

Citation for published version:

Carly Keyes, Lizette Nolte, Timothy I. Williams, 'The battle of living with obsessive compulsive disorder: a qualitative study of young people's experiences', *Child and Adolescent Mental Health*, April 2017.

DOI:

<https://doi.org/10.1111/camh.12216>

Document Version:

This is the Accepted Manuscript version.

The version in the University of Hertfordshire Research Archive may differ from the final published version.

Copyright and Reuse:

© 2017 Association for Child and Adolescent Mental Health.

This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Self-Archiving](#).

Enquiries

If you believe this document infringes copyright, please contact the Research & Scholarly Communications Team at rsc@herts.ac.uk

This is a post-print of an article published in Child and Adolescent Mental Health. The definitive publisher-authenticated version for Keyes, C., Nolte, L. & Williams, T. (2017) The battle of living with OCD: A qualitative study of young people's experiences, can be found here: <http://shop.bps.org.uk/publications/publication-by-series/clinical-psychology-forum/clinical-psychology-forum-no-283-july-2016.html>

The battle of living with OCD: A qualitative study of young people's experiences

Dr. Carly Keyes, Dr. Lizette Nolte

Dr. Timothy I Williams

University of Hertfordshire
Health & Human Sciences Research Institute
Room 1F414, Health Research Building
College Lane Campus
University of Hertfordshire
Hatfield, United Kingdom
AL10 9AB

University of Reading
Institute of Education
London Road Campus
4 Redlands Road
University of Reading
Reading, United Kingdom
RG1 5EX

Author Note

Corresponding author: Dr. Carly Keyes University of Hertfordshire, Health & Human Sciences Research Institute, Room 1F414, Health Research

Building, College Lane Campus, University of Hertfordshire, Hatfield, AL10 9AB, cv_keyes@hotmail.com

Word Count: 5500

YOUNG PEOPLE'S EXPERIENCES OF OCD

Abstract

Background: There has been an abundance of studies that have employed quantitative methods to research Obsessive Compulsive Disorder (OCD) and its neurobiology and neurochemistry. However, there appears to be a paucity of research investigating how OCD is experienced by those living with the diagnosis, particularly young people.

Method: A qualitative cross-sectional semi-structured interview design was used to address this lack of research. Ten young people, aged 14-17 years old, with a diagnosis of OCD were recruited from Child and Adolescent Mental Health Services in the United Kingdom. Thematic Analysis was used to analyse the data.

Results: Four themes were identified: 'Traumatic and stressful life events', 'Responses to signs of OCD', 'The battle of living with OCD', and 'Ambivalent relationship to help'. Young people reported experiencing stressful or traumatic life events prior to obsessive and compulsive behaviour. OCD-behaviours were misunderstood by the young people and others, leading to delays in finding help. A sense of shame amongst the young people led them to keep their OCD secret due to feeling 'crazy'. The all-encompassing nature of OCD led the young people to withdraw socially. Most of the young people experienced an inner conflict between fighting and giving in to the compulsions.

Conclusions: Traumatic experiences may be an important factor in the development of OCD for young people, which might indicate a direction for prevention. The sense of shame and stigma

YOUNG PEOPLE'S EXPERIENCES OF OCD

needs addressing if young people are to access help earlier. Education of the public, medical professionals and educators should be a priority.

Key Practitioner Message:

- Where young people are given a diagnosis of OCD formulations of their difficulties should attend to previous traumatic or stressful life events and addressing these should form a central part of therapy.
- Interventions that help young people with an OCD-diagnosis to connect with other young people with similar difficulties should be given priority. This could include support groups, but also leaflets, booklets and videos developed by or in collaboration with experts by experience.
- A family-based approach to therapy should be offered where clinicians and family members can help guide exposure therapy in a graded and supportive manner in the young person's everyday settings outside of the therapy room. Intervention should also include psycho-education for family members.
- Training sessions for school staff involved in the schooling of a young person with an OCD-diagnosis as part of a therapy plan could help teachers understand the young person's difficulties and how to respond to it and best support the young person. Clinicians could also contribute to awareness-raising in schools to combat stigma.

YOUNG PEOPLE'S EXPERIENCES OF OCD

- Further qualitative research with young people who experience obsessive and compulsive behaviour can increase our understanding of their lived experiences, the impact of their difficulties on their lives and relationships and what they find helpful.

Keywords: Obsessive Compulsive Disorder; Thematic Analysis; Qualitative research; Trauma;

Stigma; Family interventions

YOUNG PEOPLE'S EXPERIENCES OF OCD

This is a post-print of an article published in Child and Adolescent Mental Health. The definitive publisher-authenticated version for Keyes, C., Nolte, L. & Williams, T. (2017) The battle of living

with OCD: A qualitative study of young people's experiences, can be found here:

<http://shop.bps.org.uk/publications/publication-by-series/clinical-psychology-forum/clinical-psychology-forum-no-283-july-2016.html>

The battle of living with OCD: A qualitative study of young people's experiences

In this thematic analysis we investigated the lived experiences of young people with a diagnosis of Obsessive Compulsive Disorder (OCD). OCD is the fourth most frequently diagnosed mental health problem (Barrett & Healy, 2003) and has been identified as one of the most persistent and costly forms of mental health difficulty (Lopez & Murray, 1998), including for children and young people.

