ORIGINAL RESEARCH

The experiences of help-seeking in people with obsessive compulsive disorder: an internet survey

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Abstract. Obsessive compulsive disorder (OCD) is a debilitating mental health disorder, with prevalence in adults of around 3.1%. The social and economic consequences of OCD are high for patients and their families. It is unlikely to improve without treatment. Help-seeking for treatment is often delayed and studies have found an average treatment gap of up to 17 years. This study aimed to explore the factors that influenced how, when and why people sought help and to identify any issues that they faced during help-seeking. Individuals experiencing OCD were invited to complete a web-based survey hosted on a national OCD charity website over a 3-month period. Eighty-eight individuals took part. Most had sought help from their general practitioner (GP), while others accessed websites and private services. Lack of awareness and understanding by health professionals was reported as a problem, as was the speed of referral or getting the right treatment. There is a need for further training and education for health professionals and GPs. Education and awareness campaigns for the general public, with more focus on how help can be sought, and on the different types of OCD may contribute to improving recognition of symptoms and accessing timely help.

Key words: Help-seeking, obsessive compulsive disorder, patient experience, survey.

Introduction

Obsessive compulsive disorder (OCD) is a disabling mental health disorder. It is characterized by persistent disturbing and intrusive thoughts or images. These lead to cause anxiety (obsessions) and purposeful repetitive behaviours that are performed in order to reduce this anxiety and/or 'prevent' a dreaded event (compulsions) (Vanin, 1990).

Symptom onset is gradual and often chronic, and compared to other mental health disorders such as major depression and alcohol abuse, OCD does not improve without treatment. There is evidence that without adequate treatment OCD tends to have a fluctuating course, emphasizing the importance of timely and adequate treatment (Kohn *et al.* 2004; NICE, 2005).

The social and economic impact of OCD for individuals and their families is great. It is more likely to have a negative impact on relationships compared to anxiety disorders (Koran

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et al. 2000; Zohar, 2007). It interferes with an individual's career, lifestyle and education which can lead to lower educational achievement, lower occupational attainment or unemployment (Koran *et al*. 2000; Zohar, 2007). OCD is associated with increased suicide attempts; with 26% of OCD sufferers reporting at least one suicide attempt during their lifetime (Torres *et al*. 2006). The economic impact of OCD has been estimated to amount to 3 years of wages lost in the lifetime of a sufferer (Layard *et al*. 2012), a cost carried by the taxpayer.

The National Institute of Health and Clinical Excellence (NICE) guidelines for OCD (NICE, 2005) recommend the provision of cognitive behavioural therapy (CBT) including Exposure Response Prevention in a stepped-care approach in the management of OCD. This approach may include the addition of pharmacological interventions if deemed appropriate. Despite the identification of evidence-based treatments, only a small number of people experiencing OCD are in receipt of recommended treatment (Torres *et al*. 2006). Although OCD has become a more commonly used term in society (Kelly & Winterman, 2011), delays in seeking help still persist. A substantial gap between symptom onset and accessing treatment of up to 20 years has been established (Lovell & Bee, 2008; Belloch *et al*. 2009; Marques *et al*. 2010; Subramaniam *et al*. 2012). Seeking help directly from a health professional varies from 8% to 38.4% (Caraveo-Anduaga & Bermudez, 2004; Belloch *et al*. 2009; Subramaniam *et al*. 2012). Variation may occur as a result of cultural differences, e.g. access to mental health services or stigma.

There is a paucity of research surrounding the reasons for the delay in help-seeking, specifically within the UK context. Limited evidence on reported barriers include worries about medical insurance and cost of treatment (Baer & Minichiello, 2008; Marques *et al*. 2010), fear of stigma and shame (Marques *et al*. 2010; Belloch *et al*. 2009), and views about treatment ineffectiveness (Baer & Minichiello, 2008; Marques *et al*. 2010; Goodwin *et al*. 2002). There is a recognition of the issues associated with the help-seeking delay, but an exploration of the factors that may prompt or enable help-seeking is lacking. Further research, particularly in the UK population may highlight more culturally specific reasons for delay, which may provide insight in to the actions that can be taken to improve the help-seeking process.

