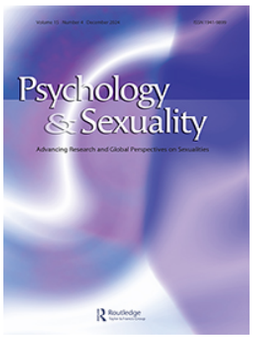

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RESEARCH ARTICLE

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"One dead bedroom": exploring the lived experience of sex and sexuality for women with self-reported obsessive-compulsive disorder

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ABSTRACT

This study explored lived experiences of sexuality for women with self-reported obsessive-compulsive disorder (OCD), with a particular focus on the felt impact of OCD on their sexual identities, practices and relationships, and their experiences of help-seeking. One hundred and thirty-four women completed an online qualitative survey. One *Skype* interview was also undertaken at the request of a participant. We analysed the data using reflexive thematic analysis and developed four themes: 'My distorted reality'; 'OCD as sex killjoy'; 'What is normal sex?', and 'I'm scared and you're not helping'. The participants reported experiencing anxiety around their 'true' sexuality and distinguishing between authentic sexual thoughts and intrusive thoughts. They managed the anxiety associated with intrusive thoughts by avoiding sex as much as possible, or altogether. Women who talked about sex in therapy experienced judgements about their sexuality and sexist advice. The analysis locates the distress the women experienced within a patriarchal and heteronormative social context. We argue that dominate discourses around sex and gender have material and embodied consequences for the participants as they navigated their sexual identities and relationships.

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Compulsions; consent; feminism; qualitative survey; reflexive thematic analysis

1. Introduction

Research on obsessive compulsive disorder (OCD) and experiences of sex is limited (Koolwal et al., 2020; Pozza et al., 2020). Quantitative research suggests that sexual difficulties are a concern for people with OCD, but this is complicated by lower rates of marriage/relationships, and less sexual experience in people with OCD (Freund & Steketee, 1989; Koolwal et al., 2020). Research that focusses specifically on women's sexual problems in relation to OCD is even more limited; however, a small number of (mostly quantitative) studies indicate that women with OCD experience higher rates of sexual dysfunction than both men with OCD (e.g. Ghassemzadeh et al., 2017) and female controls (e.g. Vulink et al., 2006).

Prevalence rates for sexual dysfunction in the general population vary – a German study using the 11th edition of the International Classification of Diseases guidelines reported sexual dysfunction causing marked distress in 17.5% of sexually active women from a nationally representative sample (Briken et al., 2020), whereas the third British National Survey of Sexual Attitudes and Lifestyles (Natsal-3) using the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders criteria

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reported a sexual dysfunction prevalence rates of 3.6% for women (Mitchell et al., 2016). Definitions and diagnostic criteria are hugely significant for prevalence rates – for example, more loosely defined 'sexual problems' (difficulties in sexual functioning) tend to be more prevalent. In the Natsal-3 sample, for example, 22.8% of women reported at least one sexual problem (Mitchell et al., 2016).

In this study, we begin the exploration of lived experiences of sex and sexuality for women with OCD. Our aim was not to focus on clinically defined sexual dysfunction, or even self-reported sexual difficulties, but on the wholesale experience of sexual practices, relationships and identities for women with OCD, and their experiences of talking about sex and OCD (or not) in therapy. To contextualise our study, we offer a brief definition of OCD and discuss one of the main focuses for research to date with regard to sexuality and OCD – other than measuring rates and types of sexual dysfunction in clinical samples – sexual obsessions, before briefly overviewing the limited literature on experiences of sexual problems for women with OCD.

1.1. Defining OCD

OCD is estimated to affect 2–3% of the world's population (Monteiro & Feng, 2016); the incidence for women has sometimes been reported as somewhat higher (e.g. Fireman et al., 2001). Furthermore, service user statistics from a UK charity indicate 75% of people seeking support for OCD are women (OCD UK, 2018), and research indicates that women seek help earlier than men (Stengler et al., 2013). However, given the gender gap in wider mental health service use and the greater shame and stigma men associate with mental health problems (Pattyn et al., 2015), it may be that women and men experience OCD at similar rates but women are more willing to disclose OCD symptoms and seek treatment (earlier) for these.