Given the high prevalence of OCD-related difficulties for young people, the context within which young people develop obsessive thoughts or compulsive behaviours is important. In particular, the influence of trauma and stress has been highlighted in quantitative literature. **However, no qualitative research exploring young people's experiences of trauma and OCD was found. Research showed** a significant increase in traumatic or stressful life events reported in the six months (Khanna, Rajendra, & Channabasavanna, 1988) or one year (Gothelf, Aharonovsky, Horesh, Carty, & Apter, 2004) prior to development of OCD-related difficulties. Guidano and Liotti (1983) theorize that where, within the context of traumatic or stressful life experiences, a child comes to see the world as threatening but controllable, this can translate into

YOUNG PEOPLE'S EXPERIENCES OF OCD

active attempts to control the environment through obsessive thoughts and compulsive behaviours. Sarkhel, Praharaj, and Sinha examined the frequency of life events in adult patients with OCD as compared to normal healthy controls. 10 patients of OCD fulfilling ICD-10 criteria were rated with Yale Brown Obsessive Compulsive Scale (YBOCS), Hamilton Rating Scale for Depression (HAM-D) and Presumptive Stressful Life Event Scale (PSLES). A group of 10 controls were also rated on PSLES. The findings showed that the frequency of life events six months and lifetime were significantly higher in the patient group in comparison to controls. PSLES scores showed significant correlation with YBOCS scores. However, there was no correlation between PSLES and HDRS scores. Linear regression analysis showed obsessive and compulsive scores significantly predicted PSLES scores. Lochner et al. (2002) examined the association between childhood trauma and OCD. Specifically, the researchers assessed physical, emotional, and sexual abuse and physical and emotional neglect using the Childhood Trauma Questionnaire in 74 women with OCD, 36 women with trichotillomania, and 31 control women. They found that levels of childhood trauma in general, and emotional neglect in particular, were higher in subjects with OCD and trichotillomania than in controls. Lafleur et al. (2011) explored the relationship between OCD and traumatic life events in children and adolescents. The researchers examined the prevalence of traumatic life events and Post Traumatic Stress Disorder (PTSD) in a large sample of systematically assessed children with OCD. OCD symptoms and severity were assessed using the Children's Yale Brown Obsessive Compulsive Scale (CY-BOCS) in those with and without concurrent PTSD. Rate of PTSD and trauma exposure was higher in children with OCD than in a comparable control group of non-OCD youth matched for age, gender and SES. Children with concurrent PTSD had more

YOUNG PEOPLE'S EXPERIENCES OF OCD

intrusive fears and distress and less control over their rituals than children with OCD but without PTSD. Total CY-BOCS scores were higher in those with concurrent PTSD. Thus it was found that a history of psychologically traumatic events may be over-represented in children with OCD.

Despite the potentially devastating impact of OCD-related difficulties on young people's lives, fewer than 20% of these young people access services. It has been found that 50% of adults diagnosed with OCD recall difficulties developing in childhood, yet did not seek help at that stage (Heyman, 2005) and an average delay of 7.6 years was found from development of difficulties to search for professional help (Rasmussen & Tsuang, 1986). Where young people do access talking therapies these have been shown to improve long-term outcomes for young people (Bolton, Luckie, & Steinberg, 1995). In particular, there is substantial evidence that Cognitive Behaviour Therapy (CBT), involving exposure and response prevention (ERP), is an effective intervention for young people diagnosed with OCD (Abramowitz, Whiteside, & Deacon, 2005). However, what is referred to as 'family accommodation' (that is, where family members become involved in and support the young person's rituals) has been repeatedly tied to more severe difficulties (Merlo, Lehmkuhl, Geffken, & Storch, 2009), reduction in quality of life (Storch et al., 2009), and worse therapy outcomes (Ferro et al., 2006). Thus, involvement of families in CBT is currently recommended in the United Kingdom (NICE, 2005). Conversely, a recent randomized controlled trial of parental involvement in CBT (Reynolds et al., 2013) showed that parental involvement reduced anxiety for young people, but had less effect on effectiveness of the intervention in reducing OCD-related difficulties, indicating that more research is needed.

While all these factors have been the focus of research, there is a paucity of qualitative

