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Running head: *Seeking help for OCD*

Seeking help for obsessive compulsive disorder (OCD): a qualitative study of the enablers and barriers conducted by a researcher with personal experience of OCD

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Seeking help for obsessive compulsive disorder (OCD): a qualitative study of the enablers and barriers conducted by a researcher with personal experience of OCD

Abstract

Objectives

Obsessive compulsive disorder (OCD) can be hugely disabling. Although very effective psychological treatments exist, many people delay years before seeking help or never seek treatment. There have been clinical observation and short questionnaire studies on why people delay, but little qualitative research on this complex subject. The present qualitative study aimed to identify the barriers to seeking treatment and the factors which encourage or push people to seek help for their OCD (positive and negative enablers).

Design

A qualitative exploratory study using in-depth, individual, semi-structured interviews was conducted by a researcher with personal experience of OCD.

Methods

17 people with OCD, contacted through the charity OCD-UK, were interviewed about the factors which impacted on their decision to seek help, or not. The interviews were analysed using thematic analysis.

Results

Barriers identified were: stigma, 'internal / cognitive' factors, not knowing what their problem was, factors relating to their GP or treatment, and fear of criminalisation. Positive enablers identified were: being supported to seek help, information and personal accounts of OCD in the media, and confidence in their GP. Negative enablers were: reaching a crisis point and for some participants (whose intrusive thoughts were about harming children) feeling driven to seek treatment because of the nature of the thoughts i.e. seeking help in order to prevent the 'harm' they feared they were capable of doing.

Conclusions

Participants identified a range of barriers and enablers which impacted on their decision to seek help, or not. These give important indicators about the likely causes for delayed help-seeking in OCD, and ways in which people might be encouraged to seek help earlier.

Practitioner Points

- * People with OCD may face a wide range of barriers to seeking help, including concern about the reaction of health professionals.
- * The level of awareness, kindness and understanding shown by first-line practitioners can be very important to those seeking help.
- * Acknowledging a person's journey prior to seeking help is likely to foster trust between therapist and patient.
- * Some barriers to seeking help, e.g. fear of criminalisation, may continue to have an important effect afterwards unless sensitively explored and understood.

Introduction

Obsessive compulsive disorder (OCD) is an anxiety disorder which can have a profoundly negative effect on people's lives. However, many people delay a considerable time before seeking help.

OCD is not particularly common. Torres et al. (2006) describe it as "a rare yet severe mental disorder ... an atypical neurosis". They found a prevalence rate of 1.1%. However, the extent to which it can interfere with people's lives is huge, "sometimes reaching a level of impairment comparable to that seen in psychotic disorders" (Torres & Prince, 2004). OCD is associated with more comorbidity and more marked social and occupational impairment than the common mental disorders it is often grouped with (Torres et al., 2006). There are now very effective psychological treatments for OCD (cognitive behavioural therapy incorporating exposure and response prevention, Rachman & Hodgson, 1980; Salkovskis, 1999) and some promising new approaches are being developed in mental contamination (Coughtrey, Shafran, Knibbs & Rachman, 2012; Coughtrey, Shafran, Lee, & Rachman, 2013). However, a UK study found that the average time between OCD interfering significantly with a person's life and their seeking help was 6 years (Stobie, Taylor, Quigley, Ewing & Salkovskis, 2007). Garcia-Soriano, Rufer, Delsignore, & Weidt (2014) reported that the average delay from the onset of symptoms to first seeking treatment ranged from 3.28 years in Spain (Belloch, Del Valle, Morillo, Carrio & Cabedo, 2009) to 17 years in the USA (Pinto, Mancebo, Eisen, Pagano & Rasmussen, 2006).

Torres et al. (2007) found that people who only had OCD (and no comorbid disorder) were much less likely than people with OCD and a comorbid disorder to be receiving treatment (14% compared with 56%). It is possible that people with OCD and comorbid disorders sought help for their other emotional problems rather than their OCD (Torres et al, 2007).

Evidence regarding reasons for delaying is mostly derived from short questionnaires embedded in large-scale epidemiological studies. An internet survey has also been reported (Marques et al., 2010).

Goodwin, Koenen, Hellman, Guardino and Struening (2002) argued that it may be that only those whose OCD is most severe and disabling seek help. However, it could be that factors such as stigma are preventing people from accessing treatment. In their study only 40.4% of the people who screened positive

for OCD in a national screening day had ever sought help. Those who had never sought help were asked which of eight specified barriers they endorsed. The most frequently endorsed barrier was lack of information; '*Not sure where to go*' (39.8%), then '*Can handle it on my own*' (28.4%), '*Can't afford treatment*' (24.9%), '*Afraid what others would think*' (20.5%), '*No insurance*' (16.7%), '*Afraid to take medication*' (14.7%), '*Treatment won't help*' (5.7%), and '*Don't have an anxiety disorder*' (4.5%).

Lack of information has been raised by a number of authors. Torres et al. (2007) suggested that the lower level of public awareness about OCD (as compared with depression) may be a barrier. Stengler-Wenzke and Angermeyer (2005) found that participants often did not realise the significance of their first symptoms of OCD, and nor did family members. Moreover, people may be unaware that their problem can be effectively treated (Nestad, Samuels, Romanoski, Folstein & McHugh, 1994; Fireman, Koran, Leventhal & Jacobson, 2001). Williams, Domanico, Marques, Leblanc and Turkheimer (2012) found that more African American participants indicated that they were 'unsure about who to go see or where to go' than European American participants.

Themes related to stigma are also described by a number of authors. People are embarrassed (Torres et al., 2007) and may fear that they will be considered mentally ill, hospitalised or criminalised if they describe their symptoms. Indeed, OCD has sometimes been referred to as 'the secret illness'; "People with obsessive compulsive difficulties tend to be secretive about their problems and may be confronted with many fears about admitting the content of their thoughts to others" (Salkovskis, 1990).

For their online survey, Marques et al. (2010) developed the *Barriers to Treatment Questionnaire* based on the 'broader barriers to treatment' literature. The six most frequently endorsed barriers were: '*I felt ashamed of needing help for my problem*' (58%), '*I was worried about how much it would cost*' (57.1%), '*I wanted to handle it on my own*' (54.5%), '*I felt ashamed of my problems*' (53.2%), '*I was unsure about who to see or where to go*' (50.4%) and '*I didn't think treatment would work*' (48.9%).