Strategies are required to improve services for OCD in order to reduce the level of disability and lower the overall cost to society. It is therefore important to have awareness and knowledge by the public, health professionals, and the person with OCD in order to reduce the delay in treatment.

Because OCD is a chronic, disabling disorder which does not remit without treatment, it is important to establish and understand the reasons for the delay in seeking help.

This study aims to explore the process of help-seeking in OCD sufferers, including the barriers and enablers in seeking help for the first time, and the triggers that set off the realization that individuals are experiencing symptoms. Given that there are effective treatments available and the extensive impact OCD has on the individual and their family it is important to understand the reasons why people do not seek help.

Aims

The study aimed to explore the process of help-seeking in people experiencing OCD symptoms in order to:

(1) identify factors that contribute to recognizing one's OCD;

(2) identify patterns of help-seeking for OCD;
(3) gain an understanding about the barriers and enablers faced during help-seeking.

Methods

A survey (see Supplementary material) was developed through consultation of published literature, advice and recommendations from service-user consultation and discussions with mental health researchers with previous experience of working with this population. This development process ensured that the survey questions would cover issues pertinent to individuals experiencing OCD and in improving the knowledge and awareness of this area of research that is currently not understood.

Thirty-six items were presented over two sections. The first section sought demographic information, while the second aimed to explore areas of help-seeking. The majority of questions were multiple choice; all offered the option to provide a different response if the pre-determined responses were not applicable. Example questions included: 'Who first recognized that you might have OCD?', 'What were the symptoms that were noticed first?', 'How did the OCD interfere in your daily life?', 'Who was the driving force to seek help?'. The symptom list provided to participants in order to describe their obsessions were adapted from the Yale–Brown Obsessive Compulsive Scale (YBOCS; Goodman *et al.* 1989) which covers nine categories in total, but participants were given the option of describing any 'other' symptoms they might experience. Additional questions addressed satisfaction with the help-seeking process and open-ended questions addressed how needs could have been better met and what would have made the help-seeking process easier.

Recruitment and procedures

A convenience sample of participants was recruited via an advertisement on a national OCD charity website, website forums, Facebook, Twitter and newsletters from August to November 2013. An online consent form asked participants to confirm that they were aged ≥18 years. No additional exclusion criteria were applied. Participants completed the survey anonymously. There was no guarantee that participants had an official diagnosis of OCD. In this instance their use of the charity and willingness to complete the survey was seen as sufficient.

Data analysis

Due to the quantitative nature of the data, non-parametric tests were mainly utilized. Many questions on the survey produced categorical or dichotomous variables, thus categorical analysis such as the χ^2 test for trend and the χ^2 test of association were used to establish trends between variables.

Thematic analysis (Braun & Clarke, 2006) was used on the qualitative data from the open-ended questions. The data was repeatedly read for themes in an inductive manner. Ideas were marked and coded, in a physical manner (highlighting, and cutting up phrases). Themes were identified from these codes (repeated phrases, words). This process was repeated several times in a flexible manner to ensure the themes were appropriate. This was done by one analyst and the results were shared with the research team and discussed.

Results

Eighty-eight participants completed the survey, the majority were female (73%) and white (85%) with a mean age of 33 (S.D. = 11.4) years. Demographic data are presented in Table 1.

Recognition of OCD

The majority of participants reported they recognized the OCD themselves (70.1%), followed by fewer participants whose parents/carers (10.3%), their general practitioner (GP) (9.2%), or friends (3.5%) recognized it.

The largest proportion of participants identified their OCD through internet searching (24.4%), with an additional 2.3% using the internet in conjunction with watching TV programmes about OCD.

Similar proportions identified their OCD through a health professional or having been taken to a professional by parents when young (combined 23.8%).