The fifth edition of the American Psychiatric Association (APA)'s (Glazier et al., 2013, p. 235) Diagnostic and Statistical Manual of Mental Disorders defines OCD as:

> characterized by the presence of obsessions and/or compulsions. Obsessions are recurrent and persistent thoughts, urges, or images that are experienced as intrusive and unwanted, whereas *compulsions* are repetitive behaviors or mental acts that an individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly (APA, 2013).

The repetitive behaviours or mental acts that constitute compulsions are excessive and not literally, or, in some instances, logically, connected to the things they are intended to reduce or neutralise. Accordingly, diagnostic criteria centre on the presence of obsessions or compulsions or both, which are time consuming, cause clinically significant distress and anxiety and impairment in functioning and are not attributable to the side effects of medication or another condition.

Intrusive thoughts can focus on a wide variety of things including contamination, responsibility for preventing something bad from happening, and sex and sexuality (Abramowitz & Jacoby, 2015a). OCD compulsions can include both overt actions (e.g. washing body parts) and covert mental rituals (e.g. counting silently), and commonly include decontamination, checking, repeating routine activities, ordering/arranging and counting (Abramowitz & Jacoby, 2015a). It is commonplace for people to carry out a compulsion to reduce the anxiety associated with obsessions, but the urge to repeat the compulsion increases each time it is engaged in (OCD Action, n.d..). According to Abramowitz and Jacoby (2015b), OCD is maintained through the avoidance of anxiety and negative reinforcement (anxiety is temporarily reduced when the compulsion is engaged in resulting in an increased need to perform compulsions in the future).

1.2. Sexual obsessions

As noted, intrusive thoughts or obsessions can be sexual in nature and can include fears of being a paedophile, becoming pregnant, or – if heterosexual – being gay/lesbian (often known as 'sexual-orientation obsessions' [SO-OCD] or homosexual-OCD [HOCD] among patients and

practitioners). Data from several quantitative questionnaires examining sexual obsessions indicates that these are a relatively common if little studied feature of OCD (Koolwal et al., 2020). For example, 24.9% of patients reported a history of sexual obsessions in Grant et al. (2006), with women and men equally likely to report such obsessions, but the authors noted that embarrassment with discussing sexual obsessions and the methods used in particular studies (e.g. in person interviews versus anonymous online surveys) may lead to under-reporting. Grant et al. (2006) compared men and women with OCD who experienced sexual obsessions with those who did not on a range of clinical domains (e.g. symptom severity, insight into how their OCD manifests). Although sexual drive and interest, and frequency of sexual intercourse, were not found to be different between the two groups, there was no exploration of how such thoughts might be managed during sex. Williams et al. (2015) found that SO-OCD was associated with severe distress including suicidal ideation. In general, there has been little exploration of sexual obsessions and other intrusive thoughts in a sexual context. However, Gordon (2002) reported the case of a fifty-year-old married woman whose intrusive thoughts were predominantly experienced during sex; she managed the anxiety associated with the thoughts by avoiding sex as much as possible.

1.3. OCD and sexual problems in women

'Sexual dysfunction', including anorgasmia and sexual avoidance, is commonly reported in female patients with anxiety disorders (Koolwal et al., 2020) – some comparative studies suggest higher rates in OCD compared to other anxiety disorders (Anksaray et al., 2001; Fontenelle et al., 2007; Van Minnen & Kampman, 2000). There are no studies of which we are aware specifically focused on lived experiences of sexuality for women with OCD. There are however a few mentions of sexual problems within qualitative research on OCD – with several studies suggesting a negative impact on partner relationships and increased sexual avoidance. A focus group study including nine women with OCD explored the impact of OCD on partner relationships (Walseth et al., 2017). One participant mentioned contamination fears that prevented her from engaging in sex with her partner and ultimately damaged her relationship. The participant acknowledged the difficulty of discussing sex in the focus group setting. An autoethnographic study by Brookes (2011, p. 255) detailed that the deciding factor for seeking help for OCD was when she 'winced' at her husbands 'loving touch' and her behaviour was not what she believed it should be as an intimate partner. In an exploration of 'homosexual anxiety' or HOCD, clinical psychologist Williams (2008) provided examples from an OCD online support forum that she moderated including a woman who experienced 'obsessions about being gay' (p. 198) and described the negative impact of these obsessions on the woman's partner relationship and experience of sex.