Drawing on their clinical practice, Belloch et al. (2009) designed a short questionnaire (*Interview on Help-Seeking*). The barriers most frequently endorsed by participants with OCD were; feeling that the problem was temporary, feeling that they could control the problem, believing that their behaviours / thoughts were not serious, feeling ashamed of the thought contents, and fearing stigma. The most frequently endorsed

motivators were; the problem not going away or not being able to control it, the problem interfering in what they were doing, the problem becoming more disturbing / frequent, and it making people feel sad.

The studies using short surveys give us helpful pointers as to which factors may influence help-seeking in OCD. However, the decision-making process as to whether or not to seek help is likely to be a complex one, and it is unlikely that it can be adequately captured by answering a short questionnaire alone. Given our limited level of knowledge on seeking help for OCD there is a particular need for in-depth studies. We found five qualitative studies with a bearing on this area; one on anticipated stigma and actual experience of stigma (Stengler-Wenzke, Beck, Holzinger & Angermeyer, 2004), one on pathways to psychiatric care (Stengler-Wenzke & Angermeyer, 2005) and three on the lived experience of OCD, including the experience of stigma (Murphy & Perera-Delcourt, 2014; Harrington, 2014 and Fennell & Liberato, 2007). However, we found no qualitative studies specifically examining the barriers and enablers in seeking help for OCD.

People with OCD may endure years with a vastly reduced quality of life before they seek help, or they may never seek treatment. There are likely to be a range of very powerful factors driving this. It is vital that we ask people with OCD directly, and in detail, about the whole subject of help-seeking. The present study sought to address this need for qualitative data through in-depth, individual interviews, conducted by a researcher with personal experience of OCD. The objective of the study was to identify the factors which encourage people with OCD to seek help, and the reasons why people do not seek treatment.

Personal background

The first author delayed 24 years before seeking help for her own OCD. She went on to have cognitive behavioural therapy (CBT) at a specialist NHS clinic. This proved completely life-changing. She initiated and conducted this study while having CBT and training as a mental health researcher.

Method

Design

This was a qualitative, exploratory study. It used in-depth, individual, semi-structured interviews conducted by a researcher with personal experience of OCD.

Participants

Potential participants were contacted through OCD-UK, a charity run by people with personal experience of OCD. The study was open to people with an official diagnosis and those who self-identified as having OCD, people who had sought help early, delayed seeking treatment or never sought treatment. Twenty six people contacted the researcher by phone or e-mail. Seventeen decided to take part.

Measures

Participants completed a 'Basic Information Form' (Supporting Information S.2. in Appendix S1) giving information about themselves and their OCD. An 'Interview Plan and 'Topic Guide' were also developed (Supporting Information S.3. in Appendix S1). Participants were asked to describe the story of their OCD, and then more specifically the factors which had encouraged or delayed them in seeking treatment. They gave very full answers so the prompts were largely unnecessary. After the interview participants were invited to complete the self-report version of the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) (Goodman et al., 1989) and the Y-BOCS Symptom Checklist (group headings only).

Role of researcher with personal experience of OCD

Having a researcher with personal experience of OCD was an important part of the methodology of the study. Today there are a growing number of researchers, often called service user or survivor researchers, who bring a perspective of personal experience of mental health problems and accessing services to their work (Sweeney, Beresford, Faulkner, Nettle & Rose, 2009) rather than, for example, a clinician's perspective. They are open about their mental health status in the course of their work e.g. disclosing their shared identity to potential research participants (Faulkner, 2004). In this study the researcher drew on her personal experience when framing the research question, developing the design, thinking about how to conduct the interviews, reading the interview transcripts, forming the codes and doing the analysis.

Qualitative analysis

Relevant sections of the tapes were transcribed verbatim by the first author and analysed using a simple thematic analysis (Braun & Clarke, 2006). NVivo 7 was used to create nodes reflecting themes in the text under two broad headings; barriers to seeking help and enablers. Nodes were added, merged, deleted, sub-divided and re-defined as the transcripts were analysed and the themes became clearer. They were later grouped under tree nodes. The tree nodes, or main themes (represented as rectangular boxes) and the key nodes, or sub-themes (represented as ellipses) are presented in two visual summaries (Figures 2 & 3 in the Results section). The length / width of each ellipse is proportional to the number of participants who mentioned that factor. Quotations from the interviews have been used extensively to illustrate the sub-themes.

For purposes of validity the first author had two meetings with the second author, who is very experienced in working with qualitative data, to look at the transcripts and discuss the nodes created. This was to test the first author's interpretation of the transcripts and the appropriateness of the nodes. The second author is a highly experienced service user researcher. She gave expert input to the design of the project and analysis of the findings. She does not have personal experience of OCD.

Procedure

The study was approved by a King's College Research Ethics Committee in the UK (Ref: 05/06-140). OCD-UK carried a Leaflet about the study on their website (Supporting Information S.1. in Appendix S1). It explained that the study was being conducted by a researcher with personal experience of OCD. Those interested in taking part arranged a convenient time to have the interview in a venue of their choice (e.g. at their home, in a quiet cafe or library, but deliberately not in a clinical setting). Participants gave written informed consent to be interviewed and for the interview to be audio-taped. The interview took 1-1.25 hours. Participants later received the results of the study.

Results

Participant characteristics

Of the 17 participants, 11 were women and 6 were men. Their mean age was 36, ranging from 21 to 57. Their ethnic groups were: 'White British' (15), 'White Other' (1) and 'Any Other' (1). 6 participants had CSEs / GCSEs or equivalent as their highest educational qualification, 3 had A levels or equivalent, 7 had a degree / postgraduate qualification, and for 1 participant educational status was not known. Employment status also varied; 8 participants were working, 2 were students and 7 were not working.

The age of participants when OCD first interfered significantly with their lives ranged from 7 to 48 years. The most common age-range when this occurred was 16 – 20 years old (6 participants) and the second most common was 11 – 15 years old (4 participants). The time between OCD significantly interfering with participants' lives and their seeking help ranged from a few weeks to twenty years (Figure 1). The mean delay was seven years. Five participants delayed seeking treatment for over sixteen years and one person had never sought help. However, two people sought treatment within a year.