Symptom types

Participants were asked what symptoms were noticed first, and who noticed them. The question was set up to allow participants to select multiple categories. Of participants, 56.8% reported aggressive symptoms (e.g. fear of self-harm or harming others) with miscellaneous symptoms (e.g. fear of saying certain things, intrusive images) reported by 50.0%. Participants themselves recognized their symptoms most frequently compared to others. Contamination and physical symptoms (e.g. excessive concern with illness, disease, and appearance) were reported as being recognized by both the participants and someone else. Sexual symptoms (e.g. unwanted forbidden, perverse thoughts/images/impulses) were recognized by 33% of the participants compared to 27.3% of participants recognizing contamination symptoms.

Help-seeking agent

In response to being asked who the driving force to seeking help was, the majority (57.5%) indicated they initiated the process. Some reported that their parents initiated the process in their younger years (17.2%) or during adulthood (5.7%). A very small minority had a health professional (2.3%), their friends (1.1%) or school (1.1%) initiate the help-seeking process.

Help-seeking drivers

When asked about factors that affected the decision to seek help, the largest proportion named the category 'It became harder to cope with everyday life' as the most important factor, followed by it becoming harder to cope with work, and it affecting relationships.

After recognition where was help sought?

Table 2 shows that the largest proportion of participants went to a National Health Service (NHS) GP for help, followed by using internet help sites and accessing private services.

Table 1. *Participant demographics*

Variables	Participants ($N = 88$), n (%)
Geographical location	
England	68 (78.2)
Scotland	4 (4.6)
Wales	7 (8.1)
Northern Ireland	0 (0.0)
Other	8 (9.1)
Missing data	1
Ethnicity	
White	75 (85.2)
Asian/Asian British	7 (8.0)
Mixed/multiple ethnic groups	1 (1.1)
Black/Black African/Caribbean/Black British	1 (1.1)
Other ethnic group	4 (4.5)
Highest educational level	
PhD or postdoctoral degree	1 (1.1)
University Masters or equivalent	14 (16.1)
Undergraduate University or equivalent	28 (32.2)
Sixth form/further education/college or equivalent	29 (33.3)
Secondary school or equivalent	14 (16.1)
No formal education	0 (0.0)
Other (please specify)	1 (1.2)
Missing data	1
Employment status	
Paid, employed part-time	15 (17.2)
Paid, employed full-time	32 (36.8)
Self-employed	3 (3.5)
Retired	2 (2.3)
Full-time carer/homemaker	6 (6.9)
Not employed but seeking work	7 (8.1)
Receiving benefits due to ill health	12 (13.8)
Unemployed – not seeking work	2 (2.3)
Full-time student	7 (8.1)
Other	1 (1.2)
Missing data	1
Type of employment	
Self-employed	4 (6.6)
Company with <50 people	4 (6.6)
Company with >50 people	43 (70.5)
Other	10 (16.4)
Missing data	27
Relationship status	
Married	28 (31.8)
Living with a partner	13 (14.8)
Divorced/separated	6 (6.8)
Widowed	0 (0.0)
Single	38 (43.2)
No response	3 (3.4)

Table 2. *Help-seeking sources reported by participants*

	Frequency (relative %)
Where did you go for external help?	
NHS GP	64 (72.7)
NHS Direct	1 (1.1)
Accident & Emergency	4 (4.5)
Self-referral to mental health services	8 (9.1)
School/school nurse	2 (2.3)
Internet help sites	16 (18.2)
Private therapist/psychiatrist	14 (15.9)
Self-help group	2 (2.3)
Charity for OCD	4 (4.5)
Self-help service	3 (3.4)
Other	9 (10.2)

Table 3. *Frequency of participants receiving a confirmation of their OCD*

	Frequency (relative %)
From the point when you sought help, how long was it until you received a professional confirmation of OCD?	
Immediately	23 (28.0)
A few days	3 (3.7)
1-3 weeks	13 (15.9)
1-6 months	13 (15.9)
≥1 year	5 (16.1)
Never	13 (15.9)
Other	12 (14.6)

The timing of receiving a professional confirmation of OCD was distributed. The larger proportion received confirmation almost immediately from the point of seeking help (see Table 3). Almost 15% of participants stated that they never received confirmation.