Demographic data on participant sexuality is rarely reported in existing research on sexual dysfunctions and obsessions but the use of terms like 'sexual intercourse', and a general presumption that sex equates to penetrative vaginal intercourse, suggests that research to date has mostly been conducted on women in, or presumed to be in, relationships with men (e.g. Vulink et al., 2006). Furthermore, in most sexual obsessions research, there seems to be an equation of SO-OCD with homosexual anxiety (Williams & Farris, 2011). Thus, there is a need for research that is more inclusive and diverse with regard to participant sexuality.

1.4. The Current study

Because of the dominance of quantitative methods in existing research we know very little about the nuances of how sexual problems related to OCD are manifest in daily life and how women make sense of these. The current study will be the first to offer a specific and in-depth exploration of the lived experience of sexual identities, practices and relationships, and help-seeking in relation to

these, for women with OCD. We sought to redress the heterosexual assumption in existing research by hearing from both straight and queer women.

2. Methodology

2.1. Online qualitative survey

Qualitative surveys are a relatively novel technique – used mainly in research on gender, sexuality and health (Braun et al., 2021) – and are unique in offering qualitative researchers the opportunity to gather data from a large group of participants (134 participants in this instance) with minimal resources and thus the potential to capture a wide diversity of experiences and perspectives. They are particularly recommended for sensitive research because they allow participants greater control over how and when they participate and a high level of 'felt anonymity' (Braun et al., 2021). The 'Sex and OCD: Women's experiences' survey was delivered through the *Qualtrics* survey platform. Participants responded in their own words to ten open-ended questions (see Box 1). Because of the dearth of qualitative research around women's experiences of sexuality and OCD, relevant topics/questions were identified from reading both existing qualitative and *quantitative* (e.g. Vulink et al., 2006) research, as well as personal memoires of women's lived experiences of OCD (e.g. Limburg, 2010), research on women's experiences of other anxiety disorders (e.g. Van Minnen & Kampman, 2000), and literature on OCD more broadly (e.g. Abramowitz & Jacoby, 2015b). The survey was piloted on 5 participants and some changes were made – making it more explicit that the survey was open to women of all sexualities, and transgender and cisgender women, and one question about medication was removed. Ethical approval for the study was granted by the authors' Faculty Research Ethics Committee.

2.2. Participants and recruitment

Following guidance in the limited qualitative survey methodological literature (e.g. Braun et al., 2021), we reviewed the data for depth and richness after 100 full responses had been received and at this point we determined that the data had sufficient 'information power' given the scope and purpose of the research (Malterud et al., 2016). The concept of information power invites researchers to reflect on the information richness of their dataset in relation to the aims and requirements of their research. Malterud et al. recommend that a study such as ours with a broader or exploratory aim, a diverse participant group with less data collected from each individual (e.g. written survey

Box 1: Substantive 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?

Table 1. Participants' self-reported demographic information.

Age	18–61 (mean 26 years)	
Self-identified race/ethnicity	White	113
	Biracial	10
	White Jewish	4
	Black	2
	Arab	1
	Indian American	1
	Native American	1
	Puerto Rican	1
	Roma	1
Country of residence	US	75
	UK	31
	Canada	17
	Norway	3
	Germany	3
	France	1
	Australia	1
	New Zealand	1
	Brazil	1
	Not stated	1
Relationship status	In a relationship	86
	Single	47
	Not stated	1
Social class	Middle/professional class/white collar	95
	Working/lower class/blue collar	27
	Not stated	12
Disabled	Not disabled	107
	Disabled	26
	Not stated	1
Self-identified sexuality	Heterosexual/straight/"normal"	64
	Bisexual/pansexual	41
	Lesbian/gay/homosexual/queer	14
	Mostly straight/heteroflexible/romantic	3
	Asexual/ace/demi	6
	Unsure	2
	Other (e.g. 'relaxed', 'sexual')	4

responses rather than in-depth interviews), an inductive approach to analysis, and a focus on developing themes *across* the dataset requires more data. As the review process took a few weeks, when we closed the survey there were 134 (107 full and 27 partial) responses.

As is typical for qualitative research in this area (e.g. Robinson et al., 2017) we sought a non-clinical sample of women (aged 18 and older) who self-reported as having been diagnosed with OCD or as having sought treatment for OCD. The study was advertised on various social media platforms including *Reddit*. *Reddit* is made up of subforums or *subreddits* and moderator permission was granted 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). We shared details of the study on *Facebook* and *Twitter* using our personal accounts; prominent OCD bloggers and a counselling psychology group also shared the study on their social media accounts, and a Facebook page was created to advertise the study. The study was advertised in various closed *Facebook* groups for people with OCD with moderator permission, and by various OCD charities, and in the discussion forum *Netmums*. The survey was live for around 6 months in 2017.

