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# ‘Finally, I could breathe’: the utility and impact of a diagnosis of obsessive compulsive disorder

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## Abstract

**Background:** The diagnosis of obsessive compulsive disorder (OCD) is characterised by intrusive thoughts leading to compulsions to alleviate anxiety. However, research is lacking on impact post-diagnosis. Some research suggests diagnosis may benefit treatment access, but potentially leads to higher levels of stigma and altered self-identity.

**Aims:** The present study assessed the utility (treatment access and problem identification) and impact (stigma, personal wellbeing or social identity) of receiving a diagnosis of OCD.

**Method:** Semi-structured interviews with 12 individuals who had received a diagnosis of OCD were conducted between February and April 2020, then transcribed and analysed using theoretical thematic analysis.

**Results:** Participants reported positive impacts of diagnosis on both ‘utility’ and ‘impact’.

**Conclusions:** The diagnosis of OCD was helpful for participants in making their symptoms tangible, providing relief and hope for recovery. Non-diagnostic or alternative frameworks should aim to meet this need. Future research may wish to identify how this understanding of disorders vary between different diagnoses, especially in terms of stigma and personal wellbeing.

**Keywords:** diagnosis; formulation; obsessive compulsive disorder

## Introduction

Mental health diagnoses are disputed constructs (Kinderman, 2015), and alternatives like formulation (Johnstone, 2018), framing mental distress as an understandable response to adverse environments, may have benefits around self-stigma (Seery *et al.*, 2021). Indeed, formulation is core to the practice of most mental health professionals (British Psychological Society, 2011; Royal College of Psychiatrists, 2017). Differences in diagnostic measures (Visontay *et al.*, 2019) and diagnostic overlap (Amerio *et al.*, 2014) further this debate. Diagnosis may have utility for treatment and resource allocation, although identification and access remain complex (Malhi, 2019). Indeed, utility itself is not a consistent construct (Pallesen *et al.*, 2020).

Diagnosis impacts individually (Peter and Jungbauer, 2019) and socially through discrimination, resulting in poorer well-being (Cruwys and Gunaseelan, 2016). Media reports (Quintero Johnson and Riles, 2018) and family discussions (Liegghio, 2017) impact care seeking behaviours (Corrigan *et al.*, 2014) and fear of diagnosis is arguably a barrier for treatment seeking. Misrepresentations of OCD as the display of perfectionist characteristics are common (Stewart *et al.*, 2019) and the public perception of OCD is often less serious than other disorders, which may increase internalised stigma (Chasson *et al.*, 2017).

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OCD manifestations span from obsessive fears regarding mental (Mathes *et al.*, 2019) or physical (Rachman, 2004) contamination to intrusive thoughts with violent, sexual or aggressive content (Moulding *et al.*, 2014). OCD is therefore a heterogenous diagnosis (Lochner and Stein, 2003), leading to a call to group other disorders, such as hoarding, in with ‘Obsessive Compulsive and Related Disorders’ (Brock and Hany, 2021).

OCD self-identification seems to relieve internalised and public stigma in some but not others (Homonoff and Sciutto, 2019). Such self-identification may increase self-concealment of distress (Wheaton *et al.*, 2016) and suicidality, which may be influenced by stigma (Angelakis *et al.*, 2015; Fernández de la Cruz *et al.*, 2017; Kim *et al.*, 2016; Velloso *et al.*, 2016).

Diagnosis offers tangibility (Perkins *et al.*, 2018) and may increase the self-identification as having, or ‘being’ OCD which can increase social or personal identity change (Pedley *et al.*, 2019), and illness perceptions may impact treatment quality (Dias *et al.*, 2018). The impact may be more complex and hope may not occur when views of permanency create a perspective of coping, rather than thriving.

