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Parents' experiences of Parenting a Preadolescent Child with OCD: A qualitative study

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Abstract

Obsessive Compulsive Disorder (OCD) has negative impacts on affected preadolescent children; however, little is known about parents' experiences of parenting a preadolescent child with OCD, and limited provision exists to help parents to support their children. This study aimed to explore parents' experiences of parenting a preadolescent child with OCD using semi-structured, qualitative interviews to inform the development of such provision. Twenty-two parents (15 mothers; 7 fathers) of 16 children (7- to 14-years-old) who had experienced OCD were interviewed. Reflexive thematic analysis was used to generate two overarching themes: (1) challenge and frustration, and (2) helplessness, and five themes: (1) the journey to understanding and coming to terms with OCD, (2) the battle for support, (3) navigating how to respond to OCD, (4) OCD is in control, and (5) the emotional turmoil of parenting a preadolescent child with OCD. The need for clear, accessible, and scalable support for parents of preadolescent children with OCD was identified.

Key words:

Obsessive Compulsive Disorder; Qualitative; Parents; Children

Introduction

Obsessive Compulsive Disorder (OCD) is characterised by obsessions (i.e., intrusive, unwanted thoughts, images, or urges that cause significant distress/anxiety) and/or compulsions (i.e., repetitive behaviours/mental acts that are performed to reduce the distress/anxiety caused by obsessions; American Psychiatric Association 2013). OCD commonly first occurs during preadolescent years (Geller et al. 1998; Stewart et al. 2004; Walitza et al. 2020) and is estimated to affect up to 2.9% of preadolescent children (Valleni-Basile et al., 1994). Experiencing OCD during preadolescence has been associated with impaired school and social functioning (Piacentini et al., 2003; Valderhaug & Ivarsson, 2005) as well as greater persistence of the disorder overtime (Stewart et al. 2004).

In addition to the obvious negative impacts on affected children, parents of preadolescent children with OCD report impairments to wider family functioning (Garcia et al. 2010; Piacentini et al. 2003), high levels of parental distress and anxiety (Stewart et al. 2017; Storch et al. 2009), and often feel helpless as to how to help or respond to their child's difficulties (Futh, Simonds, and Micali 2012). Furthermore, parenting a child with OCD may have distinct challenges, given that family accommodation (i.e., participation and/or facilitation of rituals, provision of reassurance, and/or facilitating avoidance of OCD triggers, Waters and Barrett 2000) is frequently reported among parents in this population (Monzani et al. 2020; Peris et al. 2008;). This highlights the need to provide support and guidance to parents of preadolescent children with OCD, which may alleviate distress both for the parents and also for their children with OCD. Indeed, parents have been shown to be able to effectively help their child to overcome OCD when supported by a therapist (e.g., Rosa-Alcázar et al. 2019). However, parent-focused programmes to date have provided levels of support for parents which may not be easily disseminated at a large scale due to the amount of specialist therapist support required (e.g., approximately 12 hours of individual specialist therapist input in Rosa-Alcázar et al. 2019).

To develop ways of supporting parents of preadolescent children with OCD that can be delivered at scale, we need to understand parents' experiences of parenting a child with OCD, to ensure that the support provided reflects parents' experiences, needs, and wishes. To date, limited research has explored this qualitatively. One exception is Futh, Simonds, and Micali (2012) who used written narratives to explore mothers' and fathers' understanding and management of their children and adolescents' (9- to 18-years-old) OCD. Using thematic analysis, Futh, Simmonds, and Micali (2012) highlighted (i) parents' difficulties making sense of their child's OCD, (ii) parents' feelings of powerlessness against OCD (commonly resulting in parental helplessness and frustration), (iii) the negative impacts of OCD on the affected child and wider family (e.g., perceived strain on parents' marital relationships, reduced parental ability to care for other children etc.), and (iv) the tension parents experienced in deciding whether or not to accommodate/their child's OCD. Although providing useful insights, the use of written narratives may have limited richness compared to, for example, interviews which allow the researcher to explicitly respond to and probe participants' responses to obtain a rich, detailed understanding of their experiences (Smith 2015). Furthermore, to date, no studies have specifically explored parents' experiences of parenting a *preadolescent* child with OCD. This is crucial, given that preadolescent children are more reliant than adolescents on their parents (Freeman et al. 2003; Hill et al. 2007) and thus, parents of preadolescent children with OCD may experience unique challenges. This study therefore conducted in-depth, semi-structured qualitative interviews to build on the existing literature and explore experiences of parenting a preadolescent child (7- to 12-years-old) with OCD. Reflexive Thematic Analysis (TA) was used to analyse the data, as this enables the researcher to generate patterns of shared meaning across a diverse range of participants (Braun and Clarke 2020a).

Method

This study was approved by London Bridge NHS Research Ethics Committee (19/LO/0514) and the University of Reading Research Ethics Committee (UREC 19/09) and is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong, Sainsbury, and Craig 2007).

Recruitment

We recruited parents of children (7- to 12-years) who were suspected of having OCD or currently diagnosed with OCD, and parents of children (7- to 14-years) who were previously diagnosed with OCD (when aged 7- to 12-years) by a mental health professional. Parents were recruited from two Child and Adolescent Mental Health Services (CAMHS) in Southeast England, UK-based mental health charities, social media, and UK-based private treatment providers.

For those recruited through CAMHS, families completed semi-structured diagnostic interviews to identify the child's presenting problem following routine procedures in both CAMHS settings. Where OCD was diagnosed, a clinical team member approached parents to provide them with study information and to seek consent for their contact details to be shared with the research team.

Parents could also refer themselves into the study using an online link. Information was made available through posters displayed in the participating CAMHS waiting rooms and were distributed to charities, private treatment providers, and across social media sites. The study researcher (CCh) contacted interested parents via telephone and/or email to discuss the study and seek written informed consent from parents to participate. After providing informed consent, parents completed a screening questionnaire collecting demographic information and information about their child’s mental health diagnoses and stage in the help-seeking process. If children were suspected to have OCD (but did not have a diagnosis provided by a mental health professional), parents were asked to complete the Children’s Obsessional Compulsive Inventory Revised Parent report (ChOCI-R-P; Uher et al., 2008) to determine their eligibility for the study. Parents were eligible for the study if their child had an impairment score >17 on the ChOCI-R-P. Parents of children (aged 7- to 14-years) who had previously been diagnosed with OCD (when aged 7- to 12-years) were only eligible for the study if their child’s diagnosis had been provided by a mental health professional.