One participant contacted the first author (FA) requesting to expand her survey responses via an online interview. We decided interviewing her was in keeping with feminist principles around 'giving voice' to participants (Clarke & Braun, 2019). The interview lasted for approximately one hour and was guided by the participant's responses to the survey questions.

Of the 134 participants, 133 identified as female and one identified as transmasculine-genderqueer. The study was predominantly completed by women living in North America, who

were in their mid-twenties, identified as white, middle class, non-disabled, and in a relationship and full-time employment. The women reported a range of sexual identities, with those identifying as heterosexual or straight comprising just under half of the participant group. The women were asked to choose a pseudonym; these are used when quoting from their responses. Table 1 provides a summary of the participants' self-reported demographic information.

2.3. Researcher positioning

The FA is a white, queer, neurodivergent, middle-class woman of English heritage, with personal experience of OCD, who was a trainee counselling psychologist at the time of conducting the research. The FA kept a reflexive journal throughout the research to record and reflect on her assumptions and feelings about the topic, and the impact of being an insider-researcher. The second author (SA) is a white, queer, physically disabled, middle-class woman of English and Irish heritage. She has no personal experience of OCD.

2.4. Data analysis

To develop patterns of meaning across the survey responses, the data were analysed with reflexive thematic analysis (Braun & Clarke, 2006, 2020). This research is located within a critical realist framework, which holds that there is a material reality, but this can never be fully known or accessed directly, and our experience of the world is situated within specific social, political and historical contexts (Maxwell, 2012). The FA led the coding and theme development process, with the SA acting as a 'critical friend' (Smith & McGannon, 2017) – offering critical feedback on the FA's developing interpretations and encouraging reflexivity (for further details of our analytic process, see Supplementary Material). The analysis produced four themes, one with three sub-themes:

(1) My distorted reality
Sub-themes: (1.1) Will my 'real' sexuality please stand up; (1.2) Look what you made me do; (1.3) OCD is a real bastard;
(2) OCD as sex killjoy;
(3) What is 'normal sex'?
(4) I'm scared and you're not helping.

3. Results

3.1. My distorted reality

This theme captures how women tried to determine the difference between a 'real' sexual thought, and an intrusive OCD-related sexual thought. A 'real' thought was one that expressed an authentic desire and was a true reflection of their identity; whereas, an intrusive sexual thought was understood as not controlled by the women and experienced as ego-dystonic. Unsurprisingly, given the nature of dominant discourses around sexuality (Nagoski, 2015), the women's accounts 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.

3.1.1. Will my "real" sexuality please stand up

This sub-theme captures the distress a large number of women reported from not being able to confidently or definitively identify their 'true' sexual identity. For EB (aged 18, homosexual), 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 an agentic entity separate from her, one that often controlled her, which served to communicate a sense of helplessness. The personification of OCD has

been noted in previous research and is argued to be used as a coping strategy to manage moral accountability for taboo thoughts (Coimbra-Gomes, 2020; Knapton, 2021). A feeling of helplessness was also evident in Isabel-2's (aged 26, heterosexual) responses: '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-2 described her OCD as if it was an autonomous and separate entity, 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.

Throughout the data, women either specifically wrote about their anxiety around their sexuality or this was implicit in their responses. Morgan (aged 23, heterosexual; 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 her need for a definitive answer about whether she was heterosexual or not. Morgan's response highlighted the proliferation of sexual identities in the wider western socio-cultural context, which she felt added to her distress. Morgan questioned which label most accurately described her sexuality. She alluded to not being able to trust her mind about what her body experienced, which resulted in her avoiding her emotions and feeling that she was left in limbo about her sexual identity. Morgan's response also shows how sexual fluidity and uncertainty were intolerable to her; this reflects normative imperatives to categorise sexuality in the broader societal context (Nicolson & Burr, 2003). If sexuality can be definitely labelled, this creates certainty and therefore reduces anxiety.

It was not only heterosexual women reporting SO-OCD (Williams & Wetterneck, 2019), queer women also experienced intrusive thoughts about their sexual identity, suggesting the frequent implicit conflation of 'SO-OCD' with 'HOCD' in some existing literature is problematic (e.g. Kuty-Pachecka, 2021). KU (27, queer) 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 anxiety about their sexuality with being in a relationship that contradicted these thoughts.