The present research investigated the utility and personal impact of diagnosis in those diagnosed with OCD. ‘Utility’ refers to how effective the diagnosis is regarding treatment accessibility and how helpful the diagnosis was in identifying symptoms and recovery. ‘Impact’ refers to the personal and social implications or possible discrimination that individuals have experienced. This includes: social and emotional functioning of the individual, how a person relates to themselves post-diagnosis, internalised stigma and personal or social identity change.

## Method

### Participants

Twelve individuals aged over 18 reporting having received a diagnosis of OCD were recruited through OCD Action, a charity supporting individuals identifying with a diagnosis of OCD, in which the first author participates as a support group facilitator. Seven women and five men, aged between 19 and 59 (mean age 30.9 years at the time of the interview) responded to an advert on the OCD Action website. Potential participants were invited to participate in a study into the ‘utility of a diagnosis of OCD, and how it impacted your life in any way’. There were no exclusion or inclusion criteria other than having received a diagnosis of OCD and being aged over 18. The youngest at which a participant reported they had first received a diagnosis of OCD was 12 years old, the oldest was 57 (mean age of diagnosis 24.0 years) with no attrition. All participants could recall their diagnosis. See Table 1 for a summary of participant demographic information.

Participants were selected based on self-identification with a diagnosis. This meant participants may have some variation in their experience of receiving the diagnosis, for example at a clinical psychologist or general practitioner level.

### Procedure

The audio-recorded interviews [either in person ( $n = 1$ ) or via Skype ( $n = 11$ )] were conducted alone by the first author, then a male student at the University of Liverpool. A semi-structured interview schedule was developed based on previous research into patient reactions to a schizophrenia diagnosis (Vass, 2016). Both interviewer and supervisor had experience and training in qualitative research based on past research conducted by both. Each interview lasted between 37 minutes and 47 seconds and 66 minutes and 32 seconds (mean 50 minutes and 12 seconds).

Participants were only informed the study looked at the experience of OCD diagnosis beforehand and interviews were transcribed by the first author and analysed using thematic

**Table 1.** Demographic information of participants

Pseudonym	Sex	Age at interview	Age when diagnosed	Length of interview
Participant A	M	31	21	58:12
Participant B	F	24	21	47:22
Participant C	M	21	18	42:18
Participant D	F	34	34	1:04:02
Participant E	M	27	17	1:06:32
Participant F	F	59	57	54:52
Participant G	M	57	43	48:15
Participant H	F	19	16	37:47
Participant I	F	22	20	48:28
Participant J	F	27	15	41:29
Participant K	F	23	12	46:32
Participant L	M	27	14	46:31

**Table 2.** The utility of the diagnosis of obsessive compulsive disorder

Theme	Definitiveness and tangibility	Explanation and validation	Increased treatment accessibility
Sub-themes	It became a thing	Understanding themselves	Needing label to access and progress
	It was something to target	Allows others to understand	Next steps
	Was not just anxiety	Can be researched	Therapy and medication
	It gave them an answer	Self-education OCD as a model to make sense of self and use	

analysis (Braun and Clarke, 2006; Maguire and Delahunt, 2017) with assistance from the computer program NVivo 12. The study was not pilot tested. Themes were initially identified by the first author and discussed with the co-author to ensure inter-rater reliability, coherence, clarity, and consistency with original data. Although all researchers need to be tentative in their conclusions, theoretical saturation seemed to have been achieved with 12 participants, with themes consistently repeated across participants (Ando *et al.*, 2014). Following completion, a summary of anonymised results were sent to all participants who approved of the findings with no critique provided.

## Results

The theoretical thematic analysis identified five themes for each of the research questions assessing the utility and the impact of a diagnosis of OCD and several sub-themes (see Table 2).