Parents were not eligible for the study if their child had a diagnosis of an Autism Spectrum Condition (ASC) or a significant learning disability, as treatments for these populations often require specific adaptations (Sze and Wood 2007). Similarly, parents were not eligible for the study if they did not live in the UK, could not speak sufficient English, or had an intellectual impairment that would interfere with their ability to complete measures or participate in an interview.

Eligible parents formed a pool of potential participants ahead of purposive sampling (see Figure 1). Parents who were selected for interview were provided with a £10 voucher.

[Figure 1 near here]

Participants

We used a purposive sampling approach to capture diversity in parents’ experiences and views, and thus, invited parents to interview who varied according to: (1) child age and gender, (2) parent gender and caregiving role, (3) stage in the help-seeking process, and (4) demographic characteristics. We used an *information power* approach to determine our sample size, which considers factors such as breadth of the research questions and diversity of participants (Malterud, Siersma, and Guassora 2016). Given that we aimed to examine breadth of experiences across a diverse range of parents, we anticipated that between 10 and 20 interviews would be required to generate a rich, complex dataset. Twenty parents (14 mothers, 6 fathers) of 14 children were initially interviewed. As recommended by Braun and Clarke (2020b) and Malterud, Siersma, and Guassora (2016), we used the data collected to decide upon our final sample size, based on its richness and complexity. Towards the end of interviewing, we noted that parents of younger children and parents from non-White backgrounds were providing additional complexity and insights – thus, we sought to recruit two additional parents who either had a younger child and/or who identified as being from a non-White background. The final sample consisted of 22 parents (15 mothers, 7 fathers) of 16 children (see Table 1 for participant characteristics).

[Table 1 near here]

Measures

Screening Questionnaire

Parents completed a brief screening questionnaire measuring parent and child age, gender (i.e., parents completed a free-text box indicating their own and their child's gender[1]), self-reported ethnicity (in accordance with the categories outlined by the Office for National Statistics, 2022), parental employment status (i.e., unemployed, employed full-time or part-time or other), parental education status (i.e., school completion, further education, higher education, or postgraduate qualification), caregiver status (i.e., primary, secondary, shared

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[1] Note. All parents who completed the screening questionnaire identified their own and their child's gender as male or female.

caregiver, or other) and parental relationship status (i.e., single, married, remarried, divorced, separated, living with partner, widowed, or not applicable) as it was anticipated that these demographic factors may influence parents' experiences of parenting their child. Children's diagnostic and treatment history and stage in the help-seeking process was also collected.

Children's Obsessional Compulsive Inventory – Revised, Parent Report (ChOCI-R-P, Uher et al. 2008)

The ChOCI-R-P is a parent-reported measure that assesses OCD symptoms and severity in children and adolescents. It consists of two sections assessing obsessions and compulsions. Each section contains 16 questions: 10 to assess the presence of symptoms using a 3-point scale, and six to assess the associated impairment using a 5-point scale. Parent reported impairment scores are summed to produce a total impairment score (out of a total of 48). A total impairment score >17 on the ChOCI-P (which derives the impairment score in the same way) has been shown to have adequate sensitivity and specificity to determine an OCD diagnosis (Shafran et al. 2003).

Procedure

A topic guide was developed based on relevant research evidence (e.g., Futh, Simonds, and Micali 2012; Storch et al. 2009; Wu et al. 2014) and the authors' clinical experience of working with families of children with anxiety disorders and OCD. Its aim was to broadly explore parents' experiences of parenting a child with OCD. Two Public and Patient Involvement (PPI) members, with experience of parenting a child with OCD, reviewed the topic guide and participated in a practice interview to increase the acceptability of the questions to families. Interviews were conducted by the first author (CCh) who is a female PhD student trained in qualitative methods and qualified Psychological Wellbeing Practitioner (PWP) with experience of delivering brief CBT interventions with parents of children with anxiety disorders. The interviewer had briefly encountered two participants prior to the study (one at a national conference where the study was advertised and one during her honorary clinical role where she introduced the study to a participant). Participants were told that the purpose of the study was to improve understanding of the experiences of parenting a child with OCD so that the research team to might design treatments that better support families. Participants were able to ask questions about the researcher and their research interests if they chose to. Interviews were conducted via telephone (n = 19) or face-to-face (n = 3) at the University of Reading. Face-to-face interviews took place in a quiet room with only the interviewer and participant present except for one interview where a participant's child (who did not have OCD and who wore headphones for the duration of the interview) attended. Interviews lasted an average of 73 minutes (range 45 – 121 minutes) and were audio-recorded. Interviews were transcribed verbatim by CCh, with identifying information removed. Field notes were made during and after each interview.

Data analysis

Reflexive Thematic Analysis (TA) was used to generate patterns of shared meaning across the dataset (Braun and Clarke 2020a). We adopted an essentialist/realist epistemological approach to data analysis, which assumes that language allows participants to express their experience and meaning (Potter and Wetherell 1987; Widdicombe and Wooffitt 1995). Reflexive TA values the researchers' subjectivity in the analytic process and encourages researchers to be aware of and reflect on their assumptions and biases (Braun and Clarke 2020b, 2020a). CCh conducted this study as part of her doctoral research that aimed to increase access to psychological treatments for children with OCD. CCh (who is a PWP), AF, CCr and BH (who are Clinical Psychologists) have experience of delivering therapist guided, parent-led CBT to parents of children with anxiety disorders, a treatment developed by CCr that is routinely delivered in NHS services. CCh, AF, CCr, and BH also have experience of delivering psychological treatments to children and adults with a range of mental health difficulties, and AF and BH have particular expertise in assessment and treatment for OCD. CCr, BH, and KH all have considerable experience of conducting and supervising qualitative research.

Data analysis followed the six-stages of reflexive TA outlined by (Braun and Clarke 2022) and was led by CCh. CCh met regularly with the research team during the initial code generation to facilitate interpretation of the data and to reflect on how CCh's prior experience may have been shaping the data. Two in-depth coding meetings with CCh, CCr, BH and KH were held during theme development and refinement. During these meetings, the research team reflected on their prior experiences and how this may have shaped the initial theme development. This facilitated discussion of alternative understandings of the data and close examination of data extracts to ensure a credible final interpretation of the data. NVivo (Bazeley and Jackson, 2013) was used to store data and support data analysis. Participants were not provided with an opportunity to give feedback on the findings but were given the option of receiving a summary of the study results.