For some women, their intrusive thoughts escalated to focus on criminal sexual behaviours, such as paedophilia or incest, which was extremely distressing. Bella (aged 25, bisexual) wrote at length about her experiences with thoughts around paedophilia:

> 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.

Bella's response creates a chaotic image of a woman not able to hold on to her (authentic) sexual identity. OCD is framed as a separate entity; one that took 'delight' in tormenting her. For Bella not only was the uncertainty created by OCD experienced in terms of intrusive thoughts about sexuality but it also manifested in bodily sensations, such as 'groinal responses' to children. This term is

defined in the diagnostic literature as 'physical sensations' including 'lubrication' of the vulva in women (Bruce et al., 2018, p. 396). The clinical terminology enables Bella to explain her bodily response as involuntary and distinct from 'normal' sexual responses. The term acknowledges that Bella's agency and control is removed, but also provides relief, because it distinguishes between what is real and what is OCD.

3.1.2. Look what you made me do

Some women experienced sexual vulnerability as a result of their inability to distinguish between intrusive and real thoughts. Throughout the data, many women used passive formulations (e.g. 'led me', 'made me') to signal their lack of agency in relation to these thoughts and associated behaviours. For example, Mira (aged 22, heterosexual) reported:

> 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. 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 in kind from those of women without OCD.

Janet (aged 18, bisexual) experienced 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). The women experienced vulnerability both when they treated their intrusive thoughts as real and acted in accordance with them and when they compulsively checked and tested whether these thoughts were real or sought to 'disprove' them. Importantly, Janet's extract describes a difficulty some women in the study experienced around consenting to sex – Janet's intrusive thoughts and the associated compulsions interfered with her ability to give enthusiastic consent. This extract also provides a further example of the personification of mental entities such as intrusive thoughts, alongside the personification of OCD, that was evident throughout the data.

Although the women most often described incidents of vulnerability in relation to sex with men, some of the women described sexual vulnerability with women. C (29, hetero) reported that uncertainty around her heterosexuality led to her '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 notes the expectation she felt, articulated by many women in the study, to find a definitive answer to the OCD fuelled uncertainty about her sexual identity. C pre-emptively framed her behaviour as 'ridiculous and entertaining', perhaps anticipating negative reactions from the reader and distancing the non-OCD rational self (who knows such behaviour is 'ridiculous') from the 'mad' OCD self (Coimbra-Gomes, 2020). Such a framing deflects from the seriousness of OCD and suggests a self-deprecating judgement, not uncommon within the data set.

3.1.3. OCD is a real bastard

The women frequently experienced sex (broadly defined as encompassing solo masturbation and sexual activity with a partner) as terrifying or scary as a result of the content of their intrusive thoughts. These could centre around infidelity, contamination or pregnancy, and social taboos and illegal activities such as paedophilia and incest. All of these types of thoughts contributed to feelings of shame:

> 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-1, aged 27, heterosexual)

The socially taboo content of a number of the women's intrusive thoughts increased the feelings of anxiety associated with these thoughts and the need to suppress or not even acknowledge them to avoid the anxiety. Women reported experiencing themselves as socially abhorrent; as Anonymous-1 (aged 34, straight) noted: 'Intrusive thoughts can make you feel like a sexual monster, like there's something wrong with you'. These thoughts were perceived to sabotage sex, in the sense that sex was associated with unpleasant thoughts and images and engaging in sexual activity risked triggering these.

Many participants reported experiencing often extreme forms of anxiety including panic attacks during sex:

> 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, aged 28, Lesbian)

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.

3.2. OCD as Sex Killjoy

This second theme captures the way the women avoided the anxiety generated by their intrusive thoughts by either shunning sex with their partner whenever it felt possible to do so or by eschewing sex and relationships altogether (Abramowitz & Jacoby, 2015a; Koolwal et al., 2020): '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, aged 22, straight). Engaging in sex was often no longer pleasurable, 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. (Isabel-2)

Isabel-2'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. The anxiety experienced by Isabel-2 and other women expanded beyond sexual activity and could encompass several weeks or even months of anxiety. Some of the women experienced solo masturbation as a less risky and more controllable alternative to sex with a partner, but for others intrusive thoughts, or the fear of these thoughts, and the associated anxiety, pervaded even masturbation and they rarely or did not masturbate to avoid potential anxiety:

> 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. (Nicole, aged 26, heteromantic)

For Nicole, intrusive thoughts were primarily experienced in a sexual context and this had devastating consequences for her capacity to 'be a sexual person'.