### *The utility of the diagnosis of obsessive compulsive disorder*

#### *Definitiveness and tangibility*

Participants reported that the diagnosis provided tangibility, and the concept of 'OCD' becoming real was common:

*'Yeah, and so it lined up perfectly with that and then I was like yeah this is definitely like . . . OCD is a real thing you know'* [Participant E]

Participants also reported that the diagnosis allowed for targeted treatment:

*'And I thought he was really good. Before I went, I did think he knew his stuff but it was very much a different approach. When she got there, it was just . . . Much more in detail and targeted once I actually got there yeah'* [Participant J]

The definitiveness of the diagnosis was described as useful, as many felt that the label 'anxiety' was not sufficient:

*'It was just labelled as anxiety, but I have a nursing background and I felt something much deeper or confusing was going on'* [Participant F]

Participants also reported that they felt diagnosis provided answers to their experiences:

*'I was really pleased to get the diagnosis because it gave an answer to what was going on'* [Participant F]

#### *Explanation and validation*

Participants reported that diagnosis helped in explanation and validation for themselves and others (especially family):

*'Yeah, it's . . . it's given me a better understanding of myself, and it's made me also realise, as I've reflected back on childhood again, that I'm fairly certain my father had it'* [Participant G]

*'in him reading about OCD he sees that "wow that is just totally my son" you know, and he started accepting me more for that and understanding that "oh well my son's brain is structured in this way" you know and because my father cares about me you know, he wants to help me'* [Participant A]

Participants discussed diagnosis and the justification of behaviour, either for other people or for themselves, and a feeling that the diagnosis validated their experiences:

*'it kind of justified my behaviour and people, well some people, with some understanding that I would . . . I was behaving the way I did because of the diagnosis'* [Participant K]

Many participants commented on scientific research making the disorder valid:

*'I know what it is, it's been validated through . . . through you know, people with the knowledge and all of that'* [Participant E]

*'Like an actual physical validation someone else rather than just physical validation rather than just my own thoughts definitely aided me I think'* [Participant C]

*'I wanted to . . . I wanted to have my um you know, my . . . my suspicions that I think I have OCD validated through the mental health system and you know, a practising psychologist'* [Participant E]

Participants commented that the diagnosis provided insight into what they were experiencing and symptoms:

*'there's a whole world of those with OCD, of intrusive thoughts, of checking, of cleaning, of . . . and different levels and you know I research it every day'* [Participant B]

Participants discussed using the diagnosis label itself as a model or a tool. One participant stated that this aided in visualising how it functions biologically:

*'so, OCD as a model makes a lot of sense you know from erm, the neurobiological aspect of it'*  
[Participant A]

One participant also mentioned that the label OCD helps in breaking down what is going on regarding obsessions and compulsions:

*'Breaking down that diagnosis into two separate parts of . . . there's obsessions and then there is these compulsions'* [Participant E]

#### *Increased treatment accessibility*

Participants' views on treatment accessibility were mixed, with many stating diagnosis increased access for them and others critiquing treatment access. A core theme was of a label being needed for accessing treatment in the first place:

*'it's very much if you don't get a label, they don't do anything basically'* [Participant D]

Participants discussed how diagnosis increased access to therapy or medication:

*'For that, however I did get access to medication, an SSRI; Escitalopram'* [Participant A]

One participant commented that people had to fight to get access to a specialist unit:

*'I'd say like a good 80 to 90% of the people that were in that specialist unit had to fight and fight and fight to be able to get referred there'* [Participant J]

Participants also mentioned their luck in receiving the diagnosis and accessing treatment, with reference to psychologist misunderstanding:

*'My mom forced me to go and then by the end of the session she told me that I had OCD which . . . I felt very lucky because a lot of people don't experience that they . . . you know, it's a lot of trial and error'* [Participant B]

Discussion about how the diagnosis allowed people to understand recovery pathways in their treatment progress was also a sub-theme:

*'I saw myself for something, you know . . . something that was good I could get better and that my parents and I were going to look, like, in the next steps of accessing treatment'*  
[Participant K]

#### ***The impact of the diagnosis of obsessive compulsive disorder***

See Table 3.