Results

A thematic map of the results is shown in Figure 2. Table 2 reports individual participant characteristics to aid interpretation of the results. Two overarching themes, five themes, and seven subthemes were generated. Although the overarching themes (i.e., 'challenge and frustration' and 'helplessness') are seen as infiltrating the subsequent themes and subthemes, descriptions of the two overarching themes are presented last, to allow the reader to develop a sense of how these overarching themes are present throughout the themes/subthemes.

[Table 2 and Figure 2 near here]

Theme 1: The journey to understanding and coming to terms with OCD

This theme describes parents’ journeys to understanding and accepting their child’s OCD. It consists of two subthemes: (1) ‘the unknown’ – capturing parents’ initial difficulties understanding and relating to their child’s OCD, and (2) ‘reaching acceptance’ – encompassing parents’ perception of the importance of accepting OCD and the perceived barriers to this.

Subtheme: *The unknown: ‘I just didn’t know what was going on with my child’ [ID31, mother]*

Parents often found it challenging when they were unaware that their child was experiencing OCD. For some, there was a sense of unfamiliarity, *‘didn’t even know it was OCD ... it just didn’t make any sense’ [ID43, father],* whereas others struggled to differentiate between normative childhood development and disordered behaviour.

- *‘I think a lot of it I didn’t really notice for a while because … kids are always running their hands along walls and tapping things and touching things, that’s what kids do when they are young’ [ID28, father]*

Even when parents knew their child had OCD, they found it hard to identify what was OCD versus other difficulties – for example, other mental health problems or hormonal changes.

- *‘It’s difficult to know how much of it is hormones, how much of it is a typical teenage tantrum, or it’s a teenage tantrum with OCD or it’s OCD. It’s really hard to distinguish between those three possibilities, which are every possibility when he is kicking off’ [ID23, mother]*

Furthermore, most participating parents found it challenging to relate to their child’s difficulties. They perceived OCD to be *‘really quite irrational’ [ID17, mother]* and found it *‘immensely frustrating’ [ID37, mother].*

- *'There's things like, we have been out for a walk, where she has ... touched a branch or something [and] you find out that there is dirt on it somewhere, or there might have been dogs gone near it ... and she gets really upset about that, the thought that she could have touched dirt or poo or something like that, um even when it's ... ridiculous that it could even, you know, that it's so remote the chance of that happening' [ID39, father].*

Despite this, understanding OCD was seen as *'the key' [ID34, father]* to supporting their child. Parents' understanding of OCD often shifted over time, helping to ease their frustrations.

- *'I think it's helped that we understand her better, so I think overtime because all of us have sort of experienced a shift in how much we understand and how much we know about OCD, we are not having so many difficult situations' [ID17, mother]*
- *'I think um, what made a big difference to me, is ... to try to understand how OCD works ... it's like if somebody had a swimming pool full of sharks and somebody said put your foot in it, no one in their right mind would do it, but ... that's what OCD does to you, it tells you stories, which are, we all know they are not true, but for that person, they are true, and that, that's the thing which is ... the hardest thought to understand' [ID34, father]*

Subtheme: *Reaching acceptance: 'you can't have a parent that goes nope don't believe in this ... it's got to be something that they say right yeah I have got to accept this' [ID38, mother]*

The importance of coming to terms with their child's difficulties was also stressed by many parents.

- *'just getting parents feeling comfortable with the whole condition and making them realise that they need help and that they need, the child needs some sort of assistance*

... it's nobody's fault, it's not bad parenting, it's not the child being inadequate ... it's just the way it is' [ID39, father]

Through this journey, some parents were able to identify the *'silver linings' [ID30, mother]* of OCD.

- *'I think there are positives you know...just to see how, how resilient she is ... how strong she is you know, yes she will have her moment but ... she has become far more stronger than I ever thought [ID30, mother]'*

Despite this, the majority of parents remarked that *'I can't see any positives' [ID44, mother]* to OCD, with some parents describing coming to terms with OCD as a long, challenging journey.

- *'I don't see that there's positives in having a child with OCD, he doesn't want it, he is so unhappy, he really doesn't like it, he's like "what's wrong with me ... I don't like OCD monster" ... there is nothing good about it, the poor little boy he's struggled' [ID31, mother]*
- *'it's taken me like a year, or something like that, to go from a point of going what the shit is happening to my family, to my daughter, what's going on, the whole world has come to an end, type feeling, um, to getting to a point of acceptance and going okay, she has got this condition, it's not nice, you know ... and being a little bit more centred and stable about the whole thing, that's taken some serious work for me' [ID43, father]*

Some parents identified barriers to coming to terms with their child's difficulties, particularly when they didn't understand that it was OCD, resulting in some parents feeling embarrassed by their child's behaviour.

- *'it's also a bit embarrassing, because your child is, so completely different from her* *friends ... so she's saying all these really weird things, that, I would pretty much only like tell my best friend ... how can you say to people "does your child think they have weed on light bulbs?", of course they don't because, it's not normal [laughs], so yeah, it's, it's embarrassing, it's secretive' [ID44, mother]*

Moreover, many parents (particularly participating mothers) perceived their child's difficulties to be misunderstood by others (e.g., family, school, mental health services, and/or the public), adding to their frustration.

- *'she's [family member] said things like "couldn't you just get a book", or ... "why do you think he's like that?" ... "do you think that's because you're worried?" and you know, just unhelpful, and she doesn't mean any harm, but that's difficult, you know that causes friction…like anyone would pretend to have a child with OCD, or make it up or you know, want to diagnose' [ID19, mother]*
- *'Because so many people joke about OCD, "Oh I'm OCD I check for this, I check for that" no you're not OCD, you just like to check because you are slightly anxious. It's a big discrepancy and it's that sort of semantics of what is OCD and what is OCD, I think society portrays it as being a little bit organised. It's not.' [ID23, mother]*

Among participating parents who identified from non-White British backgrounds, there appeared to be a disparity between their own, and their wider culture's views of mental health difficulties, adding to their challenges.

- *'it's not really recognised no, they see it as, I wouldn't say a sign of weakness, they just see it as, just get on with it ... it's not really spoken about ... it's a very different way of thinking' [ID withheld to preserve anonymity]*

Theme 2: The battle for support

This theme captures the perceived challenges, frustration, and helplessness parents' experience trying to access appropriate support for their child's OCD.