YOUNG PEOPLE'S EXPERIENCES OF OCD

research investigating the experiences of those who live with OCD-related difficulties from their own perspective. The few qualitative studies, all involving adults, shed valuable light on the experiences of those who have been diagnosed with OCD. Kobori, Salkovskis, Read, Lounes, and Wong (2012) conducted a thematic analysis investigating the ways adults with OCD diagnoses experienced seeking reassurance. They identified four overarching themes, which included participants 'interrogating their feelings to achieve a sense of certainty'; 'ceaselessly and carefully' seeking to be reassured in a range of ways; experiencing a 'reluctance to seek reassurance'; and finally, experiencing 'interpersonal concern' due to feelings of embarrassment, guilt, gratitude and compensation. An Interpretative Phenomenological Analysis involving adults with an OCD-diagnosis (Murphy & Perera-Delcourt, 2012) identified that people 'wanted to be normal and fit in'; felt that they were 'failing at life', and wanted to 'find the roots' of their difficulties. Furthermore, an auto-ethnographic study of an adult highlighted how the fear of stigmatisation, a strong sense of personal shame, and feeling 'different' functioned to keep obsessions private (Brooks, 2011). Finally, a further qualitative study (Fennell & Liberato, 2007) highlighted that adults living with OCD claimed public images of OCD refer to OCD as a 'joke condition', resulting in people not recognizing the extent of their distress. No studies were identified that explored the experiences of young people with an OCD-diagnosis. **The plethora of quantitative research has not led to an improvement in outcomes and many people fail to respond to existing interventions. Whilst the literature on OCD in young people consistently describes it as a debilitating condition, there appears to be a lack of research investigating how it is experienced by young people. As described previously, to the researcher's knowledge no qualitative research has been conducted with young peoples' experiences of OCD, which is an important rationale for the present study.** Therefore, the

YOUNG PEOPLE'S EXPERIENCES OF OCD

current study begins to address this worrying gap in the literature by investigating the issues faced by young people leading up to the development of OCD-related difficulties, and exploring their experiences of living with the challenges of obsessions and compulsions day-to-day and of finding help. **It is hoped that the findings from the present study will help clinicians to offer interventions that target the psychosocial risk factors as opposed to only the maintenance factors using CBT. The intention is that these findings would contribute to our knowledge of what is most useful as a preventative approach and of what will enable long-term maintenance of gains in OCD treatment. It is hoped that the present study will make a novel and interesting contribution to the field of clinical psychology. This is because in addition to contributing qualitative data on young people's experience of their OCD, it is hoped to identify what young people experience as helpful and unhelpful in the treatment for OCD. Due to the severe and chronic nature of OCD during childhood long-term durability of treatment effects is critical to assure clinicians and young people that the deteriorating course of OCD can be halted with appropriate treatment strategies. Given the fact that childhood onset of OCD predicts adult morbidity, identifying effective interventions for this condition in paediatric populations is imperative. A final objective of the present study is to start work on collecting narratives using audio/video recordings and transcripts that would be uploaded, with the young peoples'/parents' consent, on a website (www.healthtalk.org) in the future. The website is run by the charity DIPEX (personal experiences of health and illness) with a research group (Health Experiences Research Group) based at the University of Oxford. However, currently, there is no section on OCD on the adult or youth website. It is an aim that health care professionals, particularly those who diagnose OCD in young people, will be aware of the website and signpost young people**

YOUNG PEOPLE'S EXPERIENCES OF OCD

to it. Consequently, this may help young people access psychological therapy sooner and reduce stigma and shame.

Method

Ethical approval for the study was granted by the Berkshire Research Ethics Committee as part of the wider Health Experiences Research Group (HERG) application (12/SC/0495).

A purposive sample of 10 participants was recruited through three Tier 3 Child and Adolescent Mental Health Services (CAMHS) in the United Kingdom. Five were male and five female with ages ranging between 13 and 18 years of age (mean age 15yrs 7mths). All participants had a primary diagnosis of OCD from a psychiatrist or psychologist, using DSM V criteria **and a diagnostic interview**. Participants were excluded if they had a moderate to severe learning disability. Nine participants were White British and one was South American, living in the UK. Nine of the participants were students, attending school, sixth form, or college. One participant had left school and was unemployed at the time of the interview, due to their mental health difficulties. The participants were at different stages of therapy or had been discharged from mental health services.

The interview schedule was based on the interview format used by the HERG. In addition, one of the authors (CK) consulted with two users of mental health services and attended a support group for people with OCD diagnoses, run by the Charity OCD-UK, which further informed the interview schedule. **The interview schedule was used flexibly to facilitate the participants to determine the direction of the interview. Specific questions in the form of prompts were asked in response to the material raised by the participants. The initial questions focused on the experiences of the initial signs of OCD and if there were any**

YOUNG PEOPLE'S EXPERIENCES OF OCD

stressful life events at the time; seeking help for OCD; getting the diagnosis of OCD; and asking for the young person's message for others after reflecting on their own experiences.

The interviews lasted a maximum of one hour and participants were offered to take a break whenever they required. Finally, a pilot interview was conducted with an expert by experience, who had published a book on his experiences (Wells, 2006) who acted as consultant to the project. Interviews were audio-recorded or video-recorded, depending on informed consent. Participants and their parents further provided informed consent to extracts of their interviews being uploaded onto the Healthtalkonline website (onto a new OCD section for young people) in a format of preference at a later stage.