Deterrents

Participants were asked what deterred them from seeking help. Deterrents to seeking help were largely shame and embarrassment (76.1%) followed by fear of talking about the problem (63.6%). Fear of hospitalization and worry about the treatment were equal deterrents (29.5%). Fewer people selected worries about how it would affect work (19.3%) or disrupt life (21.6%).

Due to the literature not providing a large level of detail regarding deterrents of help-seeking, more detail was of interest. With each symptom type bringing different complications to life, it was of interest to see if symptom type affected what the perceived deterrent would be. Contingency tables were established for each individual symptom type, comparing it to each individual help-seeking deterrent, and a χ^2 test for trend was performed for all these combinations.

A significant linear association was found between contamination obsessions and fear of stigma ($\chi^2_{\text{trend}} = 7.11$, d.f. $= 1$, $p = 0.008$). Of the 40 participants that had contamination obsessions, 23 (57.5%) stated they feared stigma. Contamination obsession was linearly associated with being worried about the treatment ($\chi^2_{\text{trend}} = 3.81$, d.f. $= 1$, $p = 0.05$).

A linear association was also found for physical obsessions and fear of stigma ($\chi^2_{\text{trend}} = 7.43$, d.f. $= 1$, $p = 0.006$). Of the 42 participants who had physical obsessions, 24 (57.1%) were afraid of the stigma. Participants with physical obsessions were also associated with fear of talking about the problem ($\chi^2_{\text{trend}} = 5.41$, d.f. $= 1$, $p = 0.02$), and 32 (76.2%) with feeling ashamed and embarrassed ($\chi^2_{\text{trend}} = 8.99$, d.f. $= 1$, $p = 0.003$).

Receiving help

Of the participants, 54.2% found receiving initial help was inadequate. Over half (54.8%) of the participants went on to seek further help. Forms of other help were OCD charity websites or magazines.

Further help sought was reported to be adequate and inadequate in similar proportions (47.5% and 44.1%, respectively).

Of the 46 participants that found initial help adequate, only 19 went on to seek further help. Of those who were not satisfied 14 (35%) sought further help. No significant association was found between the two variables ($\chi^2_{\text{trend}} = 2.90$, d.f. $= 1$, $p = 0.088$).

It was of interest to see whether receiving initial help in the form of medication or treatment would affect the decision to seek further help.

Receiving medication was significantly associated with going for further help ($\chi^2_{\text{trend}} = 13.11$, d.f. $= 2$, $p = 0.001$), as was receiving CBT ($\chi^2_{\text{trend}} = 6.72$, d.f. $= 2$, $p = 0.04$), and being referred to a mental health professional for an assessment ($\chi^2_{\text{trend}} = 11.75$, d.f. $= 2$, $p = 0.003$).

Qualitative data

Four main themes were identified:

(1) Awareness and understanding.
(2) The healthcare system.
(3) CBT.
(4) Information.

Awareness and understanding

Participants repeatedly reported a lack of understanding by health professionals, particularly their GP, the public and family. Some indicated this resulted in them not having the opportunity to discuss their difficulties:

> I felt that my GP was in too much of a hurry to prescribe antidepressants rather than offer me the chance to talk about my obsessive thoughts (participant 74, female, age 44).

Due to their GPs lack of understanding participants they felt they were often referred to inappropriate treatment. Some felt misunderstood, unsupported, isolated and mistreated while others reported that such issues hindered their recovery:

> I spent over 2 years crying to my GP begging to be locked away and he continued to tell me it was 'just anxiety' it wasn't until I hit rock bottom and had the CMHT visiting my home for one week that I was referred to a psychiatrist for a proper diagnosis (participant 33, female, age 24).

The healthcare system

Negative comments regarding the NHS and the way the system hindered the help-seeking process were common. Issues surrounding long waiting times, misdiagnosis, and lack of understanding were raised.