Figure 1

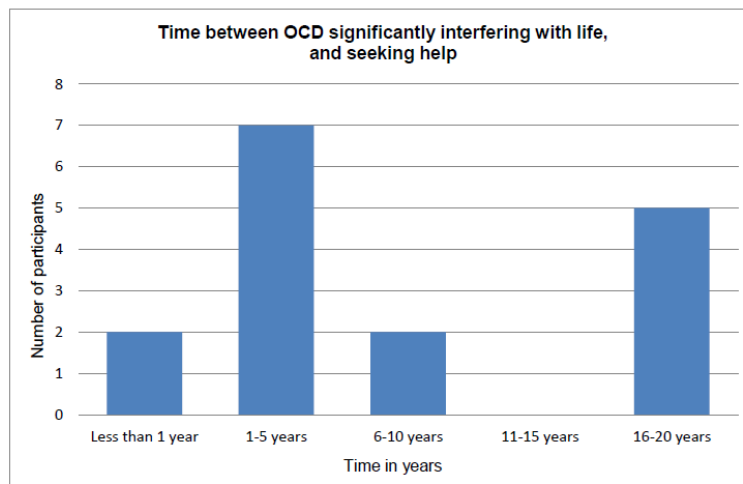


Figure 1

Time between OCD significantly interfering with participants' lives, and their seeking help, if they have done

Sixteen participants completed the Y-BOCS Symptom Checklist (group headings only), one preferring not to. Participants reported currently experiencing a range of types of obsessions; aggression (9), contamination (6), sexual (3), hoarding / saving (4), religious (3), symmetry / exactness (5), miscellaneous (8), and somatic (7). Many participants reported obsessions under more than one heading. Reported current compulsions were cleaning / washing (4), checking (6), repeating (8), counting (4), ordering / arranging (5), and miscellaneous (12). Additionally, one participant described hoarding in the interview. One participant reported no compulsions. Many participants reported compulsions under more than one heading.

15 out of 17 participants completed the Y-BOCS Scale. According to the Scale, 3 participants were regarded as 'Subclinical', 3 had 'Mild OCD', 7 had 'Moderate OCD', and 2 had 'Severe OCD'. 14 out of the 15 participants who completed the Scale had had an official diagnosis of OCD; the participant who had never sought help had 'Moderate OCD'. The mean score of the 12 participants who completed the Scale, and whose score was at a clinical level, was 18.2. The 3 participants who were in the 'Subclinical' range had all had an official diagnosis of OCD in the past, and had had / were having successful treatment.

Interview findings

In the interviews we focused on the barriers and enablers to seeking help. The findings are therefore presented in the following two sections;

- * Factors which caused people to delay seeking help (barriers)
- * Factors which encouraged or pushed people to seek help (enablers)

Factors which caused people to delay seeking help (barriers)

Five main themes were identified as barriers to seeking help;

- * Stigma
- * 'Internal / cognitive' factors causing people to delay

- * Not knowing what it was
- * Factors related to GP / treatment
- * Fear of criminalisation

These five main themes, and their sub-themes, are represented in a visual summary on the following page, 'Factors which caused people to delay seeking help for their OCD (barriers)' (Fig. 2). They are described in more detail below, illustrated by quotations from the transcripts. Participants often described more than one of the themes.

Stigma

When participants talked about any barriers they had experienced to seeking help, stigma emerged as a very important main theme. Participants feared stigma in a range of contexts and relationships, as described in the following five sub-themes.

Not wanting to tell people

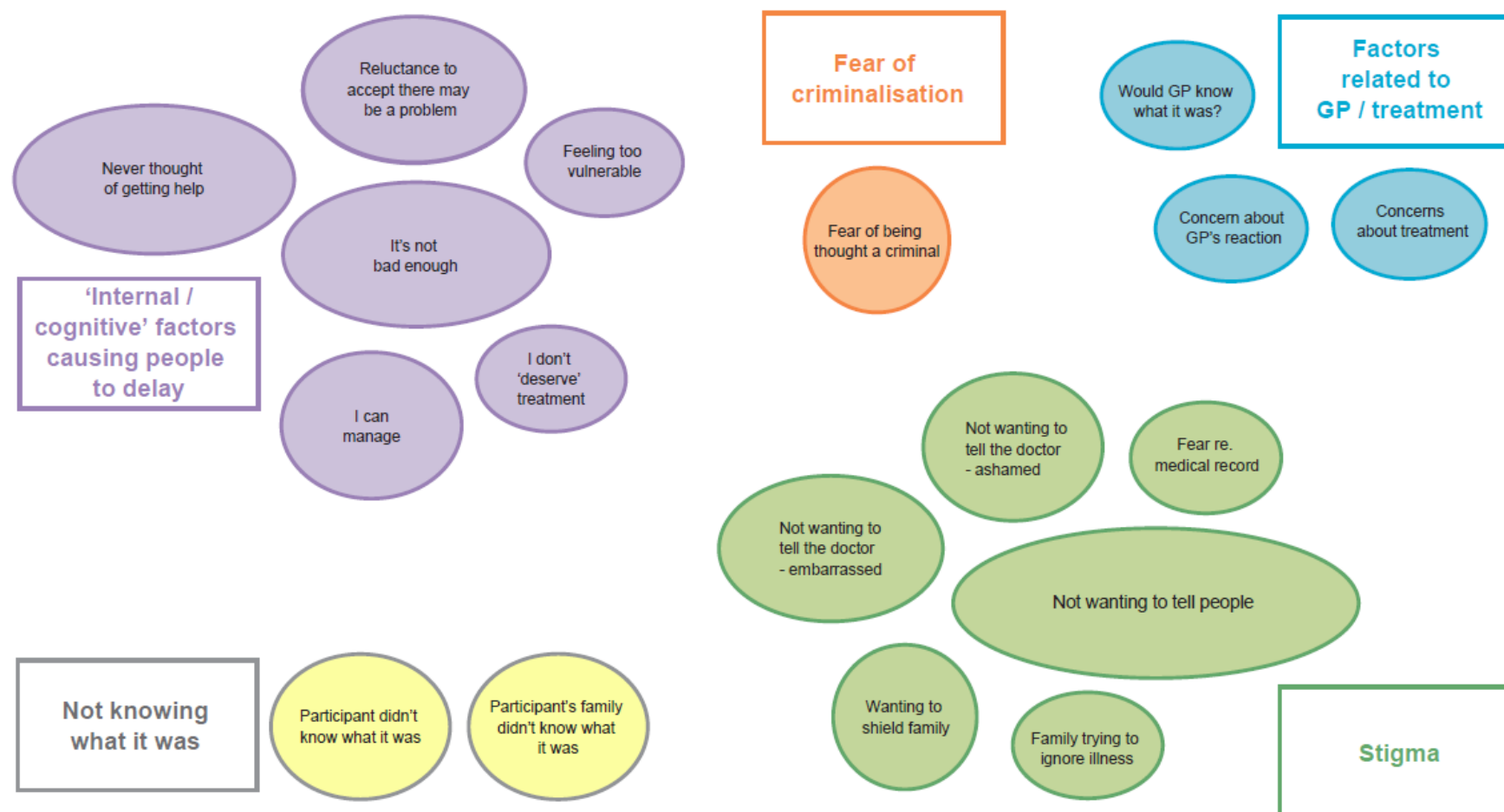
Nine participants spoke of the efforts they made to hide their OCD from other people, including friends, family and work colleagues. "Nobody knows – nobody had ever known I had it ... And you don't want people to know." Two participants described keeping the illness secret from their family; "But you know all ...through this time my family ... didn't know really anything that was going on. Then I did take sick leave. Obviously I had to sort of let them know. And then that was the first time in my life that I told them." Two participants described not telling their partners, over many years, about their OCD. Asked about telling her / his partner, one participant who had intrusive thoughts about harming their children, replied; "No, never ... but I was very open about it once I was diagnosed."

