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ORIGINAL ARTICLE

Patient Perceptions of Illness Causes and Treatment Preferences for Obsessive-Compulsive Disorder: A Mixed-Methods Study

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Abstract

Obsessive-compulsive disorder (OCD) is a condition with high patient morbidity and mortality. Research shows that eliciting patient explanations about illness causes and treatment preferences promotes cross-cultural work and engagement in health services. These topics are in the Cultural Formulation Interview (CFI), a semi-structured interview first published in DSM-5 that applies anthropological approaches within mental health services to promote person-centered care. This study focuses on the New York City site of an international multi-site study that used qualitative-quantitative mixed methods to: (1) analyze CFI transcripts with 55 adults with OCD to explore perceived illness causes and treatment preferences, and (2) explore whether past treatment experiences are related to perceptions about causes of current symptoms. The most commonly named causes were circumstantial stressors ($n = 16$), genetics ($n = 12$), personal psychological traits ($n = 9$), an interaction between circumstantial stressors and participants' brains ($n = 6$), and a non-specific brain problem ($n = 6$). The most common treatment preferences were psychotherapy ($n = 42$), anything ($n = 4$), nothing ($n = 4$), and medications ($n = 2$). Those with a prior medication history had twice the odds of reporting a biological cause, though this was not a statistically significant difference. Our findings suggest that providers should ask patients about illness causes and treatment preferences to guide treatment choice.

Keywords Obsessive-compulsive disorder · Cultural formulation interview · Explanatory models · Cultural competence · Cultural psychiatry

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Introduction

According to the Text Revision of the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), the diagnostic criteria of Obsessive-Compulsive Disorder (OCD) require an individual to have obsessions, compulsions, or both. *Obsessions* are recurrent and persistent thoughts, urges, or images that are intrusive, unwanted, and distressing, whereas *compulsions* are repetitive, observable or mental acts that are performed in response to an obsession or according to rigid rules to reduce distress, but the acts are excessive or not realistically connected to their triggering stimuli (American Psychiatric Association, 2022). Twelve-month prevalence estimates in US community samples for full OCD and for subthreshold symptoms that do not meet all diagnostic criteria are 0.3–3% and 0.6–4.9%, respectively (Adam et al., 2012). OCD is a debilitating condition, with many patients experiencing symptom reductions without significant improvements in quality of life (Norberg et al., 2008). Quality-of-life level for patients whose symptoms are in remission is between that of healthy controls and those with acute symptoms (Remmerswaal et al., 2020). OCD causes high disease burden: > 10% of patients attempt suicide, ~50% report suicidal thoughts (Pellegrini et al., 2020).

This high burden of illness has prompted a search for factors within the patient-provider relationship that could enhance treatment planning and response. Care providers for psychiatric disorders typically assume that treatment resistance or partial responses are due to treatment inefficacy, with many providers not routinely inquiring about patient preferences for care (Howes et al., 2022). Compared to providers who offer treatment as usual, those who ask patients about preferences for care can improve therapeutic alliance, which increases patient adherence to interventions such as psychotherapy and reduces the severity of post-treatment OCD symptoms (Maher et al., 2012). Discussing patient treatment preferences can facilitate treatment selection, and some studies have identified key topics for clinicians to probe: past/current treatment preferences, beliefs or concerns about treatments, and causes of illness (Patel & Simpson, 2010; Patel et al., 2017). Patients want providers to initiate these conversations to personalize care, but time constraints, clinicians emphasizing certain treatments over others, and the availability of certain types of treatments are barriers to these kinds of discussion (Rodenburg-Vandenbussche et al., 2020). Recent guidelines for practitioners have proposed that eliciting patient explanations about illness causes and formulating treatment plans around patient treatment preferences can promote cross-cultural work in OCD (Williams et al., 2020).

The Cultural Formulation Interview (CFI) offers one method to promote such work. Published in 2013 with DSM-5, the CFI is a semi-structured interview for providers to assess cultural factors related to diagnosis and treatment with patients (American Psychiatric Association, 2013). The CFI builds upon theories in cultural psychiatry and medical anthropology which assume that providers focus on *disease* (abnormalities in the structure and function of physiological systems) whereas patients focus on *illness* (abnormalities in daily functioning and role performances) in clinical interactions (Eisenberg, 1977). Applied anthropologists in internal medicine (Kleinman et al., 1978) and psychiatric settings (Kleinman & Benson, 2006) have recommended that eliciting patient explanations of illness can reveal patient cultural understandings to increase the likelihood of appointment retention and treatment adherence with the hope of decreasing symptoms and ultimately increasing quality of life (Aggarwal et al., 2016a). To create the CFI, the DSM-5 cross-cultural issues subgroup (DCCIS)—mostly composed of psychiatrists, psychologists, and anthropologists—conducted a literature review of studies on cultural assessments in mental health from 1965 to 1994 and case studies on the DSM-IV outline for cultural formulation (OCF) from 1994 to 2011 across psychiatry, anthropology, and psychology (Lewis-Fernández et al., 2014). A 14-item draft was developed with experts from OCF-based consultation services, field-tested with 321 patients, 75 clinicians, and 86 family members in six countries in 2011 and 2012, and revised based on patient and clinician feedback (Aggarwal et al., 2016b). Patients and clinicians found the CFI clinically feasible, acceptable, and useful, with all questions completed in ~23 min (Lewis-Fernández et al., 2017). A systematic review of all studies on the CFI after DSM-5's publication in 2013 (Aggarwal et al., 2020) showed that most studies replicated an early finding (Aggarwal et al., 2015) of the CFI improving information exchange among patients and providers. Because providers have used the CFI with individuals from different ethnic, linguistic, racial, and religious backgrounds, it is increasingly regarded as a tool for promoting clinician cultural competence through person-centered care (Aggarwal et al., 2022; Lewis-Fernández et al., 2020).