Participating parents frequently described challenges obtaining support from mental health services and, in some cases, schools. This resulted in parental desperation, helplessness, and frustration, with parents describing *'getting through that waiting list and just waiting and waiting, that is like, the worst time of your life' [ID31, mother]* and *'soul destroying' [ID15, mother]*.

- *'I suppose the ridiculousness of the fact that ... you have diagnosed someone with a mental health condition and you're expected to wait 2 years for the next, next appointment, because there is no one available ... if he'd had a brain tumour would they have left him for two years ... you know that would be seen as unacceptable' [ID28, father]*
- *'well I was given a telephone number and told if there was a crisis then, then, but the thing is, what constitutes a crisis? I mean, my day, every day was a crisis. And, and it's like "okay, well you are still on the waiting list, maybe you could go down to 6 months", well hey well that still doesn't help me today. That still doesn't help me get her into school when she is hiding under the bed refusing to put her clothes on. That still doesn't help me when she is trying to ... run into the middle of the road. That still doesn't help me when ... she won't eat anything whilst we are out, and she is physically losing weight.' [ID15, mother]*

As a result, parents often had to rely on themselves to help their child or seek alternative support, including private treatment, alternative (often non-evidence based) therapies, school support, and ad-hoc information from friends.

- *'any input would have been useful because we did it all, off our own back, we didn't* *have any support with any of it so you know everything we did was, was just sort of what we had read on the internet' [ID25, mother]*

Even when parents were able to access support (either NHS or private), the battle persisted, with some parents perceiving their therapist and/or assessment and treatment as inadequate.

- *'It's quite insulting when like someone like that [CAMHS professional], who hasn't been there at 3 o'clock in the morning, every morning when your child is, you know, blinking at the ceiling otherwise she is going to be, a lesbian, telling me that she hasn't got OCD' [ID40, mother]*
- *'again with hindsight, after the first session or two [of treatment] I should have gone, "what the shit is this?" but um, I think you know at the time I didn't know, um you just go well maybe you know, maybe she [the therapist] knows what she is doing, I'm going to run with this, uh cos I didn't exactly have an alternative strategy, so you just do it' [ID43, father]*

However, many parents valued the support they received and the benefits this brought to their child.

- *'until you then start, your child gets seen, and then it's like a light bulb moment, because suddenly there's people who do understand and do get it, and actually you can see the improvements' [ID31, mother]*

Theme 3: Navigating how to respond to OCD

This theme describes the challenges parents experience navigating how to respond to their child's OCD. It consists of two subthemes: (1) 'not knowing how to help' – capturing parents' desire yet helplessness as to how best support their child, and (2) 'fighting back at OCD' – capturing parents attempts to lessen the grip that OCD has over their child/family.

Subtheme: *Not knowing how to help: 'It's the whole feeling of wanting to help, but not knowing how to' [ID38, mother]*

Many parents didn't know *'what is the right thing to do' [ID25, mother]* when responding to their child's OCD. Parents typically accommodated OCD (either knowingly or unknowingly), often feeling that they had no choice but to do this, to keep their child functioning.

- *'well we could stop doing everything [i.e., accommodating the child's OCD] and we have thought about that, but then, I am very keen to keep [child's name] at school you see, and functioning' [ID24, mother]'*

Some parents experienced an internal conflict about whether to accommodate their child's OCD. They often knew that accommodation would perpetuate their child's difficulties, but they did not know how else to respond in these situations, particularly when there was a perceived time pressure (e.g., before school or bedtime).

- *'it was real conflict with myself because I knew it wasn't helpful, but ... especially in the morning, I needed to get him to school, he wouldn't leave, you know, if I didn't do it, well I had one morning where I wouldn't reassure him about putting his clothes on ... I said "no, that's enough, I am not doing this, it is ridiculous ... you weren't doing this a week ago, you are suddenly doing it" ... went downstairs to deal with the other [children], came upstairs 15 minutes later and he's got no clothes on and he's crying, what do you do? I need to get him to school, you know, I've got the other [children], I can't have a stand-off, plus he is distressed, you know, which as a parent, you don't want to see' [ID19, mother]*

Some parents also experienced conflict with other caregivers about the best way to respond to their child.

- *'my husband just was not impre[ssed]: "that's pandering to it, that's just not going to help him because the more you do that kind of thing, the more he is going to expect you to do that kind of thing, and then we are going round in a vicious circle"' [ID23, mother]*

Subtheme: *Fighting back at OCD: 'maybe next time, I will only give you three reassurances…rather than thirty' [ID15, mother]*

Despite not knowing how best to respond, over half of the participating parents described attempts to fight back at their child's OCD, either by resisting accommodation, trying to rationalise their child's fears, or encouraging their child to face their fears, which had varying success.

- *'she was scared of petrol stations, and uh, I need petrol, so that's life, um and so every time we went, her panic attack was like, 10 and now it's completely gone because she just realised that nothing is going to happen at a petrol station, but that took a lot of determination' [ID40, mother]*
- *'we try and do um logical thinking ... let's go back to that example of where he said, "are you overdosing me" and I said to him, "do you think I would, I am your mum?" and he said "no, I know you wouldn't but my head keeps tell me that you would, that you are doing it" ... and I asked him "do you understand what overdosing means? and that it's against the law?" and "why would I want to hurt my child?" ... and he said fine, and then the next day he said it again' [ID38, mother]*

Some parents perceived particular OCD presentations to be easier to help their child with than others. For example, *'physical things'* or *'smaller' [ID15, mother]* compulsions were viewed as easier than the *'internal stuff, you know, the things that are going round in his head' [ID38, mother].*

- *'but to be honest, it's counting which worries me the most, because um, it doesn't really have a, physical manifestation which you can deal with' [ID35, mother]*

Theme 4: OCD is in control

This theme captures the control that OCD is perceived to have on affected families and is organised into three subthemes: (1) OCD controls the child, (2) OCD controls the parent, and (3) OCD controls the wider family.

Subtheme: *OCD controls the child: 'it was controlling her, she couldn't control it' [ID15, mother]*

Participating parents frequently described how OCD completely controlled their child. Children were perceived to be in a *'constant battle' [ID25, mother]* with OCD, resulting in impaired daily functioning and physical damage, with children washing their hands until *'they were raw, bleeding from here to here' [ID23, mother]*.

- *'it's just constant … to get her out of bed in the morning sometimes it can take her two hours because she can't face getting out of bed, because she has so many thoughts and rituals like, things like gulping, long blinks, saying a chain of thoughts without blinking and then blinking at the end … and then that's just getting out of bed' [ID24, mother]*

Many parents also felt that OCD had changed their child's behaviour, describing how OCD made their child angry, explosive, and aggressive.