Not wanting to tell the doctor

Participants also spoke specifically about not wanting to tell the doctor. Five participants said this was because they felt embarrassed. "I felt embarrassed as well about it, cos I didn't understand why I was doing it. That's one of the main reasons why I did delay for so long because I was embarrassed."

Figure 2

Factors which caused people to delay seeking help for their OCD (Barriers)



Note: Main themes are represented as rectangular boxes. Subthemes are represented as ellipses. The length / width of an ellipse is proportional to the number of participants who mentioned that factor.

Three participants spoke of not wanting to tell the doctor because they felt ashamed, and one spoke of feeling humiliated if she went to the doctor. "I would never have gone ... it is a sense of shame of it."

Fear about having OCD on your medical record

Two participants said an important reason they did not seek treatment was that they didn't want OCD on their medical record; "Also I didn't want it on my record ... I didn't want to have to be admitting to it for the rest of my life ... I felt if I went to the doctor, that was it, it was official, and I would always have to put that from then on, it was always going to be a reality ... if I tried to get another job, and there was a medical form, I'd have to say I have OCD and I wasn't strong enough at that point to say that." One of these participants delayed seeking help for twenty years because of fear of discrimination; fear that a mental health record would jeopardise her / his career. It was only when s/he was at the top of her / his profession that s/he felt able to seek help: "I said, what if my GP knows, and then, if I go for interviews and it goes on the Occupational Health form [*inaudible*] against me? Probably it wouldn't have been. But you don't know."

Wanting to shield the family

Three participants mentioned wanting to shield their families from the knowledge that they had a mental illness; "Also just the fear of like admitting to your parents as well, that you've got that problem, and wondering whether, whether your parents would be, they might be upset about knowing their child has a psychological issue."

Family not wanting to acknowledge participant had an illness

Two participants described their families not wanting to acknowledge that they had an illness. "Maybe they felt they'd somehow failed if I was carrying on like this. And maybe they thought what if there's something really wrong about, what, [s/he's] mental or something. Just try and ignore it and [s/he] might stop."

'Internal / cognitive' factors causing people to delay

Also very important was a range of factors which we grouped under a main theme heading; 'Internal / cognitive' factors causing people to delay. By this we meant people's internal appraisals of their problem or

people's internal state causing them to delay. There were six sub-themes under this main theme;

It's not bad enough

Six participants said they felt that their OCD was not bad enough to seek treatment. A participant whose OCD obsessions and rituals were taking up about three hours a day said, "No, no. Because to me it didn't affect me enough." Because s/he was able to go to work and go out, s/he didn't feel it was interfering sufficiently to seek help. One participant was nearly prevented from having children by her / his OCD, and yet did not feel that the OCD was significantly interfering with her / his life during this period. One participant's account of a visit to the doctor illustrates the difference between her / his view of the severity of her / his OCD and the doctor's view; "And he immediately referred me and I was so surprised because I thought what I told him was not sort of, of much sort of significance almost."

I can manage

Four participants described delaying seeking help because they felt they could manage the problem themselves; "I think for a long time I felt maybe I could deal with it myself. I felt I wanted to deal with it myself."

Reluctance to accept that there may be a problem

Five participants described how they, or their parents, did not accept that they had a problem, or thought that it would go away; "But I think maybe it was just kind of, if we don't focus on it, it will go away. If we pretend it's not happening, it's not really there ..."

Never thought of getting help

Six participants said that, at least for a period, it had not occurred to them to seek help. Two of these participants linked this with their OCD having become so much a part of their everyday life. One said their OCD, "had always been there. Yeah, it's like ... every day." Asked if s/he had thought someone would be able to help, s/he said, "No, I never thought about it ... No, never entered my head." One participant said, "I suppose you also don't know how much different things can be, if you do get the right advice and treatment ... cos that's what, that's the only thing you've ever experienced."

Two of the six participants described the difficulty of knowing whether it was 'only you' doing these things: "But you do think you're in a unique situation ... and you're kind of like nobody's ever going to understand why I'm doing this, and what I'm doing, which I guess is another reason you don't go and tell people."

I don't 'deserve' treatment

Two participants described feeling they didn't 'deserve' treatment. One participant, who was currently taking medication, talked about whether s/he would seek CBT; "I don't feel it becoming worse. And therefore ... you know, the NHS spirit, rightly or wrongly I call it, that ... that other people's needs are greater than mine and if they sign up and get it first then, it's probably they deserve to, or need to, more than I do. But I certainly haven't ruled it out."

