my hands when my symptoms are acting up. As a lesbian this is a typical part of sex. Sometimes this will cause me to change sexual activities or stop having sex in that moment. It makes me feel guilty because I don't find my partner's body gross but I find the sensation of fluids on my hands triggers my OCD.
Nikkie (18, Heterosexual, Arab)	I think I've started to fear sex. Anything related to it brings me anxiety, and I try to avoid the very subject at all costs. I wish I could just delete anything sexual about myself, in all honesty.
MJ (31, Straight, White)	I have obsessed about my partners desire towards me or feelings about my performance which has caused me to avoid sex with a partner all together. I have also had fears of infection from masturbation, so I will compulsively wash myself and toys if I use them.
Meghan (40, Gay, White)	Has had a significant impact on sex, very little if any desire to engage in any sexual activity. The thought of kissing or exchanging bodily fluids causes me to feel very stressed. I do not like to think about it and find it very difficult to watch on television.

Michaela (22, Straight, White)	OCD has made me want to avoid sex because of uncomfortable thoughts and images experienced or the fear of experiencing uncomfortable thoughts and images
Jennifer (35, Bisexual, White)	I avoid romantic relationships totally at this point and haven't had sex in 8 years.

What is 'Normal' Sex?

Participant Identifier	Quote
Anon (28, Straight, White)	Thank you for asking this question! I would advise you to learn as much as you can about religion and the shame that is involved in some interpretations of religion. Also to be aware that people with OCD can take relatively subtle messages and take them totally on board - there was not a lot of overt anti-sex messaging at the churches I went to, but being in that culture was enough for me to develop huge issues around it. And be aware that OCD often begins early, so people may have trouble identifying what healthy sexuality is because it has always been through the lens of OCD.
Sarah (23, Queer, Mixed White Chinese/ British)	Has generally made being on the receiving end of sexual contact not that enjoyable - prefer to give rather than receive.
Nicole (30, Bisexual, White British)	As I mentioned before, I ruminate to the point of sexual dysfunction, I would say that is the main issue I have, I obsess over having an orgasm and pleasing my partner to the point that I cannot. This has gotten to the point that I struggle even by myself now, whereas before I could self pleasure.
Meghan (40, Gay, White)	Given the social representations of sex, I feel quite inadequate. The majority of my friends love sex and talk very openly about how much they enjoy it. I cannot connect to this narrative at all and find myself feeling isolated, like there is something really wrong with me. I feel able to talk about sex openly and I am quite frank about my dislike of it, this normally causes the usual jokes from friends and in some cases disbelief as some think 'I must be lying'.
Lily (28, Straight, White)	OCD has made me afraid of my own sexuality. Things that I once took for granted as parts of my sexual identity are now sources of extreme anxiety. To take an example, I used to

	<p>fantasize quite a bit about the idea of two men having sex with one another, and it never occurred to me that it was anything other than another aspect of being a straight woman. Then one day I came across a comment about LGBT women watching gay male porn, and it completely threw me; I began questioning all of my relationships, fantasies, crushes, etc. and worrying that they weren't in line with what a "normal" straight woman "should" want.</p>
<p>Samantha (29, Pansexual, Native American)</p>	<p>Since I planned my loss of virginity I have found that I try to do certain things I might not necessarily want to do, just because I feel a compulsion to in order to succeed with both my partners and myself</p>
<p>Lara (26, Heterosexual, White)</p>	<p>I'm pretty disgusted by my vagina and fluids. Only now, at 26 am I starting to be comfortable with the idea of masturbation and even then, I will shower straight afterwards. Ironically I was always fine with a partner touching my body and never minded my partners bodily fluids. I've also recently started using a vibrator in a bid to feel more sexual freedom and hopefully experience an orgasm one day (I've never had one).</p>
<p>KF (24, Lesbian or Queer Woman, White)</p>	<p>I have a hard time with bodily fluids on my hands when my symptoms are acting up. As a lesbian this is a typical part of sex. Sometimes this will cause me to change sexual activities or stop having sex in that moment. It makes me feel guilty because I don't find my partner's body gross but I find the sensation of fluids on my hands triggers my OCD.</p>
<p>Janet (18, Bisexual, White)</p>	<p>I'll sometimes see sex as something I have to do, even if I do not want to. I'll have sex even if I do not want to. I feel like sex is a way to connect with someone but also that it is a way to degrade myself</p>
<p>Jessica (32, Relaxed, White)</p>	<p>Gave far more guys oral than vaginal Felt unclean Had body image issues and I'm 168cm tall 112 lbs</p> <p>Horrendously shy about getting oral and never have orgasmed from oral without considerable manual stimulation</p>
<p>Isabel (27, Heterosexual, White and White-Jewish)</p>	<p>OCD generally affects my ability to interact socially, and it can be worse with intimate partners. Sometimes the anxious thoughts feel too loud to be fully present in any moment--I feel like I'm half in my mind and half in the</p>