#### *Relief and hope*

Relief or hope were grouped together, with relief described as key:

*'I keep coming back to this phrase relieved'* [Participant G]

**Table 3.** The impact of the diagnosis of obsessive compulsive disorder

Theme	Relief and hope	Changed identity	Awareness/empowerment
Sub-themes	Relief to receive Hope for right treatment Hope to get through it	Changed role in family or friends Became identity Positive change in social role Stigma from public/practitioners	Resilience and strength Confidence to beat it Feeling like a survivor Spread awareness Validate experiences and feelings

*'It was like... like finally I could breathe and put a name to why I'm feeling this way'*  
[Participant B]

This frequently led to hope, specifically, hope of receiving treatment:

*'I guess I felt like there was hope that I could get the right treatment'* [Participant D]

The diagnosis informed them they would receive tailored treatment.

Additionally, the diagnosis provided hope they would be able to get through their distress and provide hope for recovery:

*'I definitely felt more confident, and you know gave me the hope I could actually get through this... I... get through this um horrible period in my life'* [Participant L]

### **Changed identity**

Participants raised the concept of a changed identity or social role, especially the idea of a changed role in family and friends post-diagnosis. This related to a change in caretaker roles:

*'it changed the relationship yes fundamentally the expectation. I was like a sole carer for somebody in most ways and so that's changed'* [Participant F]

A common theme that emerged was a change in personal identity, specifically with the diagnosis becoming an identity in itself:

*'you know when I was younger definitely you know I have OCD like I really identified with my diagnosis and in a big way when I was younger, like it was almost a part of my identity then you know like I am... I have OCD. I'm just a really neurotic person you know I almost kind of... yeah like took that on as like an identity'* [Participant E]

Whilst some discussed this idea of a change of personal identity, some referred to the diagnosis fading to the background as they recovered:

*'The diagnosis itself has kind of phased into, like a background part of my identity in that my OCD today is not as bad as it used to be'* [Participant C]

Participants also discussed a positive change in their social identity or role:

*'I suppose my social identity has changed in a way yes... I wouldn't say necessarily in like a bad way because it's helped me yeah'* [Participant J]

Stigma following on from the difference in identity was also discussed:

*'It can be really difficult receiving a diagnosis like OCD because of the associated stigma'* [Participant K]

*'I think because, that stigma . . . people with that whole oh I'm so OCD thing'* [Participant D]

Stigma was brought up in terms of being taken seriously, as some participants felt they were not going to be taken seriously by family members:

*'Are you sure it's OCD like that doesn't sound like OCD', and I thought they were going to doubt the diagnosis'* [Participant B]

In one instance, a participant described their experience of not being taken seriously by practitioners due to feeling they were self-diagnosing.

*'He was like yeah ok this is OCD but if I went in and said, "I think I have OCD" they'd have been like "no don't be stupid"'* [Participant D]

### **Awareness/empowerment**

Participants discussed the impact of diagnosis on their personal feelings of strength and confidence, resilience, and self-efficacy:

*'I think I almost have kind of developed this kind of like . . . more resilience kind of like . . . I don't care I'm just going to do what want anyway kind of attitude'* [Participant D]

Participants felt diagnosis gave them the confidence to overcome their negative experiences, and the confidence to talk about their experiences:

*'I definitely, after the diagnosis, felt more confident and that I could actually beat it yeah'* [Participant L]

Participants discussed feeling like a survivor and in acknowledging their strengths they felt their experiences made them feel stronger as a result:

*'Kind of felt I saw myself as a bit of a survivor and it kinda like, almost like dawned on me how much I have been through . . . that I even like forget about a lot of the time and don't really choose to think about, um . . . it kind of remind me . . . I kind of felt like you know I am a . . . I kind of felt strong'* [Participant D]

Participants also commented that the diagnosis gave them the motivation to spread awareness of OCD:

*'Then ever since then I felt very um compelled to talk about it to bring awareness to it because think about how many people must have experienced what I did and have taken their life, or you know it's . . . it's just . . . it gets to be scary sometimes'* [Participant B]