The CFI's use across diverse clinical settings and populations suggests its utility in eliciting illness explanations and treatment preferences in individuals with OCD but, to date, there is no published study of its use in this population. The aims of this paper are to use qualitative-quantitative mixed methods to: (1) analyze CFI transcripts completed with a sample of adults with OCD who participated in a research study in New York City to explore different perceived illness causes and treatment preferences, and (2) explore whether past treatment experiences are related to perceptions about the cause of current OCD symptoms.

Methods

Study Setting

These data come from an international study funded by the National Institute of Mental Health to discover biosignatures for cognitive and clinical profiles that could be common to individuals with OCD across different cultural contexts. The parent study also explored whether "environmental" factors (e.g., level of religiosity) moderate the relationship between biosignatures (e.g., neuroimaging) and clinical profiles (e.g., symptom types). The CFI was used to elicit the illness experience of participants with OCD, delineate their cultural background, and clarify scale-based data on religiosity. The CFI data were then used to inform the parent study's quantitative analyses and to describe OCD experiences in cultural context. Our study presents CFI data solely from the US site in New York City to create a codebook that could be adapted in future for use in other sites—Brazil, India, Netherlands, and South Africa—in the parent study.

All research presented here was conducted at the New York State Psychiatric Institute (NYSPI), whose Institutional Review Board approved all study procedures. All subjects provided written informed consent prior to participation.

Overview of the Study Design

The international study included brain imaging, clinical, and neurocognitive assessments to compare medication-free OCD patients, siblings without OCD, and healthy controls. Once deemed eligible and after providing informed consent, participants received clinical and neurocognitive assessments as well as brain imaging, all within one week of each other. OCD participants who wanted treatment could then be referred, including to clinics at NYSPI. A detailed description of all of these methods is provided in xx (REF). The methods with direct relevance to the present paper are described below.

Participants

Adults with OCD could be referred by providers or on their own through media advertisements, information in self-help books, and Internet searches. To be eligible, participants had to have a primary diagnosis of OCD with at least moderate severity (explained below) and be 18-50 years old. Exclusion criteria were: a lifetime diagnosis of psychosis, bipolar disorder, anorexia, autism, or Tourette disorder; current chronic tic disorder, substance-use disorder, binge-eating disorder, bulimia, or suicidality; current use of psychotropic medications or cognitive-behavioral therapy for OCD; major medical or neurological diseases; IQ score < 80; and contraindications to magnetic resonance imaging.

Study Assessments

Clinical Assessments

After initial phone contact, a trained rater completed a clinical evaluation to confirm eligibility for the OCD participants that included the Structured Clinical Interview for DSM-5 to confirm the diagnosis of OCD (First, 2014) and the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) to assess OCD severity (Goodman et al., 1989). The Y-BOCS consists of 10 items that cover 5 rating dimensions for obsessions and compulsions: time spent or occupied; interference with functioning or relationships; degree of distress; resistance; and control. Each item is scored on a four-point scale from 0 (no symptoms) to 4 (extreme symptoms). A Y-BOCS ≥ 16 at initial screening was used as a definition for moderate severity and the minimum score required for OCD patients to be included. A trained rater repeated the Y-BOCS (as needed) to be within one week of the brain imaging. Procedures for rater training are provided in (REF: Methods paper).

During the clinical evaluation, the rater also included questions about treatment, using a Treatment History form to assess current and past use of psychiatric medications, non-psychiatric medications, and psychotherapy. All participants completed demographic surveys with questions on age, gender, racial/ethnic background, employment, education, and religion.

CFI Administration

After participants were deemed eligible and provided informed consent for the study, research staff administered the CFI during the same week they received the clinical and neurocognitive assessments and the brain imaging. Evidence-based methods were used to train staff in CFI administration. The training mixed active and passive adult learning strategies from the DSM-5 field trial, such as reviewing a copy of the CFI, watching a video on its use, and administering the CFI with expert supervision to customize improvement (Aggarwal et al., 2016c). To ensure fidelity to the CFI and avoid incomplete administrations (Aggarwal et al., 2014), research personnel from the international trial conducting CFIs participated in monthly supervision calls with the senior author (who chaired the DSM-5 DCCIS) for quality improvement during the period when subjects were clinically evaluated. All CFI interviews at the New York City site were audiotaped and transcribed by trained research staff (Bernard, 2006).

DSM-5 does not specify how the CFI should be used in research settings (American Psychiatric Association, 2013). The core 16-item version in DSM-5 may need to be modified to serve the aims of research studies without assuming that there is lack of provider adherence or competence (Aggarwal et al., 2014). The role of religiosity—the salience of religion in a person's life—to OCD has long been debated, with some investigators finding no conclusive relationship (Raphael et al., 1996; Tek & Ulug, 2001) and others positing that greater religiosity is correlated to greater obsessions (Himle et al., 2012; Inozu et al., 2012) and overall disorder severity (Rakesh et al., 2021). To minimize participant burden (March et al., 2005) and explore whether religiosity moderates the link between neuroimaging signatures and clinical/cognitive profiles—which we do not report here—the primary investigators modified the CFI. Specifically, the following modifications were made: Core CFI question 1 (What brings you here today?) was removed because all subjects presented to the clinic for study enrollment; Core CFI questions 6 (on social supports), 7 (on stressors), 10 (on general life problems), 12 (on past help-seeking), 13 (on barriers to care), and 16 (on patient-clinical potential misunderstandings) were removed to focus on religiosity by introducing questions from the Spirituality, Religion, and Moral Traditions Supplementary Module of the CFI (Gellerman & Lu, 2016).