	<p>world. This makes sex challenging, I can't let go and enjoy the moment. I have gotten a lot better at this, and am able to commit fully to sex, but as a teenager and in my early 20s it caused a lot of anxiety (compounded on the original anxiety).</p>
<p>Eems (22, Heterosexual, White)</p>	<p>OCD makes me feel worthless. It makes me so tired and frustrated. I always feel I'm not performing good enough and it really impacts my confidence and body image. It destroys my mind. When I feel like this, sex is the last thing I want. I feel if I don't do well enough in having sex, I've let my husband down and then bad things will happen.</p>
<p>Charlotte (32, Bisexual, White)</p>	<p>Pre-treatment, I believe there were times I had sex compulsively as a means of "checking" that I was still desirable, that a certain person found me attractive, that a partner didn't want to leave me, etc., so my frequency of new partners seemed higher than my peers. I seemed a little less into toys than some of my friends-- I think I just saw them as another think to have to worry about during the act of sex.</p> <p>I took birth control for 10 years, owned the occasional vibrator, always used condoms on top of birth control with new + non-exclusive partners. That part is pretty on par with my peers, from what I can tell.</p>
<p>Daisy (31, Asexual/Pansexual?, White)</p>	<p>Generally my relationships end when my date realizes I'm not comfortable with hand holding, kissing, and sex was definitely off the table. I've had one long term boyfriend, who was okay with the glacial pace of my comfort with intimacy. However, his patience always weirded me out a bit, because he made it obvious he was interested in sex without pressuring me. I could never figure out why he stayed with me.</p>
<p>Katie (23, Straight, White)</p>	<p>I am lucky because during sex I'm often able to let go a bit and enjoy myself. It's the before and after that really bother me. Before sex I cant relax and I am very very concerned about my cleanliness, smell, etc. I often reject my partner because I don't feel exactly right to be able to have sex. After sex I often get this overwhelming "bad" or "dirty" feeling. I struggle with the smell of the condom and bodily fluids, and the feeling of bodily fluids on my thighs. I often get very agitated or anxious immediately after sex and sometimes I cry. Sometimes I am more or less okay, but other times I have to get in the shower right after. I am</p>

	<p>really not able to receive oral because of this. I have been with my boyfriend for 7 years and he has only given me oral 3 times because I usually just can't even take the idea of it. I am also not able to give him oral. The only way I can give him a blowjob is if we take a shower and I wash him and then give him oral in the shower. Again I struggle with the bodily fluids so he cums somewhere in the shower instead of in my mouth. Overall I feel very inhibited and there are so many "rules" I have to follow to have sex. My boyfriend is very understanding but it makes me self conscious and I often don't want to bother with sex at all.</p>
<p>Morgan (23, Heterosexual, White) (Survey)</p>	<p>I was in a hotel lobby and there was a lesbian conference going on around me. I had a panic attack and ran upstairs away from the event- my mom followed and from that moment on I remember being extremely worried about my sexuality and would ask my mom for reassurance and would do many mental compulsions. So, my OCD most definitely had an impact on my developing sexuality. I was so insanely scared to do anything sexual with a male because I was worried that I would find out that I was lesbian. I lost my virginity senior year of college while extremely intoxicated. The whole reason I lost my virginity to a guy I did not know was because I was so worried about graduating college a virgin, and I was worried that guys would not date me if I was a virgin. So basically OCD messes with any type of logic one can possibly have and make the thoughts extremely illogical (but, one does not know they are illogical if they have not received proper treatment) 2 months after I lost my virginity I was compulsively googling and came across HOCD. BASICALLY- OCD had every and any type of possible negative impact on my developing sexuality and early sexual experience. At 23 it still has an impact.</p>
<p>Anonymous (36, Heterosexual, White British)</p>	<p>I think you'd need to provide them with examples. It wasn't until i really thought about i that i realised that it was ocd affecting my sex life. before that, it was very easy for me to just put it down to stereotypical things such as being a mum, with my partner a long time. I think avoidance will be a big thing too. Working through it and doing exposure etc, is not romantic or sexual at all so the knowledge that treatment may involve that may put women off. Some would much rather avoid than face the treatment. i think it would also be really important to consider the self esteem of the woman. its very easy to consider yourself a failure when you really struggle to do something that according to the press and media, everyone else loves.</p>