- *'I think surprising as well because, um he has gone from being a very placid, very affectionate child to being quite aggressive, and angry, really angry' [ID23, mother]*

Subtheme: *OCD controls the parent: 'I was washing him, I was dressing him, he slept in my bed for two years … I was doing everything for him' [ID31, mother]*

Parents identified that OCD controlled their own lives – for example, through the need to provide constant reassurance or to vigilantly monitor their child's difficulties. In some cases, their child was reliant on them for basic functioning (e.g., eating).

- *'everything he did, he needed to check really whether that was okay "Is it okay if I put this shoe on first? Is it okay if I do these laces up? Is it okay if I don't take this book to school today because I am not going to need it?" ... it started first thing in the morning, and it went through probably just about everything he did really' [ID37, mother]*
- *'you have to ... be on high alert, knowing you have a child with OCD, you can't let things go, if she is behaving a bit weirdly, it's OCD, so what's happening, we need to find out' [ID44, mother]*
- *'I mean there have been times when we have had to feed her, because she wasn't eating' [ID24, mother]*

Many parents identified that OCD became their top priority, with some parents describing particular impacts on their ability to work.

- *'trying to work in a full-time job with additional respons[ibilites] ... was just not possible ... so now I have got a job that's home-based ... but I can only do part-time as well, to fit in, well you've got to fit in CAMHS appointments, fit in making sure that you are doing some of the exercises with her and having some of the conversations with her between times, when she has got a full schedule of school and sport and all the other activities that teenagers do, and then you have got to fit in, managing an illness as well, then I think as a parent, you have got to be there a lot more' [ID33, mother]*

Overall, OCD appeared to control mothers' lives to the greatest extent. This was particularly identified among families where mothers and fathers of the same child participated.

- *'a lot of these things happened, kind of before school … so it was affecting [partner's name] a lot more than me because I had already gone to work by then' [ID28, father]*

Subtheme: *OCD controls the family: 'it obviously impacts the whole family' [ID22, father]*

Most parents felt that OCD negatively impacted wider family life. For example, OCD prevented family plans from being made, disrupted arrangements, and/or dictated the logistics of family activities.

- *'we can't plan anything on a weekend because she won't be able to get ready … and we have just cancelled a holiday to [location] because it was too stressful to think about going … that's just a small thing the holidays but um, well it's just everyday living' [ID24, mother]*

Parents described how OCD created *'a tension in the air at home' [ID26, father]* and disrupted family dynamics.

- *'it's wrecked the family life … the way everybody used to interact changed an awful lot, and it's you know, as parents you try to keep harmony between everybody, and it was very difficult to get that' [ID34, father]*

Many parents also perceived siblings to be negatively impacted, identifying that they had to *'just sit on the side-lines and wait until we could be there' [ID17, mother]*, which some parents felt resulted in sibling frustration.

- *‘it was more about the length of time … that I would spend with him that I couldn't then spend with other children, and I think that’s the main thing that I noted and seemed to certainly affect one of the other [children] definitely’ [ID37, mother]*
- *‘the oldest one, is very, she doesn’t like it because she perceives she is being dictated to by his OCD. And to a greater or lesser degree, an awful lot of the stuff we do do at the moment is dictated to us by his OCD’ [ID23, mother]*

However, a minority of parents identified minimal impacts of OCD on family life. Although there are many plausible explanations for this, one notable reason could be parental characteristics (e.g., parents being less likely to accommodate or not perceiving small accommodations to negatively impact family life).

- *‘his OCD doesn't affect our family life in a negative way … it didn’t prevent us from doing anything which we wanted to do’ [ID35, mother]*

Theme 5: The emotional turmoil of parenting a child with OCD

This theme captures the range of emotional challenges that parents’ experience parenting a child with OCD.

Participating parents frequently highlighted the emotional challenges of parenting a child with OCD, *‘generally, if you have got a kid with OCD, your parents, I would say are, are emotionally distraught’ [ID43, father]*. Parents’ emotions ranged from feeling *‘sad that your child is having to deal with something on top of daily challenges’ [ID18, mother]* and *‘really scared’ [ID31, mother]* to finding OCD *‘really upsetting and difficult’ [ID25, mother], ‘extremely stressful’ [ID37, father], ‘exhausting emotionally’ [ID33, mother]* and *‘all overwhelming, you are struggling to, just cope with, you know, on a day-to-day basis’ [ID43,* *father]*. Some parents also felt anxious about their child’s OCD, both now and in the future *‘well it’s worrying now, and it’s worrying whether it will go worse … because I am not sure, uh, from what I had read, if it ever goes away, and um, how he will manage’ [ID35, mother]*, exacerbating their sense of helplessness.

Moreover, parents commonly experienced blame, either self-blame (e.g., feeling they had caused/exacerbated their child’s difficulties or not sufficiently helped them) and/or blame from their wider community.

- *‘you feel a bit of a failure, like you haven't done the best for your child, I do, I feel a real failure’ [ID33, mother]*
- *‘but it's trying to live with other people's accepting it, so … coming from an Asian culture, the first thing somebody said to me was, “oh, what did you do to him?”’ [ID withheld to preserve anonymity]*

These emotional challenges meant that some parents felt isolated, perceiving themselves as the only family experiencing these difficulties. Consequently, some parents searched for belonging by trying to connect with other families of children with OCD or mental health difficulties.

- *‘immediately as soon as a parent, understands that their child has got OCD, I think they should be put in a room with other parents with children with OCD, because immediately it's really, it's such a lonely experience … and then, you know, at the point when you actually meet some other parents with children with OCD you go shit, they are going through exactly the same thing, they have to wash the clothes twenty times a day, their kid does this … that makes that experience a whole lot less lonely’ [ID43, father]*

Overarching theme: Challenge and frustration

An overarching theme of ‘challenge and frustration’ was generated to capture parents’ overall experience of parenting a child with OCD.

Parents frequently identified that parenting a child with OCD was *‘really really tough’ [ID33, mother]*. This sense of challenge was present across all themes (as illustrated throughout the theme descriptions above) and resulted in parents finding OCD *‘obviously just really frustrating’ [ID24, mother]*. Some parents’ experience of challenge and frustration improved over time, *‘we have had um a massive success in in tackling it … life is much easier, for everyone’ [ID19, mother]*, however for others, this persisted even when they were able to access treatment *‘cos I didn’t know what to do [before treatment], and then when I did know how to do it, it was still really difficult because then you have go to try and tell the whole family this is how to do things’ [ID31, mother]*.