Complete avoidance of sex was captured in Kandice's (aged 39, normal) description of the impact she felt OCD had on her sexual relationships – 'One dead bedroom'. As previously noted, the women often used personifying language to describe OCD as a separate entity that controlled their sexual desires and behaviours: 'Everyone gets mad at me because my OCD won't even let me kiss a person let alone sleep with them' (Brianna, aged 21, bisexual). The avoidance of sex for Brianna (which also included avoiding kissing), was described as though it was not a choice, but something that the 'OCD entity' did to her, which created the image of OCD as an emotionally abusive partner. Many of the women felt they had to choose between being sexually active and having partner relationships, and managing their OCD. Some of the women also used the label/identity of asexual to describe their sexuality:

> 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, aged 40, gay)

Meghan draws on the personifying language evident throughout the data to convey her sense of her OCD classifying her sexuality without her active involvement. Meghan strove to split off her sexuality from the rest of her being. Asexuality was a label to make sense of sexuality, and manage feelings, in the context of OCD, it was not always an authentic expression of self.

3.3. What is "normal" sex?

The women's accounts, especially of those in relationships with men, reflected the gendered nature of sex. The women attempted to please their male partners, through engaging in obligatory sex: 'I do it for my husband, not for me' (Anonymous-2, aged 36, heterosexual). They also engaged in significant emotional labour through prioritising the needs and pleasure of their male partner over their own wants and needs (Fahs & Swank, 2016). The women compared themselves to others including their partners, and to media depictions of sex, throughout their responses, often positioning themselves as 'completely abnormal' (Katie, aged 23, straight) and 'a failure' (Anonymous-2) compared to others' perceived comfort with, and media depictions of, sex. Such comparisons seemed to exacerbate the women's anxiety around sex. However, research shows that most people experience at least some anxiety around the 'normality' of their sexual desires and experiences (Paine et al., 2019). Thus, the anxiety the women in this study reported may be different in degree but not kind from that experienced by the general population. Annie's (aged 32, heterosexual) responses offered an insight into just how far she would go to engage in receptive anal intercourse (AI) for the sake of 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. [. . .] 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.

Consistent with research on women's experiences of receptive AI more broadly, Annie engaged in the act for her male partner's benefit and pleasure not because she wanted to, and she experienced discomfort in the process (e.g. Fahs & Gonzalez, 2014). She also engaged in considerable emotional labour by protecting her male partner from any knowledge of her physical and mental discomfort. This obligatory sex contrasts with more progressive and reciprocal models of sexual practices in which partners openly negotiate their desires and boundaries and all experience pleasure and

satisfaction (see Braun et al., 2003). Annie described her preparation for AI as 'drastic' and 'lengthy' implying a serious amount of commitment and determination to engage in this sex act. It seems as if there is no space within Annie's relationship for her to negotiate what she wants from sex, as her partner's wants and needs took priority.

Annie appeared to lack agency in her engagement with AI as she positioned OCD as a separate entity that made the experience of AI even worse than it would have been without OCD intrusive thoughts and compulsions to contend with. The only way Annie could negotiate any agency was to avoid AI '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, in making sense of her experiences; in this instance, that women's sexual needs are subservient to those of men (Frith & Kitzinger, 2001). Annie goes to great lengths to 'perform' the kind of sex her partner wants; however, this is just that, a *performance* and not an authentic expression of her sexual desires.

3.4. I'm scared, and you're not helping

The women reported great difficulty in being open with therapists about the perceived impact of OCD on their sexual experiences. Many women either implied or explicitly stated they feared sharing information about sexuality in therapy because of the potential to be judged by the therapist. Although most of the participants had accessed therapy for OCD, they reported that they rarely discussed sexual experiences, and so were not receiving the support they needed. When women were asked about their experiences of seeking help, feelings of shame and embarrassment were often mentioned in relation to sexually-related intrusive thoughts and compulsions. Alex (aged 26, gay) 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 (aged 19, bisexual) avoided the anxiety she felt around sex by not talking about it in therapy: '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'. At the same time, some of the women who did want to talk about sex with their therapist noted their therapist's inability to initiate discussions around sex: '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.)' (Annie). Annie's experience mirrored literature reporting that clients test their therapist's willingness to talk about sex and therapists often fail to respond to client cues (Hill, 2013).