Katie (23, Straight, White)	I feel like my sexuality is in a box. There are parameters. There are "rules." I don't think I can be a truly sexual being. I get the feeling that others experience sex in a completely different way than I do. I struggle with this very much. I feel different from other people and I feel that I am outside of a normal experience. I feel that I have nothing to offer a sexual partner and this causes me distress.
Samantha (27, Mostly Straight, White)	It's forced him to be understanding of my mental health and how it'll affect sex. While he is happy not having sex during my periods of struggling with OCD I often feel obligated to please him.
Anon (28, Straight, White)	I actually have problems with the skin around my vagina, which was originally misdiagnosed as psychological and vaginismus. It took years to get the right diagnosis. Recently I got an appointment with a specialist in vulval skin and she thinks that the fact that I dry myself extensively whenever I do a wee is likely to be contributing to the problem. So that is a way that OCD directly affects sex for me - I have never been able to have penis in vagina sex without pain. At the moment it is too painful even to get my partner's penis in, despite lots of lubricant and some local anaesthetic. Frequency of sex is very low because of the pain and the feelings of shame.
Anonymous (36, Heterosexual, White British)	I think as someone with a young family, it doesn't differ in terms of frequency too much at the moment. From what I know of friends, as parents of young children everyone is too tired to have sex. but I'm pretty sure I dread it more than others and struggle a whole heap more to complete the act itself. I'm not adventurous and very much have the lie back and think of England mindset. I do it for my husband, not for me.
Annie (32, Heterosexual, Half White/Half Asian)	My contamination obsessions make it difficult to engage in certain sex acts. For example: I have severe contamination obsessions about fecal matter. I wear latex gloves while defecating (a compulsion), and then I wash my hands for 6 minutes after that (another compulsion), and then I shower (compulsion). At this point, I cannot defecate without doing the glove-handwash-shower procedure. I do those compulsions in order to limit my contamination by fecal matter. So as you can imagine, engaging in anal sex is difficult for me to do because of this fecal matter obsession. My partner enjoys anal sex almost more than vaginal sex, so I try to "handle the obsession" and engage in it for his

	<p>benefit. However, the drastic OCD-related anal-cleansing procedure I do prior to anal sex -- and the lengthy hand washing (and body washing) cleansing procedure I do after it -- does cause me considerable mental discomfort, and it makes the entire anal sex experience extremely unpleasant for me. (Of course I do not tell my partner this.) But the truth is: I do dread anal sex because of the OCD. (If I did not have OCD, I probably would still only tolerate -- not enjoy -- anal sex because I find it physically uncomfortable, but the OCD causes me to dread it, obsess about it in a negative way, and avoid it as much as possible.)</p> <p>Another example is fellatio. Fellatio used to be extremely difficult for me to do because of my contamination obsession. I used to feel that the penis was horribly contaminated by fecal bacteria and other bacteria. (While trying to perform fellatio, my mind would bombard me with obsessions about my partner's hand touching the public bathroom doorknobs, then touching his penis at the urinal -- which makes the penis feel contaminated to me.) I do actually enjoy giving my partner fellatio, so I have done ERP exposures (didn't tell my therapist about these exposures -- too embarrassing) to help myself habituate to the high SUDS that I used to get while doing fellatio. Since I have done these exposures, it is now easier (but not totally free of SUDS) to perform fellatio. However, on days that I forget to take my NAC dose, or on days that the OCD feels worse (or when I know my partner has defecated that day without showering after), it is still very challenging for me to perform fellatio on him. The obsessions just make me have so much anxiety.</p>
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To Share or Not to Share?