For participants, the awareness of the disorder validated their experiences, making them feel empowered to discuss themselves:

*'it's become easier as it's gave me the validation to confidently talk about it and acknowledge my experiences'* [Participant C]

*'I'm like I handled intrusive thoughts like I can handle anything like I was like literally thought these things an I'm OK and I'm here like I can okay this is fine I could do whatever, so it makes me feel strong definitely'* [Participant B]

## Discussion

This qualitative thematic analysis investigated the utility and impact of a diagnosis of OCD. Utility was defined in terms of treatment access and identification of symptoms, and impact defined by personal well-being, social identity, and stigmatisation.

The primary theme for utility related to definitiveness and tangibility. The label provides something tangible to hold onto and use as a guideline. Other themes related to understanding and learning, raising awareness, and treatment accessibility. The primary theme that related to impact was relief or hope inspired from having the label. This related to hope for future treatment and relief for having an answer to what they were experiencing. Other themes associated with impact included a changed identity or social role, feeling empowered, self-explanation, and frustration.

Previous literature suggests labels help people describe their experiences (Perkins *et al.*, 2018), an observation made in respect to other disorder labels including borderline personality disorder (Bartsch *et al.*, 2016) and current findings help relate this to the diagnosis of OCD. This study adds to the wider literature on patient attitudes to diagnosis on OCD by suggesting diagnosis allows individuals to identify thought processes and maintain a sense of stability, leading to hope and relief.

Hope may be beneficial for recovery in the case of people with a diagnosis of personality disorder (Elsegood *et al.*, 2018). Mental health recovery narratives have the potential to increase the likelihood of positive treatment outcomes when diagnosed (Rennick-Egglestone *et al.*, 2019) and current findings appear to mirror this in OCD. In this study, hope was inspired by naming symptoms. In the present study, an OCD diagnosis inspired hope and led to a sense of relief. This was reflected in Participant B feeling she could 'breathe' post-diagnosis. Similar findings have been found with a diagnosis of schizophrenia (Loughland *et al.*, 2015).

Previous findings that identity alters after diagnosis by identifying as 'having OCD' (Pedley *et al.*, 2019) were replicated here. Participants noted a self-described positive social and personal identity change. This in some cases led to identifying as their diagnosis. Self-identification as having the illness can have complex and occasionally adverse effects especially in cases when symptomology greatly reduces post-treatment, an experience known as the 'burden of normality' (Wilson *et al.*, 2001) which has been observed in OCD (Bosanac *et al.*, 2018), and future research may wish to examine this. Despite this, identification with the disorder was discussed positively in the present research, often relating to a changed sense of social identity and increased confidence. Participants often linked this back to the concept of tangibility.

The theme of a changed social role was also discussed in the context of family relationships. This related to a more positive caring role, which has also been found in previous research into family identity and severe mental illness (Acero *et al.*, 2017) and in the present study with a diagnosis of OCD appearing to facilitate this transition to a carer role in others. This was seen in Participant F's comment: *'other people's expectations of me it's not "sure just get on with it", it's let's share the load more'*.



Identification with OCD may increase symptom severity concealment (Wheaton *et al.*, 2016). Whilst this was observed in some participants, only a minority discussed this concept. This often related to stigma through identity change as well as frustration at inappropriate questions. Stigmatising views of OCD as comedic (Chasson *et al.*, 2017) was also discussed in relation to misunderstanding around the symptoms, including OCD described only in terms of contamination fears.

Research relating to stigma of mental health generally leading to poorer well-being and discrimination (Cruwys and Gunaseelan, 2016) was only partially found in those with OCD. Participants discussed some family members stigmatising them, relating to previously cited research (Corrigan *et al.*, 2014). Specifically, participants who raised this explained that some family members would not believe their diagnosis. Stigma was often discussed with a cost benefit analysis; weighing in favour of the positives of being diagnosed previously discussed compared with the negatives.