Waiting times could span years, caused frustration and anxiety, and forced some to seek costly private treatment. Participants' attitudes and trust levels towards healthcare professionals were affected, sometimes deterring any desire to seek help. Some reported that help received through private care, self-help materials, or university services was more beneficial compared to what was offered by the NHS. Participants wanted a faster more communicative service:

> The NHS waiting lists severely affected my treatment and attitude to treatment. I waited six months for counselling, then was diagnosed … and put on a different waiting list, which lasted a year. This … made me very suspicious of medical professionals … I am reluctant to return to the doctor if my symptoms worsen (participant 65, female, age 21).

Self-referral was regarded as a solution to avoid years being led down 'an incorrect treatment path', which in some cases led to severe actions (e.g. suicide attempt).

CBT

Participants desired a CBT referral, suggesting they were knowledgeable about effective treatments. However, long term-efficacy, resource constraints and the CBT approach adopted, specifically when delivered in a group, was not positive for all.

> It's just that the CBT didn't work. I tried two courses, but if anything my fears worsened. I think I would have benefited from one-to-one sessions, but these were group courses. But I do appreciate there aren't the resources for every sufferer to have one-to-one sessions (participant 86, female, age 30).

Some participants commented that treatment helped to a point, but then no further progress was made, or recurrence of symptoms resulted in the help-seeking process recommencing. Hopelessness was experienced by two participants who were still looking for help. Some felt treatment helped them understand OCD but did not 'cure' it.

Last, a significant call for OCD specialists was made. This relates back to understanding, and a lack of support as participants felt treatment would have been better if an OCD specialist provided it rather than a CBT therapist that did not have the speciality.

> Doctors and CBT therapists don't specialize in OCD or understand it and how many different forms of it there are. Would have liked to speak to an OCD specialist (participant 82, female, age 35).

Information

Two types of information were mentioned most – practical information about coping with OCD, and information on the lesser-known aspects of OCD.

Some participants discussed the increase in television coverage about OCD through documentaries. While assisting in increasing public awareness about OCD some participants reported that they were potentially 'exploitative' in nature and not beneficial. A focus on the help-seeking process, the medically informative side of OCD and practical advice was deemed important to assist with lowering the stigmatization of OCD.

> I am not sure if documentaries are commissioned with medical information objectives in mind – it would be good if some were (participant 61, female, age 30).

Participants generally felt more information regarding the lesser known symptoms of OCD, such as the sexual obsessions or 'pure O', was required to help patients identify their OCD.

> there's so much more to washing your hands lots of times a day, which is all I knew about it at the time (participant 85, female, age 30).

Discussion

Help-seeking

Involvement of health professionals in the identification of OCD was low, with the majority of participants reporting they first recognized their OCD symptoms. Friends, family and carers, while identifying symptoms less, were more readily reported in comparison to professionals. Participants drove the help-seeking process themselves, the majority of whom presented to their GP while a smaller proportion sought help on internet sites. Media sources appeared most important in the earlier stages of gathering information and recognition, but the standard method of contacting 'front-line' services, i.e. the GP, was subsequently used to actually seek help.

Recent literature has demonstrated small short-term benefits of the increasing online mental health literature available as a mechanism to increase knowledge/awareness of available services and reduce stigma (Livingston *et al.* 2014). Evidence from this study suggests that there is a need for more accessible information and knowledge about OCD and that information campaigns may be beneficial.

The less reported symptoms of OCD

Aggressive and miscellaneous symptoms were the most commonly reported obsessions. Contamination obsessions were less frequent than sexual obsessions, although they are the stereotypical symptoms in the public's awareness of OCD (Simonds & Thorpe, 2003). These findings support recent studies investigating the prevalence of these symptom types (i.e. Moulding *et al.* 2014). Previous research, however, regarded aggressive and sexual subtypes as rare (Christensen *et al.* 1987). More information, especially on the 'lesser known' symptoms such as sexual obsessions was desired suggesting this to be an area requiring focus and further education.