Feeling too vulnerable

The process of seeking help takes mental and emotional energy in itself. Two participants spoke about this sub-theme; "I also think, I just wasn't strong enough to talk about it at the time. Um, like when I told the doctor, I cried ... I wasn't strong enough to talk about it and think about it, I guess. Um, so that was part of it as well, I was so exhausted, I was so ill, and stressed."

Not knowing what it was

Another important barrier to seeking help was not knowing what the problem was; a lack of knowledge or information about OCD. This theme was divided into two sub-themes;

Participant didn't know what it was

Four participants described having no idea what they had; "And, I remember ... one of the reasons I didn't ask for help when everything started is because I had no idea of what was going on."

Participant's family didn't know what it was

Four participants described their families not knowing what it was. "And in those days people didn't know about OCD and you know, my parents certainly didn't ... And I don't really think, until I actually told them in

this letter that I gave them last year, that they realised that I had OCD. They realised that I was a bit strange! But they didn't know exactly what it was ... So I think it's a sort of um, you know, a huge lack of knowledge."

Factors related to GP / treatment

Another type of barrier which participants experienced related to the person's GP or the treatment they thought they might be offered. There were three sub-themes here;

Would the GP know what the problem was?

Two participants were concerned that the GP may not be able to identify what the problem was; "I suppose, yeah, um, doubting whether the doctors would know what it was and be able to help, would have been one of those compounding factors." Uncertainty about a doctor's level of knowledge about OCD and its treatment therefore acted as a barrier to seeking help. Indeed one participant said that s/he only felt able to go to the GP when s/he had worked out what the problem was, and had a fairly good understanding of OCD.

Concern about the GP's reaction

Two participants were concerned about their doctor's reaction to their seeking help for their OCD; "I didn't know sort of what it would be like and I suppose what they would think." Under the 'Stigma' theme above we wrote about participants not wanting to tell the doctor because they felt embarrassed or ashamed. Here the barrier is uncertainty and concern about how the GP would react.

Concerns about treatment

Two participants described concerns about the treatment they might be offered as contributing to their delay in seeking help. For one participant this was about medication, for the other it was about psychological treatment; "You don't know whether they're going to give you medicines, and you know, that might seem a bit of a sledgehammer to crack a nut." "I think in a sense ... not having to go through the hard process of CBT ... not having this long process of getting better."

Fear of criminalisation

For three participants fear of criminalisation was a huge barrier to seeking help. Participants whose intrusive thoughts were about harming children feared that they might be locked up and that their children might be taken away from them. A participant whose intrusive thoughts were about sexually abusing children feared the authorities might think s/he was a paedophile. “Oh ... I really thought that if I told them what I was thinking that I’d be either sectioned or sent to prison ... Really, that was like the scariest thing ... I don’t think anyone wants to be sectioned or sent to prison, do they? ... So that’s why. I just thought ... other people would think, ‘Oh my God’, you know, ‘What a monster’. That’s why I never told anybody.”

Factors which encouraged or pushed people to seek help (enablers)

Five main themes were identified as enablers to seeking help;

- * Being supported or urged to seek treatment
- * Crisis / crunch point
- * Media / information
- * Confidence in GP / mental health professionals
- * Driven to seek treatment because of the nature of the thoughts

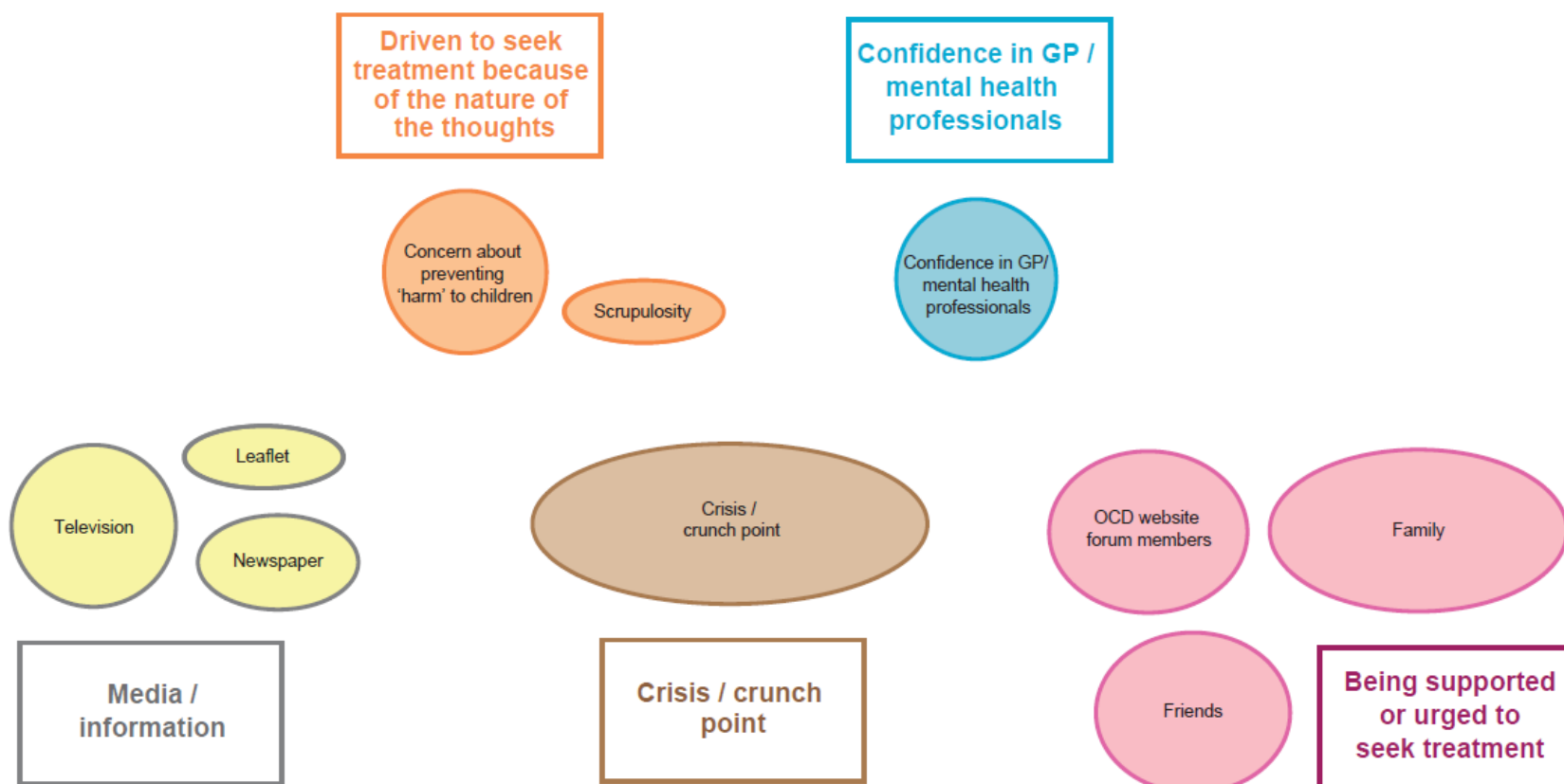
The five main themes, and their sub-themes, have been represented in the visual summary on the following page, ‘Factors which encouraged or pushed people to seek help for their OCD (enablers)’ (Fig. 3). They are described in more detail below, illustrated by quotations from the transcripts. Participants often described more than one of the themes.