Participant Identifier	Quote
Cheyanne (26, Pansexual, White)	Honestly just be really validating. One of the things that makes a huge difference for me with my current therapist is when she validates my feelings on things and makes me not feel like a crazy person. She does mention that things are just intrusive thoughts, but at the same time she knows they are real to me and is considerate of that. I think talking about sex and sexuality makes people feel very vulnerable, so extra care should be taken.

Morgan (23, Heterosexual, White)	ERP! ERP changed my life! That's pretty much all I have to say about OCD treatment...ERP really works especially when combined with medication.
Annie (32, Heterosexual, Half White/Half Asian)	It might be helpful if you are as open and understanding as possible about issues related to sex (don't shy away from these topics), and also, it would be helpful if you initiate conversations about sex. I say this because my current therapist *never* mentions the topic, and even when I have tried to broach the subject with her, she seems to shy away from it. (It has almost seemed like she didn't want to engage in discussion about the topic, so I just stopped talking about it.) It would be really helpful to me if my current therapist could be completely un-judgmental about topics related to sex and not shy about it. (For all I know, she *might* be un-judgmental about sex-related topics, but because she has never expressed that, I just don't know if that is the case. So maybe it would be good if you told your patients -- and remind them every so often -- that anything sex-related is open for discussion and that nothing the patient says will disgust you or cause you to see them negatively.)
Charlotte (32, Bisexual, White)	I did about two years of therapy with one therapist. I found DBT to be more helpful than CBT. Understanding my emotions, learning how to tolerate them as opposed to frantically trying not to feel them, and learning how to focus on the moment vs. the past/the future were the keys to my recovery. CBT made me feel anxious over the disparity in rational thought vs. the way that I thought. I felt like it simply highlighted how disordered I was without giving me the tools to deal with how that made me feel about myself.
Leyla (30, Bisexual, Greek/Jewish/American)	verbalizing your obsessions is so hard. It makes them "real" and it's always terrifying that you'll be told your fears are well-founded and that you're right to be afraid. In the first few sessions with my therapist I could not bring myself to say my real obsessions. I think that many therapists don't realize how frightening it is to share this.
Amanda (22, Bisexual, White)	Don't stereotype, my therapist assumes that I have a crush on everyone because I'm bi (we've talked about that and it's cool now). Take some sort of ally training, even if you're queer, it's a dope training all around.
Elizabeth (61, Heterosexual, White)	Having found a great therapist myself, I think developing trust is very important. Sexuality is a very intimate topic but easier to discuss if you feel a connection with your therapist.

Mira (22, Heterosexual, Arab/Mixed)	Went to see a therapist for the sexual assault and she told me I was gay because of the OCD thoughts. It sent me into a mental breakdown where I felt I couldn't trust myself. It took 2 years to be diagnosed and properly medicated. But until then, I dealt with having my own therapist doubting my thoughts and preferences as well as me.
Charlotte (32, Bisexual, White)	Mindfulness therapy was also invaluable. I could not enjoy sex as I do today if I hadn't learned how to keep myself in the moment, focus on feeling physical existence and sensations, and to "notice" I am feeling an emotion (as opposed to having it consume me). DBT goes hand-in-hand with this.
Bella (25, Bisexual, White British)	The most invalidating thing was when people questioned if I was really a paedophile,
R.S. (20, Lesbian, White)	I am unfortunately a bit embarrassed to talk about sex in therapy, but sometimes we do. She has had implied that my intrusive thoughts about sex with men (that include my close family) are real, while informally and through books I've discovered that they are ego dystonic.
EB (18, Homosexual, White)	I often find it more comfortable to discuss these things with my close friend who also has OCD, because I feel less judged and it's just easier...although I do understand the benefit of formalised therapy in this area.
C (29, Hetero, White Irish)	Before I was diagnosed with ocd, i would become so distressed and anxious starting a relationship/dating that i saw a private psychologist every 2 weeks or so to help me manage. Unfortunately, she didn't pick up that it was ocd...
Cathy (31, Heterosexual, White other)	For me I wish my therapists had pushed me a little more to open up about my sexuality and sexual experiences. All the counsellors I've seen have been female, and I identify as female, so I thought I would feel more comfortable with being open about my sexuality, but I still felt there was a barrier to being open about it. I would have loved for one of them to say, when the topic came up, "please feel free to be as open as you want to" or something of that nature. Or even to have been prompted to talk about it by the therapist rather than wondering if it was okay to bring it up. At times when I wanted to talk about it, I felt too ashamed to do so, so that extra bit of reassurance would have been very valuable.