This unexpectedly high level of sexual and aggressive symptoms in our sample questions whether this is due to an actual increase in these symptoms or whether people have grown confident to voice their symptoms. It is possible reporting of sexual symptoms is related to the UK's current sensitive and fragile climate regarding sexual behaviour by adults towards adults or children. With the advent of the scandals of celebrities' sexual assault cases coming to light, the topic of paedophilia has become prominent in the media and thus the minds of the public (Easton, 2014). This may influence or trigger a symptom manifestation, related to the cultural occurrence, causing distress and fear (i.e. Benuto *et al.* 2014).

The apparent rarity of sexual symptoms that other studies had discovered, may be attributed to a low representation for treatment, possibly due to negative experiences of help-seeking. The social consequences of an incorrect diagnosis for these symptom types can be catastrophic legally and psychologically, making it understandable that they are difficult to voice. It is possible that due to the anonymous nature of the survey, participants were able to speak more freely.

Barriers to seeking treatment

Deterrents to help-seeking were shame/embarrassment, fear of stigma and of talking about the problem; factors associated with each other in a cyclical nature. In contrast to other studies (i.e. Goodwin *et al.* 2002), participants did not perceive the barrier of treatment being ineffective. In fact qualitative data demonstrated participants wanted treatment, but struggled to obtain it.

While participants recognized the media had reduced stigma to some extent, there was a demand for more accurate information about OCD to be presented to further awareness and understanding. The growing use of the term OCD while increasing awareness was also viewed negatively with some participants reporting that they felt the severity of their problems was minimized.

Long NHS waiting lists were viewed as a barrier to help-seeking and caused frustration, requiring tenacity to carry on seeking help. While some IAPT services that have adopted a stepped-care approach offer the option of self-referral, lack of awareness was evident about this option, reiterating the need for information about OCD but also where to seek help, and the available options.

Around half of the participants thought the help they had received was inadequate. This sentiment was echoed in a recent report on patients referred to talking therapies compared to those entering treatment (Wise, 2014).

Receiving help

Around half of the participants thought the help they received was inadequate. This sentiment is echoed by Wise (2014) in a report concerning mental health as a whole. It found over 760 000 people had been referred to psychological therapies, in England, with only half of the referrals entering treatment. In the report Vicki Nash, head of policy and campaigns at Mind stated:

> The gap between the numbers of people being referred and those actually entering treatment is cause for significant concern ... people are waiting far too long between referral and starting

therapy. The longer someone has to wait for the treatment they need, the greater the risk they will become more unwell and need more intensive treatment down the line (Wise, 2014, p. 348).

The data from this study supports this statement. Many participants reported a lack of support, awareness, and understanding provided by GPs or mental health professionals. There were a lot of negative comments regarding the current NHS system with long waiting lists spanning years, and misdiagnosis/being lead down a wrong treatment path.

The overall experience of help-seeking described by our participants appeared negative. General satisfaction was distributed with 23.8% being 'highly unsatisfied' and 21.3% 'very unsatisfied', but 20% scoring 'highly satisfied' The split in perception of adequacy does suggest that there are differing needs/preferences that require addressing. Further research into what is needed by these patients would help to address this issue.

Study strengths and weaknesses

There are some limitations to this study. The majority of the sample was female and the use of a convenience sample, rather than utilizing multiple recruitment approaches, may have limited the final sample size and reliability. Other studies found an equal sex ratio for people with OCD (Kessler & Üstün 2004; Abramowitz *et al.* 2009; Veale & Roberts, 2014). Some studies, however, demonstrated a predominance of OCD in women (Torres *et al.* 2006), for example Meltzer *et al.* (1995) found OCD diagnosed in 1.5% of women compared to 1.0% of men. It is possible that the high ratio of female respondents may be due to the gender differences in responding to surveys in general. Sax *et al.* (2003) found female response rates were much higher in various forms of survey types (web, mail, email) at a rate of 26.6% *vs*. 13.4%. Clinical and epidemiological studies have in the past demonstrated a predominant female sample in adult studies about OCD (e.g. Fontenelle & Hasler 2008).