Overarching theme: Helplessness

An overarching theme of ‘helplessness’ was generated to reflect parents’ overall experience of parenting a child with OCD.

Parental helplessness stemmed from the challenge and frustration of parenting a child with OCD. For example, parents often felt helpless as a result of the challenges and frustrations of being unable to access support for their child’s OCD. Helplessness was present across all themes (as illustrated through the theme descriptions above), particularly where parents did not know how to support their child, *‘I just feel like what can I do? What can I do? If it was like a cut or if it was, even a broken arm, you know you can plaster it over but this, it’s all inside him, I don’t know how I can, other than hug him and love him and give him all the cuddles, these worries every night are the same and I just come away feeling sick in my stomach, thinking how can I help my child?’ [ID38, mother]*. Similarly, for some parents, helplessness improved over time, whereas for others, this persisted *‘so now … we are not* *sending her to any therapist … because she'll get therapy um fatigue, and um, we need to just make sure … it's going to be, as useful as it possibly can be, you know, otherwise we don't want another wasted eight sessions' [ID43, father].*

Discussion

This study used in-depth, semi-structured interviews to explore parents' experiences of parenting a preadolescent child with OCD. We used reflexive thematic analysis to generate themes which captured the breadth of parents' experiences, allowing us to identify key implications for the development of support for parents of preadolescent children with OCD that can be widely disseminated.

The themes generated from this research compliment and expand existing quantitative research in this field. Mirroring the findings of Piacentini et al. (2003) and Stewart et al. (2017), participating parents reported disruptions to family life (e.g., disrupted bedtime/morning routines, disrupted mealtimes) as a result of their child's OCD. Despite these similar findings, the current study provides a greater insight into these challenges that are not captured in existing quantitative studies (e.g., the extent of the difficulties parents can face helping their child to get out of bed on a morning). Moreover, although participating parents frequently reported accommodating their child's OCD (in line with previous quantitative research e.g., Monzani et al. 2020; Peris et al. 2008), the qualitative nature of this study facilitated the identification of specific challenges parents face in deciding whether or not to accommodate their child's OCD and the factors that influence this decision. This detailed insight is critical to ensure that support that is developed for parents is sensitive to the challenges they experience caring for their child.

Consistent with previous qualitative research (e.g., Futh, Simonds, and Micali 2012), we identified clear challenges that parents experienced in trying to understand their child's difficulties, navigating how to respond to their child's OCD, the control that OCD had on their family, and the emotional difficulties of parenting a child with OCD. Extending previous qualitative research, our findings provided further insights into the specific difficulties parents experienced understanding and coming to terms with their child's OCD. For example, parents often experienced frustration due to OCD being misunderstood, either by other family members and/or by wider society. This appeared to be particularly challenging for parents from non-White British backgrounds who identified differences between their own and their wider communities' cultural beliefs surrounding mental illness. This finding is consistent with the wider literature which has also found distinctions between eastern and western understandings of, and views towards, mental health difficulties such as OCD (Yang et al. 2018). This highlights the need to sensitively consider possible family or cultural barriers to understanding OCD when developing support for parents.

Building on Futh, Simonds, and Micali (2012), our study provided detailed insights into how parents navigated responding to OCD. Parents often felt they had no choice but to accommodate their child's OCD, particularly when they perceived accommodation as necessary to enable their child to function (e.g., to eat, to go to school) and when there was a perceived time pressure (e.g., mornings, bedtimes). Some parents experienced both conflict within themselves as to how best to respond, and also with their partners. Thus, support for parents needs to provide clear and manageable alternatives to accommodation, that can be shared by caregivers, to empower parents to respond in ways that help to reduce their child's OCD. Given that parents may already be blaming themselves or feel blamed by others for their child's difficulties, this support clearly needs to be provided in a non-judgemental way.

In-depth interviews also provided further depth regarding the control that OCD had on children, parents, and the wider family. For example, OCD resulted in some children’s hands bleeding from repetitive handwashing, and resulted in some parents needing to wash, dress, and feed their child. We also identified the perceived control that OCD had on siblings, including reduced parental attention and perceived sibling frustration at having to adhere to OCD’s demands. The extent of this control may be particular to families of preadolescent children with OCD, given that preadolescent children are heavily reliant on their parents and family environment (Freeman et al. 2003). Such insights are crucial to be aware of when developing support for parents to ensure this reflects their experiences and needs.

Notably, we identified the battle that parents experience in accessing appropriate treatment for their child. In contrast to Futh, Simonds, and Micali (2012) (who also did not explicitly ask parents about their experiences of accessing support), parents who participated in this study frequently and spontaneously described challenges accessing treatment. Such difficulties are unsurprising, given that only around ⅓ families who seek treatment for anxiety disorders receive any kind of mental health support, and less than 3% receive evidence-based treatment (Reardon, Harvey, and Creswell 2020). These challenges often led to a sense of parental helplessness, frustration, and desperation – highlighting the need to develop support for parents which is accessible and scalable.

Strengths of this study include the use of in-depth, semi-structured qualitative interviews to provide rich meaningful insights into parents’ experiences of parenting a preadolescent child with OCD. The use of a purposive sampling approach enabled us to capture diversity in parents’ experiences, allowing us to generate a complex dataset that captured a range of parents' experiences. Specifically, we were able to capture the experiences of mothers and fathers, parents who were at different stages of the help-seeking process for their child, and parents whose children had received different types of treatment/treatment providers. We also sought to ensure high-quality data analysis by following the recommendations of Braun and Clarke (2022). For example, we reflected on the research team's knowledge and experience and considered how this shaped the data analysis and actively considered alternative possible interpretations of the data during coding meetings. This was further aided by the inclusion in the research team of KH, who brought both qualitative expertise and different research interests to the more clinically oriented members, and from obtaining feedback on preliminary data analyses from wider research teams and at conferences. Moreover, the team worked together throughout the study to ensure high quality interviews, to review initial coding, and to review analytic writing. This use of a paper trail also ensured the study was conducted in a systematic and thorough way (Braun and Clarke 2022). However, a limitation of the study is that we did not conduct diagnostic interviews to establish current or past OCD but relied on parental report regarding previous clinical diagnoses and/or children meeting clinical cut-offs on a screening measure. This meant that we could not formally confirm whether children had met diagnostic criteria for OCD (and any comorbid diagnoses). Furthermore, although parents from non-White ethnic backgrounds did participate, over 80% of the parents that were interviewed identified as White British or Other White backgrounds and the majority of parents (81.8%) had at least an undergraduate degree. Moreover, all parents had sought support for their child's difficulties. This may have been the result of our recruitment pathways, as although we advertised the study on social media (with the aim of reaching a diverse range of parents who may not have yet sought support for their child's difficulties), over half of participants were recruited from CAMHS or private treatment providers and therefore may have had to overcome several barriers to access this support

(Anderson et al. 2017; Reardon et al. 2017). Thus, the transferability of this research to parents who have not sought help and to other settings may be limited (Braun and Clarke 2022) and further research is warranted that specifically addresses this.