Being supported or urged to seek treatment

Six participants described their partners or other members of the family encouraging them to seek help or making the decision for them. Two of these participants, whose OCD developed when they were children,

Figure 3

Factors which encouraged or pushed people to seek help for their OCD (Enablers)



Note: Main themes are represented as rectangular boxes. Subthemes are represented as ellipses. The length / width of an ellipse is proportional to the number of participants who mentioned that factor.

described their parents making the decision to go to the doctor: “I can remember sitting there, and they said to him, Oh, [s/he’s] got the weight of the world on [her/his] shoulders.”

Four participants described friends being influential; “She had said you must have treatment. There’s treatment out there ... she kept on, I mean it was over a period, for about a year she kept on at me ... but you know every time she mentioned it, I wouldn’t talk about it ... I’d brush it off. I’d be so, so horrendously embarrassed ... but it was through her pushing me ... to do something about the OCD. There could be something done about it. I wasn’t aware of treatment till she started telling me.”

Four participants described being supported by OCD website forum members; “I can remember writing on the forums on the websites, saying, you know, I’m going to the GP and ... everyone thought, ‘Oh, well done.’ You know. ‘You’ll be fine.’ ‘Don’t be scared.’ And getting loads of replies back.”

Crisis / crunch point

Eight participants said that it was reaching a crisis / crunch point that finally pushed them to seek treatment. “I got to another stage where, um, the head wasn’t coping again, and I was getting extremely depressed. The only reason I went to the doctor in the first place was I left my [partner] a note ... and I’d been drinking one night, and left [her / him] a note, ‘I want to die’. I couldn’t cope. And I thought I wanted to take an overdose. So my [partner] took me to see my doctor. Which was a good thing.”

Media / information

Six participants discovered what their mental health problem was through the media; three from watching a television programme, two through a newspaper article and one from a leaflet. None of these media outlets were connected to the National Health Service. None of the six participants had sought help for their OCD at the point when they discovered what their problem was. All subsequently did so: sometimes quickly, sometimes after several years.

One participant had seen a psychiatrist, psychologist and community psychiatric nurse, at different times, and had been diagnosed with anxiety. However, s/he had never been able to tell them about her / his

intrusive thoughts about harming children. “No, I didn’t say anything. I was too scared.” Then s/he caught a few minutes of the television programme ‘This Morning’; “I seen that lady on the tele ... I watched her tell her story and I thought, ‘Oh my God!’ It was just like a revelation! ... relief poured down ... I wasn’t relieved to find out that I’d got OCD, but I was relieved to find out, you know, I weren’t going to get sectioned or sent to prison.” This participant sought help for her / his OCD one week later.

Confidence in GP / mental health professionals

Three people described having some or considerable confidence that their GP, or mental health professionals, would be able to help. One participant, after delaying seeking treatment for over three years, deliberately chose to see a doctor who s/he “had a vague memory was good at listening to people”. Her / his choice proved to be a good one; “I was nervous before I went, obviously, um, but I felt that I can do this... I got there and ... at that point I sort of crouched, and I was like ‘I’ve got OCD’, and I just burst into tears basically. But she was really good ... I was lucky, because she knew a lot about OCD, she knew about treatments ... and she was very kind.” A second participant had confidence in mental health professionals because of the positive experience of a family member.

Driven to seek treatment because of the nature of the thoughts

Three participants were driven to seek treatment because they had intrusive thoughts about harming children. They were very frightened by these thoughts and mistakenly interpreted them as meaning they were capable of harming children. They sought help (one immediately and two after lengthy delays) to try to prevent the harm they feared they were capable of doing; “And at this stage ... I thought my children were in immense danger.” This participant sought help, “firstly for my children ... I thought you’ve got to be a decent person.”

A fourth participant was driven to talk to a health professional about her / his OCD for the first time because of her / his intrusive thoughts related to scrupulosity; “At the point I got the permanent job I had to fill in an Occupational Health form ... and one of the bits was anxiety disorders. And ... I guess with the confessing thing, having to be 100% clear I was telling the truth, which I also understand is an OCD thing,

and so I felt I had to fill it in ... but I was really wound up by that, and upset, because I'd never told anybody".

Discussion

The study identified a formidable array of factors which caused people to delay seeking help (barriers) and a strikingly smaller number of enablers. Comparing barriers and enablers side by side (Figs. 2 & 3) it is clear that as well as being more numerous the barriers were also mentioned by more people than the enablers. As the enablers included factors which drove people to seek help (negative enablers) as well as factors which encouraged people to seek help (positive enablers), the contrast between the number of barriers and *purely positive* motivators for seeking help was particularly stark.