### **Implications of the findings**

The findings highlight a key issue often missed by those adopting approaches alternative to diagnosis (Kinderman, 2015); that for some, diagnoses inspires hope and relief due to their tangibility and definitive nature. Formulation is, of course, central to cognitive behavioural therapy (e.g. Beck, 1979; Persons, 2008), and particularly for interventions aimed at addressing obsessions and compulsions (Rachman, 2004; Zivor *et al.*, 2013). Formulation perspectives (Johnstone, 2018) such as the Power Threat Meaning Framework (Johnstone and Boyle, 2018) encourage narrative construction to help understand an individual's mental distress as opposed to labelling. The present study provides understanding that a diagnosis creates hope and relief, from a patient-centred perspective; a perspective often neglected. This adds to the argument provided by Dariusz Galasiński (Galasiński, 2018), which critiques the perspective of Kinderman (2015); arguing that moving away from diagnostic language does not mean wholesale rejection of labels or categorical descriptors.

The current study adds to the understanding of a positive change in identity. Positive social identity for example has been identified in aiding recovery in the case of eating disorders (McNamara and Parsons, 2016), which found a shared sense of identity helped with recovery. Whilst the present study did not identify a strong impact from a shared OCD identity, the study made note of a positive social identity change in some post-diagnosis. The use of a diagnosis may provide a changed social role that could aid in recovery. Whilst research makes note of the over identification as having OCD (Pedley *et al.*, 2019), identification as having OCD in this study was not viewed as negative.

These results have implications for stigmatisation and misunderstanding. Previous research suggests diagnosis aids in reducing stigma (Smith and Applegate, 2018), particularly through mental health literacy (Jorm, 2012; Lincoln *et al.*, 2017). Whilst the diagnosis label itself holds stigma and misunderstanding, participants noted that this is not the fault of the label *per se* but result fault of broader misinformation.

### **Limitations**

All research of this nature has potential bias. Participants' self-reported diagnosis had been offered by different professionals, which at least one participant brought up as an issue: '*I guess it depends what you define it as diagnosis because there's the diagnosis from the psychiatrist that comes like official*' (Participant H). Participant B notes that diagnosis can be offered by different professionals, including GP, with some considering only psychiatrists' diagnoses 'official'. Participants may have varying experiences depending on from whom they received the diagnosis, but this was not part of our analysis.

Whilst participants were recruited from OCD Action, a UK-based charity, people visit their website from outside the UK. This may affect discussion of the utility of the diagnosis as the UK has universal healthcare free at the point of need via the NHS compared (for example) with the USA.

In addition, qualitative research like this may be prone to researcher bias. The primary researcher volunteers with the charity OCD Action, whereas the co-author is from a pro-formulation perspective. While these perspectives were acknowledged and discussed in the process of thematic analysis, personal opinions on the OCD diagnosis and personal experience with the diagnosis may introduce bias.

Generalisability was also an issue. Whilst the study aimed to investigate utility and impact of diagnosis, this was only applicable to OCD diagnosis. Application of research like this requires further study on stigmatised disorders like that of psychotic disorders or personality disorders.

### Conclusions

The theoretical thematic analysis of 12 interviews of those who identified with an OCD diagnosis revealed that the diagnosis has utility in providing tangibility and definitiveness in respect to their problems, which related largely to the impact of the diagnosis providing relief and hope for future treatment options. The findings reveal the important functions served by diagnostic labels. Alternative adiagnostic approaches to mental health provision, such as the power threat meaning framework (Johnston and Boyle, 2018) may need to provide the tangibility and definitiveness important to those with a diagnosis of OCD. Future research may wish to investigate how this could be applied in such non-diagnostic approaches, as well as how concepts of tangibility and definitiveness and subsequent relief and hope relate to other disorders.

**Data availability statement.** The data that support the findings of this study have not been made openly available due to ethical considerations regarding the content discussed in the interview transcripts and under ethical guidelines from The University of Liverpool ethics committee under GDPR for this study

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