Conclusion

This study highlights a number of key aspects of the experiences of parents with a preadolescent child with OCD. Parental challenges and frustrations were widespread and commonly resulted in a sense of helplessness. Parents found it difficult to understand and respond to their child's OCD, to access appropriate treatment for their child, and to cope with the emotional challenges and control that OCD imposed on their families' lives. Going forward, it is important that support is provided for parents of preadolescent children with OCD that recognises (and is sensitive to) the challenges and frustrations that parents experience. Clear practical guidance on how to respond to OCD is needed to reduce parental helplessness and to empower parents to respond to their child's requests for accommodation/reassurance in ways that are both helpful for the children and manageable for the parents. Critically, this support must be able to be delivered at scale and accessible early on when families first need support, to help prevent the battle that parents often experience to access appropriate support for their child.

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Disclosure statement

The authors report there are no competing interests to declare.

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Table 1. Participant Characteristics

Child	
n	16
Mean age (range), years	11.8 (8 – 14)
Mean age of diagnosis (range), years	10.3 (6 – 12)
Female, n (%)	9 (56.3%)
Ethnicity[a]	
White British, n (%)	13 (81.3%)
Any other white background, n (%)	1 (6.3%)
Mixed background, n (%)	1 (6.3%)
Asian background, n (%)	1 (6.3%)
Parent	
n	22
Mean age (range), years	44.6 (35 - 56)
Mother, n (%)	15 (68.2%)
Ethnicity	
White British, n (%)	16 (72.7%)
Any other white background, n (%)	2 (9.1%)
Asian background, n (%)	2 (9.1%)
Not stated	2 (9.1%)
Caregiving role	
Primary caregiver, n (%)	9 (41.0%)
Secondary caregiver, n (%)	3 (13.6%)
Shared caregiver, n (%)	10 (45.5%)

Parent education	
School completion, n (%)	1 (4.5%)
Further education (e.g., college, vocational courses), n (%)	3 (13.6%)
Higher education (e.g., undergraduate degree), n (%)	12 (54.5%)
Postgraduate education, n (%)	6 (27.3%)
Parent employment status	
Unemployed, n (%)	2 (9.1%)
Employed (part-time), n (%)	9 (41.0%)
Employed (full-time), n (%)	10 (45.5%)
Other (self-employed), n (%)	1 (4.5%)
Help-seeking	
Not sought treatment, n (%)	0
Waitlist for treatment, n (%)	8 (50%)
Local CAMHS, n (%)	7 (44%)
Specialist CAMHS, n (%)	1 (6%)
Currently receiving treatment, n (%)	8 (50%)
CAMHS, n (%)	4 (25%)
Private treatment provider, n (%)	4 (25%)
Previously received treatment, n (%)	5 (31.3%)
Recruitment source	
CAMHS	12 (54.5%)
Other (e.g., charities, social media, private treatment providers)	10 (45.5%)

Note. [a] Ethnicity categories taken from Office for National Statistics (2022). CAMHS = Child and Adolescent Mental Health Service.

Table 2. Individual participant characteristics

Participant ID	Caregiver	Child age	Child gender	Received any treatment
15	Mother	7 – 11	Female	No
17	Mother	7 – 11	Female	No
18	Mother	12 – 14	Male	No
19	Mother	7 – 11	Female	Yes
23	Mother	12 – 14	Male	Yes
24	Mother	12 – 14	Female	Yes
25	Mother	12 – 14	Female	Yes
30	Mother	12 – 14	Female	Yes
31	Mother	7 – 11	Male	Yes
33	Mother	12 – 14	Female	Yes
35	Mother	12 – 14	Male	Yes
37	Mother	12 – 14	Male	Yes
38	Mother	12 – 14	Male	No
40	Mother	12 – 14	Female	Yes
44	Mother	7 – 11	Female	Yes
22	Father	7 – 11	Female	No
26	Father	7 – 11	Female	No
27	Father	12 – 14	Male	No
28	Father	7 – 11	Female	Yes
34	Father	12 – 14	Male	Yes
39	Father	12 – 14	Female	Yes
43	Father	12 – 14	Female	Yes

Note. To preserve the anonymity of participants, child age is reported as 7- to 11-years or 12- to 14-years and child and parent ethnicity are not reported.