Thematic analysis (TA) (Braun & Clarke, 2006) was used to analyze the data. **TA enabled the researcher to use a larger sample size than other qualitative methodologies and to look at themes between all the participants that comprise the group of young people with OCD.** All interviews were transcribed by a transcriber related to the HERG. The first author (CK) then familiarized herself with the data and then coded all interviews, progressing from more descriptive codes to more interpretive codes, where an attempt was made to theorize the significance of patterns and their broader meanings and implications for participants (Patton, 1990). All codes were then clustered into overarching and sub-themes. The themes were reviewed by checking if they worked in relation to the coded extracts and the entire data set, thus generating a thematic 'map' of the analysis. The other authors (LN, TW) reviewed samples of interviews and coding, as well as the final analysis which led to refinement of the analysis. The coding was peer-reviewed by a clinical psychologist. **Additionally, the transcripts were sent to all the participants to check and change. This should have minimised any bias towards a particular theoretical or overly personal perspective in order to ensure reliability. This**

YOUNG PEOPLE'S EXPERIENCES OF OCD

would have also minimised the researcher to under-code and only select hot spots that resonated with her. Finally, vivid and compelling examples were extracted from the data to illuminate the themes, relating back to the research question and literature. Quality of the analysis was ensured by following quality criteria for qualitative research as set out by Yardley (2008), including trustworthiness and transparency.

Results

Four overarching themes were identified through the analysis process, namely the prevalence of traumatic and stressful life events, responses to signs of OCD, the battle of living with OCD, and an ambivalent relationship to help. These themes and related sub-themes are presented in Table 1.

Traumatic and stressful life events

As described previously, stressful life events were explicitly asked about. The traumatic and stressful life events were explicitly linked to the OCD by the participants. Nine out of the ten participants experienced at least one of the following three life events just prior to or within a couple of months before the development of obsessive and compulsive behaviours namely 'Hostility in the family', 'Illness and death', or 'Bullying and friendlessness'.

Hostility in the family

Four participants reported hostility in their family. This refers to the participants witnessing verbal and/or physical arguments between family members, parental separation or divorce. For

YOUNG PEOPLE'S EXPERIENCES OF OCD

example, Alison¹ described witnessing her parents arguing:

"I know there was arguments between (my) parents. Obviously that does make you sad because you want them both to be happy."

Illness and death

Three participants experienced serious illness or losses just prior to the onset of their OCD-related behaviour. Tobias described how his teacher died and his sister was seriously ill in the month or two prior to the development of OCD-related difficulties:

"One of my teachers died a couple months earlier and then about a month or two later my sister got ill with a blood disease, ...and it's quite serious like and she's taking stuff and yeah like bad side effects. So it is quite serious."

Bullying and friendlessness

Six of the ten participants experienced either being bullied or having difficulties making friends just prior to the onset of their OCD-related behaviour. The majority of these participants had difficulties with peers during the transition to a new school, as Jack describes:

"Well I was being pretty harshly bullied at that school. I had big issues with pretty much everyone in the school. It was pretty hard. Mostly verbal but it got physical."

Within the context of these stressful or traumatic life experiences, half of the participants highlighted a need to assume heightened responsibility, potentially beyond what they were able to manage. For example, Gemma described:

¹ Pseudonyms are used in order to protect confidentiality.

YOUNG PEOPLE'S EXPERIENCES OF OCD

“I had to grow up before I should have really, because at age 12 I was making serious decisions. And my brother and sister were a lot younger, so I had to just be mature, because I was speaking to adults and I felt like right, I have to be mature about this... I was taking on all the responsibility myself and I was taking on the responsibility of everything, every single thing...”

For some, like Jade, carrying out her compulsions was a way to manage this felt sense of responsibility:

“I felt like it was all my responsibility. I felt it was my responsibility to keep everyone safe. And if I didn't do these things, bad things would happen.”

Thus, this theme shows that all but one participant described experiencing stressful or traumatic life events in the months immediately preceding developing obsessive or compulsive thoughts and behaviours. Within the context of these experiences, some experienced an increased need to take on responsibility within their families, and carrying out compulsions could become one way of responding to this sense of responsibility.

Responses to signs of OCD

Participants reported difficulties in responding to their obsessive or compulsive thoughts and behaviours, including struggling to understand their experiences, keeping it secret and worrying that they were ‘going crazy’ and feeling different from other people.

Lack of understanding of their behaviour

Most participants thought that their behaviour was ‘normal’ as it was so habitual from such a young age. For example, Charles states:

YOUNG PEOPLE'S EXPERIENCES OF OCD

"I didn't realise what I was doing but to me it was part of life..."

Also, most of the participants, like Gemma, reported that their parents thought their behaviour were childhood quirks and would pass without seeking help:

"Mum was sort of bordering on, maybe there is something there, but she is not sure. If she was more aware of what OCD was ...she might have seen the boxes and ticked them... because we were a bit clueless in what OCD was it dragged on a bit longer than it should have."

Once participants did seek help, most, like Jade, believed that their GP did not fully understand their behaviour, did not take their mental health difficulties seriously, and therefore did not refer them for psychological help:

"I had a bit of a bad experience with a doctor. My doctor actually didn't help at all. He laughed to be honest. I think with normal GPs they don't tend to understand the mental health side of things. They look at physical problems and he just laughed and I refused to leave the office. So he just handed me a piece of paper and said, 'call that number' and threw me out."

Furthermore, most participants believed that school did not understand their OCD-related difficulties, often mistaking it for misbehaving. For example, Alison states:

"No one helped me in school. The school was really bad, because I used to cross things out, but no one would help me. They just thought I was a normal school girl and they would shout at me if I didn't put pen to paper... They would tell me off because I wouldn't write."