In particular, we debated whether to exclude question 16 because perceptions of potential misunderstandings could have influenced participant responses to treatment preferences. We ultimately reasoned that research staff completing CFI administrations were not treatment providers, and that this study was not designed to provide participants with treatments.

The modified CFI used in the study is presented in Table 1.

Table 1 The modified CFI

Cultural definition of the problem

1. People often understand their problems in their own way, which may be similar to or different from how doctors describe the problem. How would you describe your problem?

2. What troubles you most about your problem?

Culture perceptions of cause, context, and support

3. Why do you think this is happening to you? What do you think are the causes of your [PROBLEM]?

4. What do others in your family, your friends, or others in your community think is causing your [PROBLEM]?

Sometimes, aspects of people's background or identity can make their [PROBLEM] better or worse. By background or identity I mean, for example, the communities you belong to, the languages you speak, where you or your family are from, your race or ethnic background, your gender or sexual orientation, and your faith or religion.

5. For you, what are the most important aspects of your background or identity?

6. Are there any aspects of your background or identity that make a difference to your [PROBLEM]?

Cultural factors affecting self-coping and past help seeking

7. Sometimes people have various ways of dealing with problems like [PROBLEM]. What have you done on your own to cope with your [PROBLEM]?

8. Often, people look for help from many different sources, including different kinds of doctors, helpers, or healers. In the past, what kinds of treatment, help, advice, or healing have you sought for your [PROBLEM]?

Role of spirituality and religion

9. Do you identify with any spiritual or religious traditions?

If yes, continue to questions 10-12

If no, continue to the next module (cultural factors affecting current help-seeking)

10. What role does [NAME(S) OF SPIRITUAL OR RELIGIOUS TRADITION(S)] play in your everyday life?

11. How has [NAME(S) OF SPIRITUAL OR RELIGIOUS TRADITION(S)] helped you cope with your [PROBLEM]?

12. Have any issues related to [NAME(S) OF SPIRITUAL, OR RELIGIOUS TRADITION(S) contributed to making your [PROBLEM] worse?

Cultural factors affecting current help seeking

Now let's talk some more about the help you need.

13. What kinds of help do you think would be most useful to you at this time for your [PROBLEM]?

14. Are there other kinds of help that your family, friends, or other people have suggested would be helpful for you now?

We developed a fidelity checklist for the modified CFI that rated clinician adherence to each question (was the CFI questioned asked—yes/no), competence in asking follow-up questions (were follow-up questions asked to elicit the intended content of each CFI question—yes/no), and patient responsiveness in answering each question relevantly (did the patient answer—0 for no, 1 for an answer that was irrelevant, and 2 for an answer that was relevant) (Aggarwal et al., 2014). All clinicians and patients in the dataset responded to each CFI question with full adherence, competence, and patient responsiveness.

Collaborative Approach to Cross-Cultural Data Analysis

Mixed-methods studies in health services research can take 3 forms: (1) analyzing two types of data separately, but integrating results during interpretation; (2) connecting qualitative and quantitative approaches in such a way that one approach builds on the other, and (3) embedding the analysis of one approach within another (Zhang & Creswell, 2013). Our study took the third form such that quantitative analysis built upon findings from qualitative analysis.

We held research meetings with the primary investigators and their personnel working with CFI data across all sites to ensure that the analytical plan introduced for the New York City dataset would be feasible, acceptable, and useful for the parent international trial. Qualitative data analyses were transformed to generate hypotheses that could be tested through quantitative analyses (Palinkas et al., 2011). Our research question was whether receiving a type of treatment in the past influenced perceptions about the cause for current OCD symptoms.

Qualitative Data Analysis

The CFI analytical team consisted of a Bachelor's-level research assistant, a postdoctoral research fellow in psychology, and two research psychiatrists who specialize in applied anthropology in mental health settings. We conducted a content analysis of all CFI transcriptions. Content analysis is a systematic method for describing and quantifying phenomena through replicable, valid inferences from data to context (Krippendorff, 2013). Deductive content analysis tests theories in new datasets through established steps: (1) selecting the textual unit of analysis, (2) developing a codebook of mutually exclusive categories based on extant theories, (3) coding data, (4) reporting data by category (Elo & Kyngäs, 2008).

Selecting the Textual Unit of Analysis

We selected each transcription as the unit of analysis and each meaning unit to be the words or sentences that relate to each other through context and content (Graneheim & Lundman, 2004).

Developing the Codebook

After a literature review, we used Nicolini et al.'s (2017) framework on the influence of culture in OCD. This framework differentiates patient explanatory models of illness based on perceived causes and treatment preferences. Examples of codes that we generated are: idioms of distress, description of symptoms, illness causes, self-coping, help-seeking, and treatment preferences. The analytical team created the codebook with definitions for codes from the article. The codebook was sent to all principal investigators and the personnel who administered the CFI at their sites to ensure that the codes would be cross-culturally applicable; any unclear codes were clarified.