Arguably a lack of therapeutic training around OCD also contributed to the women experiencing feelings of shame, embarrassment and distress in therapy. Therapists were often unable to identify taboo thoughts as OCD-related (see Glazier et al., 2013). Mira reported that:

> 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 sexual identity, but her therapist contributed to these doubts by telling her she was gay. Glazier et al. (2013) found that 77% of 360 mental health practitioners did not link sexual orientation obsessions to OCD, and 65% misdiagnosed such obsessions as sexual identity confusion. It was clearly problematic for the women when their therapists treated their intrusive thoughts as factual. When Bella disclosed her intrusive thoughts about paedophilia to her therapist, her 'whole world collapsed'. The therapist's clinical supervisor decided Bella's thoughts were a safeguarding issue because Bella worked with children. The therapist informed Bella that her manager would need to be notified about her intrusive thoughts. Fortunately, Bella's manager was extremely understanding and offered support in finding

a suitable therapist who specialised in the treatment of OCD. Bella had previously tried to access support but received judgemental responses from therapists because she worked in the medical profession. When she disclosed her distress around paedophilia-related intrusive thoughts, the therapists questioned whether she was a paedophile. Robinson et al. (2017) found that fear of criminalisation was a barrier to help seeking for some participants because of intrusive thoughts related to paedophilia. The participants feared that authorities would think they were a paedophile. Bella's experience suggests this fear might not be misplaced.

From the women's accounts, it seemed as if many of the therapists they had worked with also lacked education in feminist and queer critical perspectives on sexuality, which is unsurprising given the general lack of focus on sex in therapeutic training (Pukall, 2009) and evidence that therapists draw on heteronormative discourses to make sense of sexuality (Shah-Beckley et al., 2020). For Bella, this resulted in her therapist giving her deeply problematic sexist advice that reflected dominant heteronormative discourses around women's sexual passivity and their obligation to put their male partners needs before their own (Fahs & Plante, 2017). Bella commented that this advice was offered in a reassuring and kindly manner, which served to make the patriarchal discourses the therapist drew on all the more insidious:

> 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 therapist's advice, she was able to question and challenge their view.

Having a trusting relationship with their therapist was very important for the women, particularly when it came to discussing sex and sexuality. They strongly expressed a need for acceptance from therapists, rather than judgement, as they were already highly judgemental about themselves. They also wanted therapists to be knowledgeable about OCD and to help them understand their experiences. 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.

4. Discussion

In common with existing literature, this research found that women with OCD report difficulties with, and a lack of pleasure in, sex and often try to avoid it (e.g. Vulink et al., 2006). Existing research tends to focus on avoidance of 'sexual intercourse' (presumably with a male partner), this research found that women avoided a much wider range of sexual activities and both straight and queer women avoided sex. This suggests that future research and clinical assessment need to adopt more expansive and inclusive definitions of sexual activity. Throughout the data women described feelings of shame, embarrassment, fear and isolation. Distress was created through uncertainty around their 'true' sexual identity for both straight and queer women, suggesting SO-OCD should not be conflated with HOCD, something acknowledged but rarely demonstrated in existing literature (Williams & Wetterneck, 2019). Generally, women did not share with others details of how OCD impacted their experiences of and feelings about sex, which resulted in them managing their anxiety, intrusive thoughts and compulsions relating to sex alone.

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 relationships (Frith & Kitzinger, 2001). Consent was a consistent theme throughout the data, with some women engaging in receptive vaginal and anal intercourse purely to please a male partner, even when such sex acts were painful, or intrusive thoughts resulted in a lack of pleasure. The women's accounts raise questions about what it means to fully consent to sex. In attempting to 'prove' their OCD-related intrusive thoughts were wrong (e.g. they had sex with men to 'prove' they

were not lesbians) or feeling compelled to have sex because of intrusive thoughts (e.g. to stop something terrible from happening), some found themselves in risky sexual situations. This compulsive sexual behaviour, as with OCD compulsions more broadly, was intended to reduce anxiety and did not reflect a genuine desire for sex. Living with OCD resulted in women feeling like they had less control over the choices they made when engaging in sex. There has been some philosophical discussion of 'control' in OCD and whether compulsions are acted on from a place of agency or lack of free will (Meynen, 2012; Stein, 2012).