All participants felt that the general public does not understand the nature of OCD and

YOUNG PEOPLE'S EXPERIENCES OF OCD

perceives it in a stereotypical way, which does not acknowledge the seriousness of their distress, as Tobias describes:

“OCD isn't just having your pens in a like co-ordinated order and saying, “oh, I've got OCD”. It's more serious than that... It's a lot of stuff. It's a much wider broader thing than people think really and that it's much more serious.”

In this sub-theme it was shown that widespread lack of understanding of OCD-related difficulties delayed participants and their parents seeking help. The period of delay varied between participants from three months to eight years.

Being secretive

All participants described being secretive about their obsessive and compulsive thoughts and behaviour, hiding it from family and peers. Jade encouraged families and clinicians to be mindful that young people can be secretive about their obsessions due to the very personal nature of these obsessions:

“Don't put too much pressure on them. It can be very personal. It can be thoughts in your head which you just don't want anyone to know about.”

A further reason for secrecy was due to the stigma and shame around having a mental health 'disorder'. This secrecy also further explains why most participants delayed seeking help for their OCD behaviours. This subtheme evokes a real sense of the pressure experienced by a young person trying to navigate between the strength of their compulsions and social convention of how to act, trying to fit in and not appear 'weird'. When the young people were alone, even though

YOUNG PEOPLE'S EXPERIENCES OF OCD

their obsessions and compulsions would intensify, there seemed to be a sense of relief, a letting go, when they could carry out their compulsions without worrying about what others would think.

“I thought I was going crazy”

Six of the ten participants feared that they were going “crazy” and thus worried about stigmatization. For example, Gemma states:

“I felt crazy at the time. I was thinking, you know, things like that. But for my GP to say, ‘right, it’s OCD...’ He’s actually saying something. I’m not going crazy, it’s all good.”

This fear of going ‘going crazy’ was informed by a powerful sense of losing control of themselves and their lives, and these concerns added to secrecy and the delay in seeking help. This contributes to an understanding of why an OCD-diagnosis came as such a welcome relief to many of the young people. There was a sense of OCD being ‘not so bad’, and offering proof that they were not ‘mad’.

Feeling different

All participants described feeling ‘different’ and misunderstood. There was a sense in the data of the young people feeling alone with their experiences and longing to share their experiences with someone who really knows what it is like from the inside. Even in relationships with those trying to help them (and who are professionally trained) they seldom described feeling understood. This led the young people to appreciate any intervention (e.g. support groups) that connected them with others with similar experiences. Bradley states:

“It may have helped talking to other people that actually have OCD, because it’s hard talking to a psychologist that doesn’t actually have it, because although they sort of understand, they

YOUNG PEOPLE'S EXPERIENCES OF OCD

don't. They understand, but they don't know what it feels like. It's hard to take advice from someone that doesn't know what you're going through. I think if you have OCD ...there should be like forums or some way to connect or Facebook or something, some form of community to sort of talk about your compulsions and things you do."

This theme described how both young people and their families, as well as medical professionals, school staff and wider society hold misunderstandings about the nature and impact of OCD-related behaviour. This encourages a fear of 'going crazy' for young people, keeping experiences secret and feeling different and misunderstood.

The battle of living with OCD

All participants reported on the battle of living with OCD-related difficulties, including a struggle to cope with the internal experiences related to their difficulties, as well as the impact on their day-to-day lives.

Feeling 'right'

All participants described an emotional search for 'feeling right'. By completing their compulsions, participants could achieve this sense momentarily, but it did not last and soon they had to work for that feeling of 'right-ness' again. Thus, it could lead to frustration, anger or at times despair. Charles used a metaphor to describe this 'feeling right' experience:

"I was lining things up 'cause it just feels right. It's just, if I didn't it would seem weird and if you break something you have been doing your whole life, say it's a tradition and you sort of don't do it, you get sort of [an] odd feeling... Sort of as if you have been doing something your whole life, say you... always slept with a cuddly toy [and then] you suddenly you you'd be a bit,

YOUNG PEOPLE'S EXPERIENCES OF OCD

don't know what to do with your arms. You didn't know how to lie. You'd feel a bit exposed, that sort of feeling."

This striving for 'feeling right' was described as persistent and always present. It could be argued that this search for a sense of 'feeling right' could be related to the context of stressful or traumatic life events described earlier, leading to a potentially overwhelming sense of distress and sense of things feeling 'not-right'.

"Everyday life is now in my bedroom"

Most participants described how they withdrew from others, gave up on activities and wanted to be by themselves in their bedrooms. The main reasons described for withdrawing were due to contamination fears around others, fears of acting on violent thoughts, fears of not being able to carry out their compulsions, and wanting to close their eyes and block out their obsessions/compulsions. Tobias explains:

"Well, [for] ages I just wanted to stay in my room because [it] kind of felt safer. I didn't want to like do anything, because I was scared of doing like bad things, like violent things, because of the OCD. So I didn't want to like put anyone at risk... I just wanted to stay by myself."