Coding the Data

The research assistant and post-doctoral fellow coded 5 randomly selected CFI transcriptions with the Culture-in-OCD codebook (approximately 10% of the total interview sample). Each team member coded each meaning unit for each CFI question with a single unique code. To maintain analytical distance and reduce bias, no team member coded interviews in which they participated. Each team member independently coded transcriptions to generate preliminary codes. We discussed concordance among codes and concepts, inviting challenges to initial interpretations. We clustered codes into categories based on CFI domains to derive themes. Descriptive memos were drafted to specify code definitions and parameters (appropriate and inappropriate use) through data examples. Independent coding continued for 3 rounds with the same CFI transcripts until the research assistant and post-doctoral fellow achieved 80% inter-rater reliability. Afterwards, both team members coded all transcriptions. The entire analytical team met weekly during the process of their coding to review transcripts, discuss codes, and reach coding consensus in cases of disagreements. To ensure rigor and validity of analysis, we used an audit trail of analytical memos and meeting notes, triangulation of narrative data, peer-debriefing sessions, and team member-checking activities (Hsieh & Shannon, 2005). The codebook in all iterations is available upon request.

After both team members coded all transcriptions, the first author reviewed all instances of illness causes and then created subcodes inductively. Inductive content analysis is used when no extant theoretical frameworks describe the phenomenon under investigation (Elo & Kyngäs, 2008). Our literature review did not produce any article on patient perceptions of OCD causes. Therefore, the first author created and sent a list of all new subcodes to the coding team for additional triangulation of narrative data, peer-debriefing sessions, and team member-checking activities (Hsieh & Shannon, 2005).

Reporting Data by Category

We use descriptive statistics to rank all themes (Krippendorff, 2013). Categories for reporting sociodemographic characteristics come from the US Census Bureau.

Quantitative Data Analysis

Prior Treatment History

Participants reported their prior treatment history as none, medication-based, psychotherapy-based, or both. These responses were categorized as either: medication treatment history (with or without psychotherapy—combined due to the relatively smaller sample size) or no medication treatment history.

Perceived Cause of Problem

Through the CFI, participants were asked to describe what they believe caused OCD. These responses were categorized as primarily biological/neurological in nature (“genetics,” “problem with their brain,” “stressor + brain interaction”) or not biological (“psychological trait,” “circumstantial stressor,” “heightened senses,” “not having supportive relations”). Responses stating the cause is unknown were included in the not-biological response group. No respondent reported more than one cause, and each participant was assigned a single code from the coding team.

Due to sample size limitations, quantitative analyses were limited to frequencies using the FREQ procedure and simple logistic regression using the LOGISTIC procedure in SAS software, version 9.4 (Cary, NC).

Results

Sample Demographics

Table 2 presents the characteristics of participants who completed CFIs for this study.

Ages ranged between 20 and 30 years old, with an average duration of OCD of 10 years. Slightly more people who self-identified as female (52.7%); no participant selected a third gender option of “other, please specify.” The average severity score of the entire sample was 23.6 on the YBOCS, which exceeded the inclusion criteria of 16 for moderate severity, approaching the minimum score that defines the range for severe symptomatology (Goodman et al., 1989). Over 85% of participants were either in school or had jobs.

The OCD program at NYSPI draws research participants across New York City, Connecticut, and New Jersey. The demographic characteristics of the sample are not representative of the Washington Heights neighborhood where NYSPI is located, which is 65% Latinx and 46% foreign-born, according to the US Census Bureau (2021). Our findings should therefore be interpreted as relevant for people with OCD seeking specialty research interventions rather than for people within the neighborhood accessing routine clinical care.

Qualitative Data Analysis

Participants attributed various causes for OCD through the CFI: circumstantial stressors (*n* = 16, 29.0%), genetics (*n* = 12, 21.8%), personal psychological traits (*n* = 9, 16.4%), an interaction between circumstantial stressors and their brains (*n* = 6, 10.9%), and a non-specific brain problem (*n* = 6, 10.9%). Four participants could not name a cause, one described an issue with “heightened senses,” and one traced the cause to not having close supportive relationships.

Table 2 Sociodemographic characteristics of participants with OCD (n = 55)

	n	%	*M*
Age			27.7 [18–49]
Gender			
Female	29	52.7	
Male	26	47.3	
Race			
White	31	56.4	
Mixed/other	8	14.5	
Black	6	10.9	
South Asian	5	9.1	
East Asian	3	5.5	
American Indian	1	1.8	
Chose not to respond	1	1.8	
Ethnicity			
Non-Latinx	43	78.2	
South American	5	9.1	
Caribbean	4	7.3	
Central American	1	1.8	
Mexican, Mexican-American	1	1.8	
Chose not to respond	1	1.8	
Born in U.S.			
Yes	41	74.5	
No	14	25.5	
Current employment status			
Work full-time	22	40.0	
Student	14	25.5	
Work part-time	11	20.0	
Out of work for other than health reasons	5	9.1	
Other	1	1.8	
Chose not to respond	1	1.8	
Years of education			16 [12–27]
OCD severity			23.6 [16–30]
OCD duration (in years)			10.8 [0–37]

Participants also expressed treatment preferences. Forty-two (76.3%) thought that psychotherapy would be most helpful. Fewer people named: anything (*n* = 4, 7.2%), nothing (*n* = 4, 7.2%), and medications (*n* = 2, 3.6%). Deep brain stimulation, a combination of psychotherapy and medications, and supportive personal relationships were each named once.