Taking barriers first, the most prominent overall themes were stigma and 'internal / cognitive' factors causing people to delay. With regard to stigma, the findings from this study support the suggestion in previous studies (e.g. Belloch et al., 2009,) that fear of stigma is an important barrier to seeking help. As has been observed previously (Salkovskis, 1990), many participants in this study made considerable effort to keep their OCD secret.

However, the present study suggests that stigma is an even more powerful barrier than has previously been indicated. With the exception of the internet survey by Marques et al. (2010) the first author felt that fear of stigma may have been under-estimated in previous research which used a checklist / survey type approach (e.g. Goodwin et al., 2002). In the present qualitative study, involving in-depth individual interviews, people feared this stigma at many levels; in the reaction of their GPs, their friends and families, and current or potential future employers. It is possible that this study, conducted by a researcher with personal experience of OCD, enabled participants to talk more openly about the importance of stigma as a barrier to seeking help. The relative anonymity of the internet survey by Marques et al. (2010) may also have made it easier for participants to acknowledge stigma as a barrier.

Consistent with previous research (Goodwin et al., 2002; Belloch et al., 2009) participants in this study described factors such as thinking 'I can manage' or 'It's not bad enough' as important barriers to seeking

help. These are defined here as 'internal / cognitive' factors causing people to delay. 'Internal / cognitive' factors appear to form a formidable barrier, equal in importance to the fear of stigma.

With regard to the factors 'I can manage' and 'It's not bad enough', the first author reflected that many participants seemed to set themselves an extraordinarily high threshold with regard to the level of interference that OCD needed to cause in their lives before they considered it appropriate to seek treatment. This could be seen from the outside as a form of stoicism, or even heroism. It could also be linked with the high levels of responsibility (Salkovskis et al., 2000) and altruism shown by people with OCD more generally.

This way of understanding some of the powerful 'internal / cognitive' barriers to seeking help may also be linked to the idea of 'trying too hard' proposed by Salkovskis (1999) as a way of understanding the mechanism of behaviour in OCD; those with OCD can be described as 'trying too hard' to be certain that they have not caused harm. We suggest that this notion of 'trying too hard' could be extended to the context of delays in seeking help, i.e. it could be said that people with OCD often try way, way too hard to manage on their own.

Turning to the enablers, this study distinguished between positive and negative enablers. Amongst the relatively few positive enablers were the encouragement and support people received from friends, family and website forum members. Similar results were found by Belloch et al. (2009).

Another of the relatively few positive enablers was the availability of information, consistent with previous research (Goodwin et al., 2002). Nestling within the overall 'Media / information' theme was a positive enabler which seemed to have the potential for a particularly powerful effect, and which has not been described in previous research. Three participants discovered for the first time that their problem was OCD when they heard someone talk about their personal experience of OCD, and its successful treatment, on a television programme. Another participant discovered the same from reading a newspaper article. One participant first sought help for their OCD within a week of hearing a person describing their OCD, and its successful treatment, on television.

It seems possible that, in addition to the provision of information, the personal experience accounts were simultaneously addressing stigma and the powerful 'internal / cognitive' barriers to seeking help. The

content and effect of personal experience accounts warrant further study, and could be important in the development of future interventions to encourage people to seek help earlier.

Notably, among the already relatively small number of positive enablers, participants rarely described positive reasons for seeking help as *coming from within themselves*, i.e. positive 'internal' factors. This was in contrast to the wide range of 'internal / cognitive' factors identified as barriers to seeking help. This contrast warrants further exploration.

What then of the negative enablers? For many participants, with the hugely powerful barriers to seeking help pulling in one direction, it seemed that often it was only when there was an even more powerful force pulling in the opposite direction that people sought help. Sadly, for many participants, this more powerful force only built up when their OCD became so severe, and their life became so intolerable, that they reached a crisis and felt forced to seek help. (For three participants with intrusive thoughts about harming children, the nature of the thoughts themselves drove them to seek help). At this point they were in a sense being forced into a decision to seek help when there was no choice left – when they were completely cornered.

To what extent can the findings in this study be relied upon? The main threat to validity is the sampling strategy which relied on people volunteering to participate. At the simplest level, those who did not wish to pursue help might be particularly unlikely to volunteer. However, it could also be argued that people who had most misgivings about seeking help might be particularly motivated to participate in this study. Nearly all the participants were from the same ethnic group so we were unable to explore whether ethnic origin had any impact on the barriers or enablers people experienced. There are other sampling issues e.g. to what extent are people who access internet sites such as that of OCD-UK representative of people with OCD more generally? However, the fact that the mean length of delay found in this study (7 years from developing OCD) closely matches that of a larger study conducted in the UK (Stobie et al. 2007), and that participants described a wide range of obsessions and compulsions, increases confidence in the sampling strategy.

A unique feature of the present study was having a researcher with personal experience of OCD. We consider it likely that this made the study more appealing to some potential participants, and positively

influenced the design and conduct of the study and interpretation of the results, although this was not formally evaluated. Aware of her close identification with the theme of the study, the researcher took special care when analysing the transcripts of participants with different experiences from her own. We agree with Staley (2009) that a consistent approach to assessing the impact that people with personal experience may have on research needs to be developed, leading to a rigorous, good quality, evidence base.

This qualitative study identified and deepened understanding of a wide range of factors, both barriers and enablers, involved in help-seeking for OCD. A questionnaire now needs to be developed from the themes from this study, as part of a large-scale quantitative study, to find out if they are true for a larger population of people with OCD. This, together with further research on the effect of stigma, the 'internal / cognitive' barriers identified, and the effect of personal accounts of OCD and its successful treatment, will provide a foundation for the development of specific interventions aiming to encourage people to seek help much, much earlier.

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Seeking help for obsessive compulsive disorder (OCD): a qualitative study of the enablers and barriers conducted by a researcher with personal experience of OCD

Karen J. Robinson, Diana Rose and Paul M. Salkovskis

Supporting Information

Appendix S1

Seeking help for obsessive compulsive disorder (OCD)

Supporting Information S.1. Leaflet

Supporting Information S.2. Basic Information Form

Supporting Information S.3. Interview Plan & Topic Guide

Research Project

Seeking treatment for OCD

A study by a service user with OCD, exploring the factors which encourage people with OCD to seek treatment from the mental health service, and the reasons why people do not seek treatment.