"It's ruined everything"

All participants described how their OCD-related experiences powerfully impacted on their everyday activities, particularly school. For many, it stopped them engaging in or enjoying activities or achieving their potential. Gemma describes:

"I was washing my hands nearly sort of 20 times a day. So I was quite into my studies and

YOUNG PEOPLE'S EXPERIENCES OF OCD

school was a big thing for me, and that kind of dropped back and we noticed my grades were going slightly. [And] going on holiday is so stressful when it shouldn't be. It's meant to be a time of relaxing and having fun."

Like many other participants, Jack highlighted how time-consuming his OCD-related behaviour was:

"Well we did actually calculate that I lost about a month a year from washing my hands... At one point there were times when I would spend literally sixty minutes washing my hands..."

Most participants like Alison used language of war when describing their experience:

"That's what made me cry, because I thought to myself, 'Oh my god, this is a battle now'."

This theme powerfully illustrates the compelling, all-encompassing, and time-consuming nature of the experiences of these young people, and the potentially devastating impact on their quality of life.

Ambivalent relationship to help

Despite this significant impact of their difficulties on their quality of life, most young people described an ambivalent relationship with help, finding interventions not always timely or helpful and finding therapy challenging.

Frustrations of long waiting lists

Most participants discussed how they experienced long waiting lists for mental health service input and how this delayed getting help. This led to an ambivalent relationship to help-seeking

YOUNG PEOPLE'S EXPERIENCES OF OCD

due to the young people wanting therapy, but feeling frustrated at the long waiting times. Bella states:

“Two years after that that my mum called up and said, ‘Oh, we are still waiting for help, like we haven’t received any calls or emails or anything’. And then they said that they had lost me on the system and then it took a couple of months obviously to get me back on the system. And then I got it, but the wait was annoying.”

Conflicts around exposure therapy (ERP)

Most participants experienced a conflict between wanting to resist undergoing ERP, but sensing that it would be unhelpful to do this in the long-term. They wanted their psychologists or members of their systems to guide them through the ERP in a gradual way, outside of the therapy room, as Alison explains:

“They give me experiments and expect me to go home and I’m going to be on my own again - it’s like, no. It’s a bit like prison - if you go into prison you are going to be good, because you are being watched. But as soon as you go out of prison no one is watching you. And you’re like, ‘oh, I’m free’... I need someone to watch me ... yeah I need mum to watch me. Or someone, anyone, and teachers... It’s just, you are taking us into a room all the time and it’s like we are having a meeting. We want to do something - maybe take us somewhere so you can see how we are or maybe come to our houses or take us somewhere.”

This conflicting experience led to ambivalence in relation to psychological therapy at times.

Conflicts about accommodation of the OCD

A further therapy-related conflict described by participants related to family accommodation.

YOUNG PEOPLE'S EXPERIENCES OF OCD

Young people wanted those in their systems to accommodate their OCD-related behaviours, but acknowledged in the long-term that this was unhelpful, as Amy explains:

“Well, normally I’m with my parents and my family, so they will do it... They know that I won’t touch them, so they’ll sort of just touch it for me. My mum always carries an anti-bacterial hand gel so if I don’t have one my mum’s always got one. Not in the long term probably, but in the short term it’s nice to know that there is something there that she can help me.”

Again, this conflicting experience led to ambivalence in relation to gaining help. This theme illustrated the frustration and annoyance the young people experienced in relation to the long time it could take for them to be offered talking therapies. Once in therapy, many young people described an ambivalent relationship with help, in particular described finding exposure therapy and advice for their family to avoid accommodation difficult.

Discussion

This study found that participants commonly reported traumatic or stressful life events in the period before developing obsessive or compulsive behaviour and that these were at times accompanied by a heightened sense of responsibility. The young people described how self-stigmatisation and the fear of stigma led them to keep their experiences a secret and made them feel different and ‘crazy’. This led to a delay in seeking help described by many. Participants also reported that accessing help was further delayed due to the lack of understanding of others, including medical professionals and educators.

Unsurprisingly, OCD-related experiences were reported to negatively affect the young peoples’ lives in all areas, and in particular in relation to education, taking up much of their time

YOUNG PEOPLE'S EXPERIENCES OF OCD

and energy and leading them to isolate themselves from others. Participants described an ambivalent relationship with help, struggling in themselves between resisting and giving in to OCD-related behaviour. Accommodation by parents, struggling with exposure-related interventions, feeling misunderstood by professionals, and long waiting lists all impacted on their engagement with and progress in therapy according to these participants.

Similarities with other qualitative studies are striking. For example, this study's theme of 'The battle of living with OCD' maps onto Murphy and Perera-Delcourt's (2012) theme of 'Failing at life'. Furthermore, stigma and difference as described in the current study are omnipresent across qualitative studies on OCD e.g. 'Wanting to be normal and fit in' (Murphy and Perera-Delcourt, 2012); 'Feeling different', 'Personal shame', and 'Stigmatisation' (Brooks, 2011), 'OCD is a "joke" condition – not recognised as serious' (Fennell and Liberato, 2007).

However, there were also aspects that were particular to the experiences of young people. For example, the experience of bullying, OCD-related behaviour being misunderstood at school, and parental accommodation of compulsions particularly relates to the experiences of young people.