Qualitative researchers have suggested that data saturation—defined as the point at which no new information is elicited to generate distinct coding meta-themes—in purposive samples is often reached within 12 interviews (Guest et al., 2006). No researcher can predict whether an additional participant will reveal new information; however our dataset includes 55 CFI transcripts, and we believe that our analysis presents clear meta-themes. Below, we present representative quotations on perceived illness causes and treatment preferences to illustrate themes named by more than one participant.

Perceived Illness Causes

Circumstantial stressors—was the most common perceived illness cause. We defined this theme as any situation or event that participants named as a cause of their OCD symptoms. The coding team used DSM-5's definition of an Adjustment Disorder—the development of emotional or behavioral symptoms in response to an identifiable stressor (American Psychiatric Association, 2013)—to clarify appropriate use of this theme when coding patient responses.

Subject 5014's response is illustrative of patients identifying circumstantial causes for their illnesses. Self-identifying as a man in his early 20s, he had been in psychotherapy to treat OCD before entering the study. In response to CFI Question 1, he said, "I would describe my problem as both intrusive thoughts of images that cause me guilt, or long discussions with myself that produce guilt, usually triggered by unwanted thoughts."

> Research staff: Why do you think this is happening to you? What do you think are the causes of your problem?
> Subject 5014: Well, I think there was an event in my childhood that created guilt in me. It was after accidentally seeing porn on the Internet. I felt guilt because I felt I shouldn't have seen it. This is how it started.
> Research staff: What do others in your family, your friends, or others in your community think is causing your problem?
> Subject 5014: They think about this event as well. Or they don't know about it and therefore are unable to point to a specific point in time where everything started. Most people don't understand OCD that much.

Genetics—was the second most frequently mentioned illness cause. We defined this theme as any explanation about inheriting OCD from biological relatives. The coding theme used a broad definition for genetics—how much a syndrome runs in families (Kendler, 2006)—to clarify appropriate use of this theme when coding patient responses.

The responses of Subject 5031 well represent those who discussed an inheritance model for their symptoms. Self-identifying as a female in her late 20s, she received psychotherapy and medication management for OCD symptoms before entering the study. She described her illness experiences as, "I have obsessions and compulsions that take up a big part of my day and have become debilitating. They affect a lot of my day-to-day life, having mostly to do with contamination." Research staff asked her about illness causes, and she said, "I've always had it, and it has always been debilitating. I don't think it has much to do with me. I think that I was just born that way."

> Research staff: What do others in your family, your friends, or others in your community think is causing your problem?
> Subject 5031: My dad who passed it down to me, who has no awareness of anything that goes on ever, thinks that it's something that I should just get over and work harder to not focus on. And that if I had other things to focus on, then it wouldn't be there, which is just ridiculous.
> Research staff: So does your dad think that it's genetics?
> Subject 5031: I think most people in my family think it's genetics. We see that he has it, and my sister has a little bit of it. The guy I'm dating doesn't know a lot about it, so he thinks that it has to do with like my childhood and other crap like that, but we are teaching him slowly.

Personal psychological traits—was the third most frequently mentioned illness cause. We defined this theme as any explanation of OCD symptoms that reflected a manifestation of how patients saw themselves as thinking, feeling, or behaving. The coding team used a definition of traits—pervasive, cross-situational consistencies that are inherent to one's understanding of oneself (Zuroff, 1986)—from personality psychology to clarify appropriate use of this theme when coding patient responses.

Subject 5070's answer typifies how patients view OCD as reflecting underlying psychological traits. Self-identifying as a female in her late 20s, she had previously been in treatment for OCD with medication and psychotherapy. When asked to describe her symptoms, she said, "Maybe a baseline anxiety that in the past year, I've felt, really escalated and became more obsessional. And then when I assessed it more, it seemed like maybe I was unconsciously engaging in compulsive behaviors as well." Research staff asked her about illness causes, and she said, "If I go way back, I'm sure there's underlying childhood attachment issues… I think the past two years, I have a sense that a lot of my obsessions is surrounding a very close friend's well-being and welfare. And the past two years, he's been really unwell."

Circumstantial stressor x brain interaction—was the fourth most frequently mentioned illness cause. We defined this theme as patients naming a situation or event that interacted with their brain to produce OCD symptoms. To clarify appropriate use of this theme when analyzing patient responses, the coding team used a definition of biological-environment interactions as the biological pathways that are most relevant to a disease, and the environmental factors that are most relevant to these pathways (Hunter, 2005).

Like others who reported such interactions, Subject 5076 discussed a biological predisposition to OCD that was exacerbated through specific events. A self-identified man in his late teens, he sought psychotherapy for treatment before entering the study. He described his symptoms as self-punitive:

> "The violent and sexual intrusive thoughts are the worst, because those are so… I mean, if I wash my hands, it's not like, 'Oh, I'm such a bad person,' but when you think thoughts like, 'It's okay' or 'This is really out of character,' it really, really hurts. It always makes you second-guess yourself, your desires and inhibitions, and things like that. But I think the hardest part are the violent images and sexually intrusive thoughts."