It is important to consider how dominant discourses around sexuality and gender create pressures and expectations for women with OCD, as they do for all women. It is debatable how much free choice women have to not engage in sex with their male partner or husband when they have been taught men have a right to sex. Fahs and McClelland (2016, pp. 399–400) 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?

The participants were no different from women in general with regard to them predominantly not acknowledging that the patriarchal messages they had received around sex had contributed to their sexual difficulties. Instead, the participants internalised their sexual difficulties as evidence they were 'lacking' as sexual partners. Dominate discourses around sex and gender had material and embodied consequences for the participants as they navigated their sexual identities and relationships. For example, mainstream pornography and increasingly the broader culture normalises AI as part of the repertoire of heterosex; something men are entitled to and women should submit to and ideally experience (or perform) pleasure from (Fahs & Gonzalez, 2014). Women with OCD could be considered as 'soiled goods', less valuable as a commodity compared with women without OCD, and less wanted by others. Consequently, women with OCD may have a greater need to live up to dominant expectations around 'normal' sex within society. Conforming to norms could be a strategy for drawing attention away from areas that are shameful and embarrassing.

4.1. Implications for practice

Sex and sexuality are important contexts for clinical assessment of OCD – this research raises the question of whether clinicians are missing the opportunity to assess sex as one of the contexts in which OCD symptoms may occur, thus making treatment less effective. Based on the negative experiences of therapy reported by the women in this study, some therapists may require further training in OCD and sexuality to practice safely with this group of women and empower those who desire sex with a partner to have enthusiastically consensual and pleasurable sex. Therapists need a good enough working knowledge of OCD to not treat intrusive sexual thoughts as authentic, because of how damaging this can be for clients. Therapists should also use supervision to reflect openly and candidly on their level of comfort in working with sexual material, as well as on their own sexual selves (e.g. their knowledge of sexuality and their own sexual histories). Timm (2009) provided helpful activities for therapists to explore their sexual selves such as creating a sexual genogram and a sexuality timeline; tools to reflect on the messages they have received about sexuality and how these impacted on their own feelings about sexuality, and how these in turn might shape their willingness to talk about sex and work with sexual material in therapy. Therapists should also reflect on the extent to which their training and professional development has equipped them to recognise and critique the gendered and heteronormative assumptions about sex discussed in this paper. Clinicians are encouraged to take it upon themselves to fill any gaps through engagement in continuing education, workshops and conferences, and build their comfort and confidence with sexual material. Some of the women wanted to talk about sex and they need therapists willing and able to do so – and well educated enough to not cause further harm.

4.2. Study evaluation and suggestions for further research

The use of online qualitative surveys as a standalone technique remains relatively novel (Braun et al., 2021). In this study, this method enabled the collection of data from a 'hidden' and stigmatised population who experience profound shame about their thoughts and behaviours related to sex and sexuality. Data were predominantly obtained from the US and UK, and therefore, the results likely reflect western ideas around sex and sexuality. Research suggests there are some cross-cultural differences in the expression of OCD, with sexual obsessions potentially more common in highly religious cultures (Williams et al., 2017). Differences have been acknowledged between people who do and do not volunteer for sex research (Opperman et al., 2014), however the (relatively) anonymous mode of responding and high level of felt anonymity seems likely to have facilitated participation and disclosure – several of the women certainly commented as such, and the explicit discussion of sex in the online interview with one participant was limited compared to that in her online survey responses. Most participants were white women, and on reflection, we could have made the study more accessible to women of colour (e.g. noting that we are both white women in the participant information to build trust with participants by acknowledging our racial privilege and recruited through social media groups for women/people of the global majority); this is important because anxiety disorders are understudied in people of the global majority (Williams et al., 2013).

In conclusion, 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 attempted to avoid sex and, in some instances, partner relationships, and did not share their experiences with others. Compulsions also resulted in women being vulnerable to sexual violence and abuse, and lacking certainty around their sexuality caused them a great deal of distress. Lastly, the women needed compassion for the never-ending turmoil they experienced; something they felt they could not obtain from those close to them, their therapists and wider society.

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Author contributions

Both authors contributed to the study conception and design. Material preparation, data generation and analysis were led by Elicia Boulton with input from Victoria Clarke. The first draft of the manuscript was prepared by Elicia Boulton (method, analysis, discussion) and Victoria Clarke (introduction), and both authors commented on and edited previous versions of the manuscript. Both authors read and approved the final manuscript.

Data availability statement

Permission was not sought from participants to share their data with third parties.

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