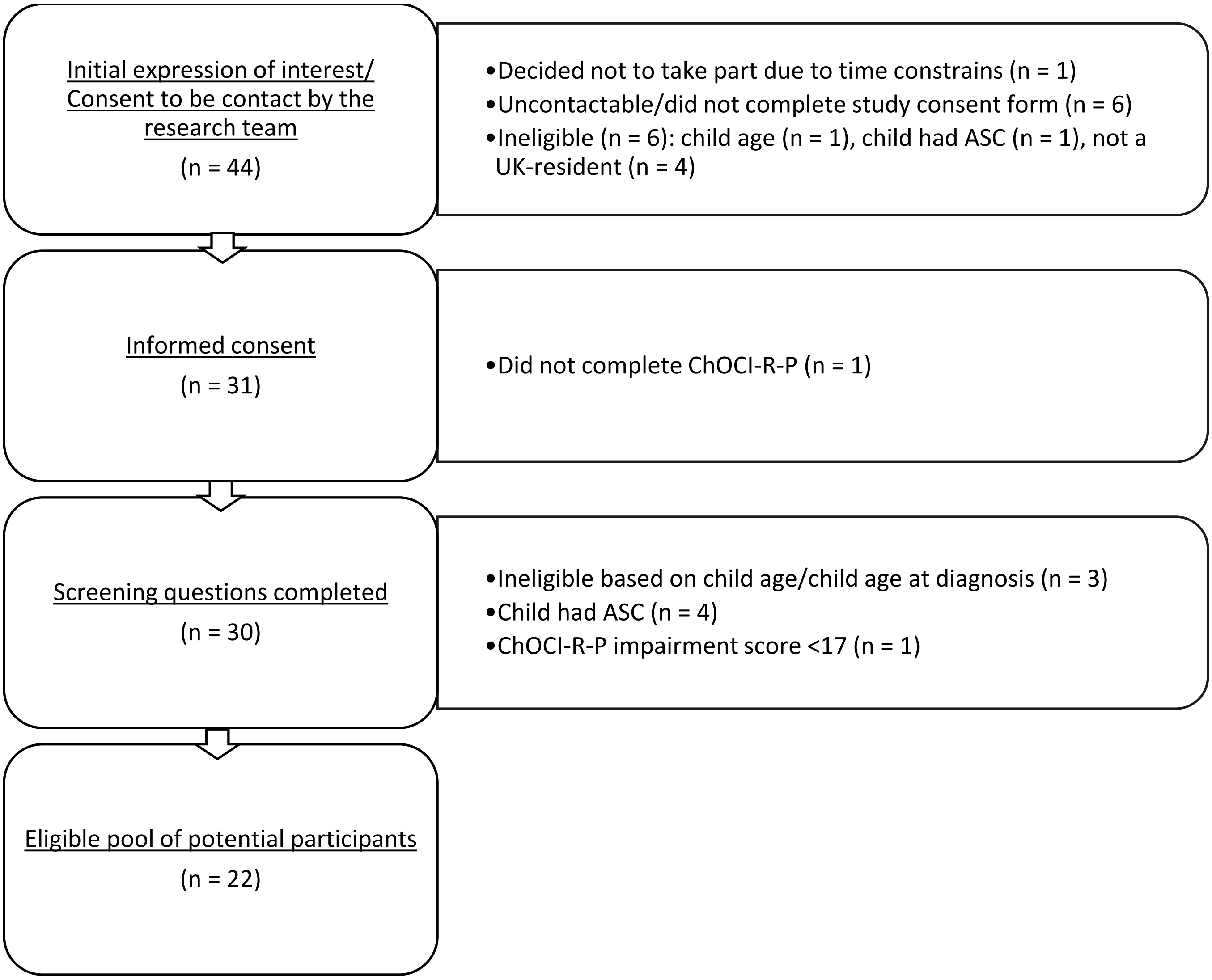

Figure 1. Recruitment of participants

Note. ASC = Autism Spectrum Condition; ChOCI-R-P = Children's Obsessional Compulsive Inventory Revised Parent report

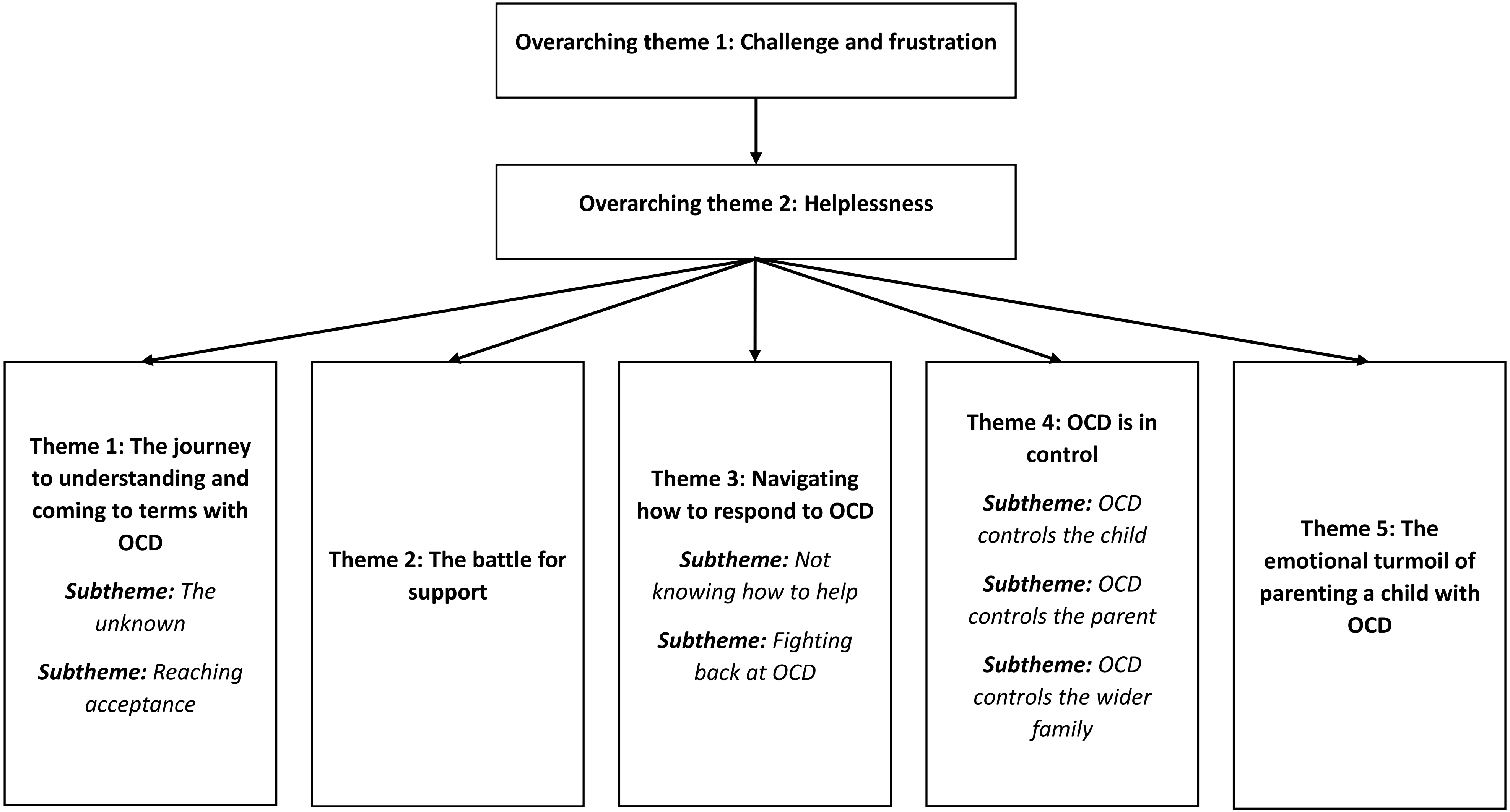

Figure 2. Thematic map