His narrative on illness causes implicated genetic-environmental interactions:

> "I assume it was genetic. My great-grandmother, they called her a chronic worrier, and she was never diagnosed, but her mental health declined her whole life. And no one really knows exactly what she had, but there were bouts of manic depression, and stuff like that. She'd talk about wanting to kill herself to her young children and stuff like that, and so I found that out when I was 17. I assumed that it was likely genetic. And then the environment that I was raised in, my father's very safety-conscious. He wouldn't check the locks an obsessive amount, but I remember one night we went to a hotel, and he blocked the door with a chair, and I don't know if we were in a sketchy area or if it was just his habits. And then my mother is always, not necessarily a compulsive hand-washer, but washes her hands a lot, so they're dry. I think everybody has their minimal obsessions of things that they're prone to keep an eye out for, so I feel like being around two different kinds, and then my brain already being prone to OCD, kind of heightened it, you know? Because people are so safety conscious and hygiene conscious. And then my brain just kind of took it and hijacked that idea. And then with the intrusive thoughts, I – like a lot of kids my age – was exposed to a lot really fast with the Internet. Especially before it started to be moderated. I remember watching a lot of graphic murder mystery TV shows and movies and stuff like that when I was young. I remember my first intense intrusive thoughts when I was twelve. I really wanted to be a detective, so I was watching a bunch of true crime stories, and then the mind, OCD, kind of flipped it on me, like what if *you* want to kill people? What if you want to do that? So a mix of just environment but then my brain."

A non-specific brain problem—was the fifth most frequently mentioned illness cause. We defined this theme as patients explaining OCD symptoms through a general problem with their brains. To maintain conceptual clarity and mutual exclusivity during coding, responses in this category could not definitively implicate ***genetics*** or ***circumstantial stressor x brain interaction*** as mechanisms, whose themes had clearer definitions.

Like other participants, Subject 5050 did not have a precise explanation for OCD. A self-identified man in his early 30s, he had been in treatment with psychotherapy and medications before entering the study. He described his symptoms as, "Intrusive thoughts that I don't feel like I can control. It's just, like, thoughts that wanna ruin everything, I suppose. And then a lot of anxiety that comes with those intrusive thoughts." He speculated on possible biological mechanisms in his answer on illness causes:

> "Part of me thinks it could be, like, some kind of circuitry that's gone wrong in my brain. I know I didn't used to always be this way, so I do remember what it was like not to have intrusive thoughts. And I remember observing them when it first began and thinking, 'What the hell is this?' Maybe part of it is age, maybe part of it is genetic, maybe part of it is past drug use. You know, I've speculated about that. I used to smoke a lot of marijuana when I was 20, and then I experimented with some other drugs in my 20s, and then I did magic

> mushrooms when I was 24. And the OCD started – if I'm remembering correctly – sometime around the time when I tried magic mushrooms. So part of me wonders if there was some kind of brain chemistry thing going on with that. I don't know."

Treatment Preferences

Psychotherapy—was the most preferred treatment. This theme captured responses in which patients exclusively opted for talk therapy. Subject 5014, who described a circumstantial stressor triggering his OCD symptoms that was presented above, exemplified such responses:

> Research staff: What kinds of help do you think would be most useful to you at this time for your problem?
> Subject 5014: Well, I think the therapy that I am going to right now is something that I needed a lot, and honestly just having someone to talk to about these things helps a lot. I think exposure therapy might also be helpful, especially for the compulsive aspects of it.
> Research staff: Are there other kinds of help that your family, friends, or other people have suggested would be helpful for you now?
> Subject 5014: My mother has suggested homeopathy. This was not now. It's something she said I could try if I ever need to be on some kind of psychiatric medicine. But since I don't think I need medicine, I haven't tried it.

Anything—was the second-most-named treatment preference. This theme referred to responses where patients were willing to explore any type of treatment.

Subject 5084's answer typified others in this category. A self-identified female in her late 40s, she had never been in treatment for OCD. She described her illness experiences in the following manner: "What brought me in was the symptoms that I have been having for the past few years. I did some research on it online, and it seemed to be checking, what they call the checking OCD, because I constantly check my stove. I check my faucet. I would spend at least twenty minutes in the kitchen each night checking before I go to bed, and I thought that was kind of alarming." She could not identify a discrete cause for her symptoms: "I don't know. I try to think back if there's any kind of trauma that may have sparked this behavior, but I can't think of anything that has triggered it." Research staff inquired about treatment preferences, and she said, "I don't know – I don't know how the therapy works. Maybe some kind of therapy? Medication? Whatever is there, I'm just willing to try it."

Nothing—was also tied for the second-most-common treatment preference. Under this theme, participants did not want treatment at this time or did not express a preference for a particular type of treatment.

Subject 5034's response was like others in this category. A self-identified male in his mid-20s, he had never been in treatment for OCD before. At the time of study enrollment, his YBOCS severity score was 21, which is in the higher end of the moderate range of 16–23. He described his symptoms as, "Constantly having to adjust things and making sure things are in order. Intrusive thoughts. It really takes up a lot of my time.” When asked about the causes of his illness, he said, “[I have] worries that other people will get hurt or they’re in pain.” His response to the question on treatment preferences indicated that he did not want treatment: “None that I can say right away. Cause now it’s [OCD] really under control. And like I said, I feel the symptoms weakening as I grow older.”

Medications—were named only by two participants. This theme captured responses in which patients exclusively opted for a pharmaceutical agent.

Subject 5020 was similar to the other participant who expressed a preference for medications. A self-identified man in his late 30s, he had never been in treatment for OCD. In describing his symptoms, he said, “I definitely have a little too much obsessive-compulsive, ingrained thought patterns. It has affected me where I overanalyze the smallest things. I repeatedly do tasks that I know I’ve done that don’t absurdly deserve that much attention.” He perceived the cause as a psychological trait toward self-destruction:

> “I think it’s an internal fear of doing things wrong or not very precise. I also think it’s a back-end horrible destructive thing inside me that wants to hurt me because the one thing I know for certain is that time is the most valuable thing, and there’s a devil in me that wants to waste it. For nothing, on nothing, too. But it’s not conscious, that devil.”