The use of a limited sample, by only advertising on one OCD charity website, rather than utilizing multiple websites, domains and magazines may have limited the final sample size and reliability. The reasoning behind this, was to establish feasibility of the study through level of interest response rate, and whether any 'gaps' may be discovered using the survey as it was. Providing individuals with the ability to complete an anonymous online survey may have resulted in sample bias, e.g. the unexpectedly high levels of individuals experiencing sexual and aggressive symptoms. Individuals may also be more similar to those who have avoided seeking help, i.e. using online resources instead for support. The current results are therefore not necessarily generalizable to the population of people with OCD, but do provide an indication, and additional knowledge to the existing literature considering the charity's large network across the country.

Another limitation affecting the reliability of the study is the fact that we did not have officially diagnosed participants. The participant information sheet asked for 'adults experiencing OCD or are in the process of understanding they might have OCD'. Thus we cannot state that this data comes from participants with an official diagnosis. But taking the integrity of the participants in to account, and the fact that they would be users and visitors to the charity, we accept them as being sufferers of OCD. Obviously this can neither be fully confirmed nor denied, thus this needs to be taken in to account when studying the evidence.

Low response rates to two questions exploring what participants did after help-seeking and if further help sought were adequate. Participants may not have found the question relevant, or lost interest. Revisions to the survey may therefore be required.

Summary

- The primary factor of internet use to gather information affected recognition of the OCD.
- Patterns of help-seeking included a time delay between onset and help-seeking of months and years.
- Severity did not affect the speed of seeking help, but functioning in daily life did. Aggressive and sexual symptoms were more common in our sample than expected.
- Participants were their own driving force and presented themselves to the GP where they most often received medication or referral to counselling/CBT.
- Opinion regarding CBT was mixed, with some participants finding it unsuccessful, and some wanting CBT but not receiving it.
- Barriers were shame/embarrassment, fear of stigma, fear of hospitalization, the health professional themselves and the NHS system.
- Enablers were the participants themselves, the effect on daily life and media/internet information.
- The overall experience was a relatively unsatisfactory one, with room for improvement on receiving a confirmation of OCD and receiving the correct treatment.

Conclusions

The data from this study implies that increased awareness by health professionals is necessary to aid the recognition of OCD in order to provide the correct treatment path. It may be beneficial to further educate health professionals, especially front-line staff, i.e. GPs, to understand OCD better. This should include improved knowledge on the lesser known symptoms of OCD such as sexual and aggressive symptoms, as the literature demonstrates a larger number of misdiagnosis for these symptoms (Glazier *et al.* 2013).

As the GP remains the primary port of call during the initial stages of help-seeking, it is necessary that they are the most knowledgeable on OCD and its heterogeneous nature on symptom expression. Secondarily, more awareness campaigns are necessary for the general public, and working environments.

This awareness should not be limited to only OCD itself but what to do, once it has been recognized. Current mental health campaigns in the UK focus on awareness alone such as the 'Time to Change' campaign (Time to Change, 2014). This is obviously a good way of attempting to reduce stigma and encourage people to talk about mental health, but it does not place emphasis on where help can be sought, and what services are available. The qualitative data showed some participants wanting to self-refer, in order to avoid the long waiting times, or the frustrations faced with health professionals. The fact that the system of self-referral already exists, but some participants still ask for it, suggests that this information requires more publicity. It is both important to identify the problem as well as what steps to take to address it, which requires the knowledge of where to seek the necessary help.

Ethical standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. The study was approved by the University of Manchester Research Ethics Committee (ref. AJ/ethics/1206/13).

Supplementary material

For supplementary material accompanying this paper visit http://dx.doi.org/10.1017/S1754470X1600009X.

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Declaration of Interest

None.

Recommended follow-up reading

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Learning objectives

- Have an understanding of help-seeking experiences of individuals with OCD.
- Be able to describe some of the barriers to help-seeking.
- Identify ways in which help-seeking experiences may be improved.
- Identify potential areas for further research.