Implications for clinicians and policymakers

The study has a number of implications for clinicians. The role of trauma and stressful life events are often not fully considered within assessment or **CBT** intervention for OCD, because the focus is most often on **current** maintenance cycles **as opposed to a focus on the past**. However, recent work on contamination fears (Coughtrey, Lee, Shafran & Rachman, 2013) has shown the importance of identifying precipitating events. It is therefore important that clinicians consider how information about the young person's history might facilitate meaning-making for the young person and enable resilience to be developed during the relapse prevention

YOUNG PEOPLE'S EXPERIENCES OF OCD

stage of therapy.

Furthermore, our results suggest that the issues of shame and stigma may impinge on the willingness of young people to engage in therapy. Therapists' sensitivity to young people 'sharing their secret' could allow for a stage of 'talking about talking' in therapy (similar to the stage described in Waite & Williams, 2009), which allows the therapist to build engagement with the young person and create a context for sharing difficult information.

Most participants experienced a conflict between wanting to resist undergoing ERP, but sensing that it would be unhelpful to do this in the long-term. They wanted their psychologists or members of their systems to guide them through the ERP in a gradual way, outside of the therapy room. Young people wanted those in their systems to accommodate their OCD-related behaviours, but acknowledged in the long-term that this was unhelpful. Also, given young people's descriptions of experiences of ERP. Therefore, actively including parents in therapy seems essential. This could include psycho-education on the negative impact of accommodation. However, it might be important to more specifically support both the young person and their parents in implementing ERP interventions, potentially including home visits and 'in vivo' work outside the therapy room.

Moreover, the participants in this research felt that teachers were not well equipped to recognize or respond to obsessive or compulsive behaviour. It might therefore be useful for therapists to provide awareness-raising events in schools; and, when working with individual young people, to offer consultation to teachers about the interventions used and explain the negative impact of accommodation. It also seems important to include awareness raising in the wider school community in order to reduce shame and stigma and increase understanding and openness.

YOUNG PEOPLE'S EXPERIENCES OF OCD

Additionally, a participant alluded to the importance of GPs to have further training in mental health and for more GPs to specialise in mental health. She highlighted the importance of medical professionals to focus on both physical and mental health.

Finally, some participants felt that contact with other young people with OCD would be particularly helpful. Support groups are not usually offered in CAMHS and the two leading OCD Charities in the UK do not fund support groups specifically for young people; thus, there is a real gap in service-provision for young people.

In addition, the study also points to implications for policymakers. Stigmatization of mental health difficulties continues and potentially has particularly worrying implications for young people. Thus, it is essential that campaigns to address this continue with rigour.

Furthermore, young people reported that they felt alone with their OCD. Books and leaflets that describe other young peoples' experiences of OCD can be particularly helpful in this regard.

Strengths and limitations of the study

To our knowledge, this is the first qualitative study of young people with OCD-related experiences. The participants included young people with co-morbidities, so can be considered more representative of young people with OCD-diagnoses in general. Service user involvement strengthened the study at all stages. Quality criteria for qualitative research and checks for trustworthiness (Yardley, 2008) were applied. In addition, member checks were carried out by sharing transcripts with participants.

Qualitative studies can be criticized for their focus on narratives provided by a small sample of participants. The themes that were identified from this study may not be generalizable

YOUNG PEOPLE'S EXPERIENCES OF OCD

to the broader OCD population. Participants in the study were predominantly White British in ethnic origin, which limits the representativeness of the findings to other ethnic groups.

Future research

It is planned to extend the current research to gain a large enough sample for the interviews to be uploaded on the Healthtalkonline website. Future qualitative research is indicated and should include young people from different cultural backgrounds.

Acknowledgments

The authors would like to express their gratitude to the voluntary organisations and the CAMHS clinics that offered us the opportunities to work with 10 young people who gave up their time to share their experiences.

YOUNG PEOPLE'S EXPERIENCES OF OCD

References

- Abramowitz, J. S., Whiteside, S. P., & Deacon, B. J. (2005). The Effectiveness of Treatment for Pediatric Obsessive-Compulsive Disorder: A Meta-Analysis. *Behavior Therapy, 36*(1), 55-63.
- Barrett, P. M., & Healy, L. J. (2003). An examination of the cognitive processes involved in childhood obsessive-compulsive disorder. *Behaviour Research and Therapy, 41*(3), 285-299.
- Bolton, D., Luckie, M., & Steinberg, D. (1995). Long-Term Course of Obsessive-Compulsive Disorder Treated in Adolescence. *Journal of the American Academy of Child and Adolescent Psychiatry, 34*(11), 1441-1450.
- Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology, 3*(2), pp. 77-101.
- Brooks, C. F. (2011). Social performance and secret ritual: battling against obsessive-compulsive disorder. *Qualitative Health Research, 21*(2), 249-61.
- Coughtrey, A. E., Shafran, R., Lee, M., & Rachman, S. (2013). The Treatment of Mental Contamination: A Case Series. *Cognitive and Behavioral Practice, 20*(2), 221-231.
- Fennell, D., & Liberato, A. (2007). Learning to live with OCD: labelling, the self, and stigma. *Deviant Behavior, 28*(4), 305-331.
- Ferro, Y., Shavitt, R., Bedin, N., de Mathis, M., Lopes, A., Fontenelle, L., et al. (2006). Clinical features associated to refractory obsessive compulsive disorder. *Journal of affective disorders, 94*(1-3), 199-209.