My name is Karen Robinson. I have OCD and delayed seeking treatment for 23 years before going to my GP. Partly as a result of my experiences seeking help for OCD, I decided I would like to train as a service user researcher. I am a part-time student on the Mental Health Services Research MSc course at King's College London. I am carrying out this research project for my dissertation.



In 2001 two researchers, Simonds and Elliot, estimated that people with OCD who sought professional help delayed 11 years before seeking treatment. I searched for qualitative studies which asked people what encouraged them to seek treatment, or what delayed or prevented them seeking treatment, but was unable to find any. I have designed this project to try to explore that question.

I wonder whether you would be interested in participating in the project. I am hoping to interview about 20 people with OCD; people who sought treatment from the mental health service early, those who delayed seeking help and people who have never sought treatment. This would include people who have an official diagnosis of OCD and people who self-identify as having OCD. I would like to interview women and men of different ages.

The research would involve an individual interview of between 1-2 hours, with each participant. It would be in a place of your choice. Some people may prefer to do the interview at home. However, I know home can be a difficult place to meet for some people with OCD. You may prefer us to meet in a friend's home or another quiet setting. I would travel to you.

King's College Research Ethics Committee Ref: 05/06-140

Most of the interview would be loosely structured to allow you to describe what encouraged you to seek treatment early or why you delayed seeking help / have never sought treatment. If you delayed seeking treatment or have never sought treatment, I would be very interested to ask you how you think barriers to seeking treatment might be removed.

If you are comfortable about it, and give your consent, I would audio-tape the interview. I would be the only person to listen to the tape and I would transcribe the interview, onto my laptop at home, removing all names. I would identify you in the transcript by a confidential number. I would send you a copy of your transcript, if you would like me to, so that you could check its accuracy. My supervisor would see the transcripts and my examiners at college may also ask to see them. I would analyse the transcripts, on a networked computer at college, and try to draw out themes. I would very much like to use direct quotes from the transcripts under appropriate theme headings in my final report. I would ask your consent to do this and, if you would like me to, I would send you a copy of the context in which your quotes would appear, before the final report is published. I would also send you a copy of the final report, if you would like one.

Towards the end of the interview, I would ask if you would mind looking over a list of criteria commonly used by clinicians to diagnose OCD, and say whether you think you meet the criteria. For participants who do not have an official diagnosis, this would help support their self-determined diagnosis. I would also ask if you could complete a symptom checklist, and an OCD scale. However, it would be fine if you did not want to do this – your participation in the study would in no way depend on this.

This study has been approved by the College Research Ethics Committee. This involved thinking about any possible negative effects the study could have on participants taking part, and any benefits. The study is on a potentially sensitive topic. I hope the interview would feel supportive. It would follow the themes which you thought were important. You could say as little or as much as you wanted, and could stop the interview at any time or have a break. In terms of benefits, there would be no direct benefits to you! However, I hope it would be a positive experience, and that the findings will contribute in a small way to the improvement of existing services for people with OCD, and the development of new ones.

Thanks for reading this! If you are interested in taking part in the project, have any questions or would like to discuss it informally, please could you contact me by phone, e-mail or post. Thanks again for your time and interest.

To contact Karen:

By phone Please could you leave a message on my supervisor Diana Rose's phone, at college, and I will phone you: xxx xxxx xxxx

By e-mail xxx

By post

Research Project

Seeking treatment for obsessive compulsive disorder (OCD)

Basic information form

1. Participant (number)
2. Age
3. Female / Male
4. Ethnic Origin
5. Education
(e.g. highest educational qualification)
6. Employment Status
(present and previous)
7. How old were you when your OCD started?
8. How old were you when your OCD started to
to interfere significantly with your life?
9. Have you ever asked for help for your OCD
from your GP or the mental health service? Yes ☐
No ☐
10. If yes, how old were you when you first asked
for help for your OCD from your GP or the
mental health service?

Thank you very much for your help.

Research Project:

Seeking treatment for obsessive compulsive disorder (OCD)

Overall interview plan

- Thank-you for participating!

- Personal background to study

Give background to study: share a little of my story and how I came to be doing the research.

- What I hope to cover

Explain what I would like to do, that it is likely to take 1- 2 hours:

- * Background information about study / confidentiality

Give information sheet about the study and discuss.

Discuss question of taping, confidentiality, how information will be used.

Emphasise that any time participant wants to stop / any question s/he does not want to answer or does not feel comfortable with, to not hesitate to say so. Or any time participant would like a break.

Ask participant if s/he has any questions.

- * Consent form

- * Filling in basic information form

- * In-depth interview (taped)

- * Scale / Symptoms Checklist for OCD

- * Feedback on interview / any comments / sending copy of transcript, quotes, final report

- Thanks again!

Research Project

Seeking treatment for obsessive compulsive disorder (OCD)

Interview Topic Guide

- Turn tape recorder on!
- Story of your OCD
 - * *I wonder whether you could tell me a little about the story of your OCD.*
 - * *when / how it started*
 - * *type of OCD (e.g. mainly checking, washing, obsessional thoughts without rituals)*
 - * *how it has affected your life*
- Other mental health difficulties?
 - * *Would you say you have had any other mental health difficulties at the same time as the OCD?*
- If sought treatment from GP / mental health service early
 - * *What would you say were the factors which encouraged you to seek treatment?*
- If delayed seeking treatment from GP / mental health service
 - * *I remember from your information form you said you delayed seeking help for / have never sought help*
 - * *One of my main questions*
I wonder if you could say what you think were the reasons for you delaying seeking help there may be quite a few intertwined I would be really interested to hear about anything which you think contributed to you delaying seeking help
 - * not knowing what it was?
 - * not knowing where to get help?
 - * embarrassment?
 - * stigma?
 - * fear of the OCD?
 - * not wanting to tell your GP?
 - * fear of family knowing?
 - * fear of work finding out?
 - * fear of having a mental health record?
 - * fear of mental health service?
 - * fear of the treatment?
 - * fear of drugs

- * After summarising the main themes raised:
Is there anything you would like to add?
- * *If you have sought help what were the things which prompted / encouraged you to seek help after delaying?*

- Anything else you'd like to add on any of the topics?

Thanks!

Tape recorder off.