<p>Anonymous (34, Straight, White)</p>	<p>Be as educated you can be on the issues of sexuality and OCD and the obsessive thoughts that relate to sex that someone may struggle with. The best thing a therapist can be is an open and non judgmental sounding board for someone plagued by these thoughts. Being able to tell a therapist and having them understand is the most relieving feeling for a patient and can really help boost their confidence in therapy.</p>
<p>Audrey (30, Hetero, White)</p>	<p>The things that I have learned through treatment is that I have to do the things that I fear the most. If I am afraid of getting for example HIV from touching someone's genitals, then that is what I have to do. For me, it is also very helpful to have in mind what "normal" people would do and think in this situation. I have also named my OCD so it is easier to determine whether it is I or the OCD who is talking.</p>
<p>Bella (25, Bisexual, White British)</p>	<p>One person suggested I have face to face counselling so I searched for a non NHS charity organisation and saw one person who was a lot older than me and new to counselling and was clearly quite shocked at Polyamory, I choose not to see her again and met with a new counsellor who was lovely and I initially felt a reduction in anxiety being able to talk through my difficulties but after a few sessions it became clear that talking was just reinforcing my OCD and the counsellor was offering "reassuring" and well meant comments like a lot of women feel like "lie back and think of other things" when having sex which just wasn't helpful because I don't think sex should be endured.</p>
<p>Bella (25, Bisexual, White British)</p>	<p>The online counselling helped a little at times but the professionals often changed and some were quite judgmental that I was a nurse and I should seek help if I tell other people too... it may not have been that harshly worded but at the time it felt like it.</p>
<p>Annie (32, Heterosexual, Half White/Half Asian)</p>	<p>Another example is fellatio. Fellatio used to be extremely difficult for me to do because of my contamination obsession. I used to feel that the penis was horribly contaminated by faecal bacteria and other bacteria. (While trying to perform fellatio, my mind would bombard me with obsessions about my partner's hand touching the public bathroom doorknobs, then touching his penis at the urinal -- which makes the penis feel contaminated to me.) I do actually enjoy giving my partner fellatio, so I have done ERP exposures (didn't tell my therapist about these exposures -- too embarrassing) to help myself habituate to the high SUDS</p>

	that I used to get while doing fellatio. Since I have done these exposures, it is now easier (but not totally free of SUDS) to perform fellatio.
Meghan (40, Gay, White)	I have felt on many occasions forced to try sex by my therapist to place myself in the uncomfortable position which I think can be quite unhelpful.
Meghan (40, Gay, White)	I have had a great deal of CBT which I did not find particularly helpful. I do talk to friends and have been to see a therapist but find it difficult as I feel others don not really understand.
Cynthia R. (27, Bisexual, White)	The therapists who had less knowledge about OCD were more likely to try to analyze my thoughts and the relationship instead of focusing on the anxiety, which was helpful to an extent but largely encouraged me to ruminate more.
Maisy (20, Bisexual, White)	Talking about sex in therapy would be weird. We touched on it but I felt like me and my therapist felt awkward plus I was scared I'd start having inappropriate sex thoughts about her and accidentally act on them.