YOUNG PEOPLE'S EXPERIENCES OF OCD

- Gothelf, D., Aharonovsky, O., Horesh, N., Carty, T., & Apter A. (2004). Life events and personality factors in children and adolescents with obsessive-compulsive disorder and other anxiety disorders. *Comprehensive Psychiatry*, *45*(3), 192-8.
- Guidano, V., & Liotti, G. (1983). *Cognitive processes and emotional disorders*. New York: Guilford Press.
- Heyman, I. (2005). Challenges in child and adolescent obsessive compulsive disorder. *Psychiatry*, *4*(8), 73-77.
- Khanna, S., Rajendra, P. N., & Channabasavanna, S. M. (1988). Life events at onset of Obsessive Compulsive Disorder. *International Journal of Social Psychiatry*, *34*(4), 305-309.
- Kobori, O., Salkovskis, P. M., Read, J., Lounes, N., & Wong, V. (2012). A qualitative study of the investigation of reassurance seeking in obsessive-compulsive disorder. *Journal of Obsessive-Compulsive and Related Disorders*, *1*(1), 25-32.
- Lafleur, D. L., Petty, C., Mancuso, E., McCarthy, K., Biederman, J., Faro, A., Levy, H. C., & Geller, D. A. (2011). Traumatic events and Obsessive Compulsive Disorder in children and adolescents: Is there a link? *Journal of Anxiety Disorders*, *25*(4), 513-519.**
- Lochner, C., du Toit, P. L., Zungu-Dirwayi, N., Marais, A., van Kradenburg, J., Seedat, S., Niehaus, D. J. H., & Stein, D. J. (2002). Childhood trauma in obsessive-compulsive disorder, trichotillomania, and controls. *Depression and Anxiety*, *15*(2), 66-68.**

YOUNG PEOPLE'S EXPERIENCES OF OCD

- Lopez, A. D., & Murray, C. C. (1998). The global burden of disease: 1990–2020. *Nature Medicine*, 4(11), 1241–1243.
- Merlo, L., Lehmkuhl, H., Geffken, G., & Storch, E. (2009). Decreased family accommodation associated with improved therapy outcome in pediatric obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology*, 77(2), 355-360.
- Murphy, H., & Perera-Delcourt, R. (2012). 'Learning to live with OCD is a little mantra I often repeat': Understanding the lived experience of obsessive-compulsive disorder (OCD) in the contemporary therapeutic context, *Psychology and Psychotherapy: Theory, Research and Practice*, 87(1), 111–125.
- NICE. (2005). *Treating Obsessive-compulsive Disorder (OCD) and Body Dysmorphic Disorder (BDD) in adults, children and young people. Understanding NICE guidance*. London: NICE.
- Patton, M. (1990). *Qualitative evaluation and research methods*. Beverly Hills, CA: Sage.
- Rasmussen, S. A., & Tsuang, M. T. (1986). Clinical characteristics and family history in DSMIII obsessive–compulsive disorder. *American Journal of Psychiatry*, 143(3), 317–322.
- Reynolds, S. A., Clark, S., Smith, H., Langdon, P. E., Payne, R., Bowers, G., Norton, E. & McIlwham, H. (2013). Randomized controlled trial of parent-enhanced CBT compared with individual CBT for obsessive-compulsive disorder in young people. *Journal of Consulting and Clinical Psychology*, 81(6), 1021-1026.

YOUNG PEOPLE'S EXPERIENCES OF OCD

Sarkhel, S., Praharaaj, S. K. & Sinha, D. K. (2010). Role of life events in obsessive compulsive disorders. *Indian Journal of Private Psychiatry, 4(1), 46-48.*

Storch, E. A., Larson, M. J., Muroff, J., Caporino, N., Geller, D., Reid, J. M., Morgan, J., Jordan, P., & Murphy, T. K. (2009). Predictors of functional impairment in pediatric obsessive-compulsive disorder. *Journal of Anxiety Disorders, 24(2), 275-83.*

Waite, P., & Williams, T. (2009). *Obsessive Compulsive Disorder: Cognitive Behaviour Therapy with Children and Young People (CBT with Children, Adolescence and Families)*. London: Routledge.

Wells, J. (2006). *Touch and Go Joe An Adolescent's Experience of OCD*. London: Jessica Kingsley Publishers.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In, J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods*. (pp. 235-251). London: SAGE Ltd.

YOUNG PEOPLE'S EXPERIENCES OF OCD

Tables

Table 1

Themes and subthemes derived from the thematic analysis

Themes	Subthemes
Traumatic and stressful life events	Hostility in the family Illness and death Bullying and friendlessness
Responses to signs of OCD	Lack of understanding of their behaviour Being secretive "I thought I was going crazy" Feeling different
The battle of living with OCD	Feeling 'right' "Everyday life is now in my bedroom" "It's ruined everything"
Ambivalent relationship to help	Frustrations of long waiting lists Conflicts around exposure therapy Conflicts about accommodation of the OCD