Asked about his current treatment preferences, he said, “I don’t want to say it this way, but drugs.”

Quantification of Qualitative Data and Mixed-Methods Comparison

Table 3 presents themes from coding sessions on OCD causes and current treatment preferences.

Presenting perceived causes alongside treatment preferences shows that most participants who expressed a perceived biological cause did not prefer a biological intervention such as medications or deep brain stimulation over psychotherapy.

Causes and Prior Treatment Experiences

Twenty-one (38.9%) participants reported prior medication treatment compared to $n = 33$ (61.1%) who did not and respondent from one data missing. Among those with prior medication treatment, $n = 12$ (57.1%) believed that their symptoms had a biological cause. Among those with no prior medication treatment history, $n = 13$ (39.4%) believed that their symptoms had a biological cause.

Participants with a prior medication history had 2.05 times higher odds than those without any history of medications to believe the cause of their illness to be biological. However, this was not a statistically significant difference (95%CI 0.68–6.23).

Table 3 Themes related to perceived illness causes and treatment preferences ($n = 55$)

Anonymized study ID	Perceived cause	Type of cause	Current treatment preference
5014	Circumstantial stressor	NB	Psychotherapy
5016	Circumstantial stressor	NB	Psychotherapy
5017	Psychological trait	NB	None
5018	Stressor + brain interaction	B	Psychotherapy
5019	Genetics	B	Medications
5020	Psychological trait	NB	Medications
5021	Circumstantial stressor	NB	Psychotherapy
5023	Circumstantial stressor	NB	Psychotherapy
5025	Problem with the brain	B	Psychotherapy
5026	Psychological trait	NB	Psychotherapy
5027	Problem with the brain	B	Anything
5031	Genetics	B	Psychotherapy
5032	Unknown	NB	Psychotherapy
5033	Problem with the brain	B	Psychotherapy
5034	Psychological trait	NB	None
5035	Problem with the brain	B	Psychotherapy
5036	Genetics	B	Psychotherapy
5037	Genetics	B	Psychotherapy
5039	Unknown	NB	Psychotherapy
5040	Unknown	NB	Psychotherapy
5041	Genetics	B	Psychotherapy
5042	Stressor + brain interaction	B	Psychotherapy
5043	Circumstantial stressor	NB	Psychotherapy
5044	Heightened senses	NB	Psychotherapy
5046	Genetics	B	Psychotherapy
5048	Stressor + brain interaction	B	Deep brain stimulation
5049	Genetics	B	Psychotherapy
5050	Problem with the brain	B	Psychotherapy
5055	Stressor + brain interaction	B	Psychotherapy and medications
5056	Circumstantial stressor	NB	Psychotherapy
5057	Circumstantial stressor	NB	Psychotherapy
5058	Circumstantial stressor	NB	Psychotherapy
5059	Circumstantial stressor	NB	Psychotherapy
5061	Genetics	B	None
5064	Circumstantial stressor	NB	Psychotherapy
5065	Circumstantial stressor	NB	None
5066	Genetics	B	Psychotherapy
5067	Problem with the brain	B	Psychotherapy
5070	Psychological trait	NB	Psychotherapy
5073	Not having supportive relations	NB	Supportive relationships
5075	Stressor + brain interaction	B	Psychotherapy
5076	Stressor + brain interaction	B	Psychotherapy

Table 3 (continued)

Anonymized study ID	Perceived cause	Type of cause	Current treatment preference
5080	Genetics	B	Psychotherapy
5084	Unknown	NB	Anything
5085	Circumstantial stressor	NB	Anything
5089	Genetics	B	Psychotherapy
5093	Circumstantial stressor	NB	Psychotherapy
5094	Circumstantial stressor	NB	Anything
5098	Psychological trait	NB	Psychotherapy
5100	Circumstantial stressor	NB	Psychotherapy
5104	Psychological trait	NB	Psychotherapy
5112	Psychological trait	NB	Psychotherapy
5113	Psychological trait	NB	Psychotherapy
5119	Circumstantial stressor	NB	Psychotherapy
5120	Genetics	B	Psychotherapy

B Biological (gray shading); *NB* non-biological (no shading)

Discussion

This is the first study to use the CFI as a systematic method for eliciting perceptions about illness causes and treatment preferences from adults with OCD and to explore whether past treatment experiences are related to perceptions about the cause of current OCD symptoms. We found the most commonly named causes were circumstantial stressors and genetics. The dominant treatment preference was psychotherapy. Participants with a prior medication history had twice the odds compared to those without past medication use to report the cause of their illness as biological, though this was not a statistically significant association. Our findings suggest that providers should ask patients about perceived illness causes and treatment preferences to avoid making assumptions about the acceptability of any treatment type.

Drawing upon the *disease-illness* distinction in medical anthropology, researchers have encouraged work on patient illness experiences, which has lagged behind epidemiological studies that have found the disease structure of OCD to be consistent across cultures (Lewis-Fernández et al., 2010; Stein & Rapoport, 1996). To date, few OCD studies have been conducted on illness explanations in clinical research settings. One research group presented two vignettes on causes of OCD—one on brain malfunctioning and another integrating biological, psychological and social factors—to 130 patients with OCD; those who subscribed to a biomedical model believed that their illness would require chronic, long-standing treatment (r = .34, p<.001) whereas those who subscribed to a biopsychosocial model believed that behavioral changes were possible (r = .22, p = .013) (Gershkovich et al., 2018). Our study complicates the distinction between purely biomedical and biopsychosocial models: 21.8% and 10.9% interpreted their illness as a genetic or a non-specific brain problem, respectively, but many of these patients believed that psychotherapy would be most helpful. While this may strike clinical researchers as inconsistent, anthropologists have pointed out that illness explanations must be understood as unique to an individual based on illness course, life trajectory, and narrative setting; alterable over time; and not necessarily determinative of medical behaviors in a mechanical way (Kleinman, 1980). The value of the CFI is that providers can potentially improve mental health service engagement by constructing person-centered treatment plans that match patient illness explanations to avoid service disengagement that leads to worse health outcomes (Lewis-Fernandez et al., 2017).

Genetics and non-specific brain problems are two perceived illness causes that have appeared in other cultural settings. Lemelson (2004) interviewed patients with OCD and traditional healers in Bali, Indonesia, finding that, "The *dukun* [healer] said that his illness was 'passed down' or inherited [b.i. *pembawaan* or *keturunan*] from his deified ancestors. This was seen as a punishment due to the family's lack of offerings [b.b. *sesajen* of the type *pekeling*] at the family temple or shrine [b.b. *sanggah*]. He needed to do a purification/sanctification [b.b. *mecaru*] ceremony" (p. 64). To be sure, none of the participants in our biomedical setting described OCD as a punishment from ancestors that required religious rituals. Still, similarities and differences in conceptions about the inheritance of OCD across cultural groups is a theme that merits further research. Participants in our study also endorsed non-specific neuroscientific causes that did not relate to genetics, in a reflection of how the general US public has adopted biomedical models of illness that have diffused throughout society. Some anthropologists have raised concerns that neuroscientific explanations for mental illnesses could prevent patients from undertaking acts of self-agency to change their thoughts, emotions, and behaviors in therapy if they perceive that there is little they can do about a biological phenomenon (Davis, 2022). Our results complicate this understanding because all participants who viewed their illness as caused by a non-specific brain problem were receptive to psychotherapy (and indeed psychotherapy has been shown to alter brain function in OCD (Baxter et al., 1992). We intend to explore these themes and potential associations in a future publication using data from all of the sites.

Our study also begins to illuminate the relationship between patient explanations of illness causes and treatment views across treatment episodes. More than 75% of all participants reported a current preference for psychotherapy, in line with prior surveys of patients showing a preference for psychotherapy with or without medications over only medications (Patel & Simpson, 2010; Patel et al., 2017). We found that participants with a prior medication history had 2.05 times higher odds than those without a medication history to believe that their cause of illness was biological in nature, similar to a trend that Patel et al. (2017) observed. Even though this association was not statistically significant, it may be clinically important. Utilization data nationwide demonstrate that outpatient physicians in routine settings treat OCD with medications over psychotherapy (Patel et al., 2014), despite interventions such as cognitive-behavioral therapy showing high remission rates of 59.2% post-treatment and 57.0% at follow-up (Öst et al., 2022). Our findings suggest that providers could ask patients about perceived illness causes and prospective treatment preferences to guide treatment choice and promote adherence. We echo Patel et al.'s (2017) call for expanding access to psychotherapy, perhaps through evidence-based

Internet-based platforms, so that patient preferences are included in treatment plans. How to incorporate patient preferences for therapy in service environments with limited access to therapists or higher costs of therapy relative to less frequent medication appointments remains an area for future research.

Our study has several limitations. First, patients may have expressed a higher preference for psychotherapy based on their perceptions of what kinds of treatments were offered at NYSPI, among other influences. The parent trial enrolled patients across several international sites that do not all offer the same types of treatment, so comparing treatment preferences across sites and at different points in care could be new lines of inquiry. Second, the parent study recruited individuals with OCD at every site who were willing to participate in brain imaging and neurocognitive testing, so this may have influenced their causation reports. Third, we were underpowered to report a statistical association between a patient's prior medication history and current perception of illness cause. Assuming 80% power, the observed proportions and odds ratio would require a sample of at least n=258 to reach statistical significance. Fourth, our smaller sample size prevents us from drawing connections between perceived causes/current treatment preferences and participant demographic characteristics such as gender, racial, and ethnic identity. We situate our work within a mixed-methods paradigm and, like other qualitative researchers, believe that useful themes for understanding how people narrowly interpret a social phenomenon (such as their illness explanations) can be elicited with a smaller sample than is needed for quantitative analyses (Guest et al., 2006).

Despite these limitations, our study is the first to use the CFI to systematically elicit illness causes and treatment preferences from adults with OCD. The elevated rates of service disengagement, morbidity, and mortality of people with OCD warrant novel approaches to caregiving in clinical contexts. The CFI is one method that can advance person-centered care for patients across a range of ethnic, linguistic, racial, and religious backgrounds. Future studies are now needed to examine how providers personalize treatment plans to match patient preferences, and whether such personalization improves engagement in mental health services, symptom reductions, and quality of life.

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Declarations

Competing interests Drs. Aggarwal and Lewis-Fernández receive royalties as editors of the American Psychiatric Association's *DSM-5 Handbook on the Cultural Formulation Interview*. Drs. Simpson and Lewis-Fernández receive institutional support from the New York State Psychiatric Institute and royalties from UptoDate. Dr. Simpson receives a stipend as an Associate Editor of *JAMA Psychiatry*. Dr. Lewis-Fernández received an honorarium for a training activity at Abbvie. No other authors have competing interests to disclose.

Ethical approval Approval was obtained from the ethics committee of each institution listed above to conduct the study. The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Informed Consent All participants provided informed written consent prior to entering the study.

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