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## Patient Preferences and Acceptability of Evidence-Based and Novel Treatments for Obsessive-Compulsive Disorder

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### Abstract

**Objective:** This study examined preferences for and acceptability of treatments for obsessive-compulsive disorder (OCD).

**Methods:** Through an online survey, adults who self-reported OCD chose their preferred evidence-based treatments, rated acceptability of novel treatments, and answered open-ended questions about their preferences. Analyses examined associations between demographic, clinical, and treatment variables and first-line and augmentation treatment preferences. Latent class analysis (LCA) explored whether distinct profiles among participants predicted preferences. Data from open-ended questions were analyzed by using qualitative methods.

**Results:** Among 216 adults with at least moderate OCD symptoms, first-line preferences for exposure and response prevention (EX/RP) and serotonin reuptake inhibitor (SRI) medications were similar (55% and 45%). However, EX/RP was significantly preferred over antipsychotic medication as an augmentation treatment for SRIs (68% and 31%;  $p < .001$ ).

Regarding first-line preferences, no factors were associated with EX/RP preference, but participants who preferred SRIs were currently receiving OCD treatment ( $p = .011$ ) or taking SRIs ( $p < .001$ ) and reported a positive treatment experience overall ( $p = .043$ ) and with medications ( $p < .001$ ).

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001). Participants who preferred EX/RP as augmentation treatment were younger ( $p < .001$ ) and female ( $p = .021$ ) and taking benzodiazepines ( $p = .050$ ). LCA analyses generated two distinct profiles, one of which preferred SRIs: those with a history of OCD diagnosis and treatment, higher income, and private insurance ( $p = .001$ ). For novel treatments, acceptance and commitment therapy was the most acceptable and deep brain stimulation the least.

**Conclusions:** Preferences for OCD treatments varied by individual characteristics. Future research should examine whether incorporating preferences into treatment planning has an impact on clinical care.

Including patient preferences in care has been shown to lead to better outcomes for patients, providers, and the health care system (1). In addition, understanding how patients derive their preferences can shape strategies that optimize engagement in care and guide treatment development. Research has shown that preferences can be influenced by an individual's beliefs about treatment and by its acceptability (2–7)—that is, by how agreeable, palatable, or satisfactory a given treatment is (8). However, few studies have examined factors associated with treatment preferences among individuals with anxiety and related disorders (2,9–12), including obsessive-compulsive disorder (OCD) (11,12). OCD is one of the most severe illnesses, with a lifetime prevalence of about 2% (that is, twice the prevalence of schizophrenia), a relatively early onset, and a typically chronic course (13,14). The purpose of this study was to describe treatment preferences and acceptability among individuals with OCD.

The hallmarks of OCD are obsessions and compulsions, and these symptoms are distressing and time consuming and can cause serious impairment in functioning across all domains of a person's life (15). First-line treatments for OCD include pharmacotherapy with serotonin reuptake inhibitors (SRIs) and cognitive-behavioral therapy consisting of exposure and response prevention (EX/RP) (16). Persons experiencing residual symptoms while taking SRI medications may augment response with EX/RP or antipsychotic medications (17). Although both are efficacious (16,17), EX/RP and medications are very different treatments, and individuals may differ in their preferences.

In an earlier study, we assessed treatment preferences of 90 treatment-seeking adults with OCD and found that they had identifiable preferences (11). Presented with three options (SRIs, EX/RP, or SRIs plus EX/RP), most participants preferred either combination treatment or EX/RP to medications alone. Using similar methodology to assess preferences, Lewin and colleagues (12) found that among 101 parents of children with OCD, all but one preferred treatments that included EX/RP. Our previous study was a first step in identifying treatment preferences; however, the study was limited by its sample size (impeding our ability to examine factors associated with these preferences), its scope (treatment preferences for augmentation strategies and acceptability of novel treatments were not assessed), and its measures (ranking methods were used, which provided information about treatments in comparison with each other as opposed to their acceptability).

To address this gap, we designed an online survey to assess preferences for evidence-based treatments and for acceptability of novel treatments in a large sample of adults with self-reported OCD symptoms. The survey incorporated mixed-methods approaches from health

economics and social sciences, including forced-choice questions, ratings assessments, and open-ended questions, to collect qualitative data. As in previous research on other psychiatric disorders (18), we hypothesized that adults with OCD would prefer psychotherapy to medications and that this preference might be stronger among women and younger participants. Using latent class analysis (LCA), we identified subgroups with similar characteristics and examined their association with preferences. Finally, we explored the acceptability of novel OCD treatments, and we report on beliefs regarding treatment and services.

## METHODS

### Overview

Participants seeking information on OCD or its treatment on the Internet were recruited between April 2010 and September 2014 via a Web-link advertisement that linked to the survey on the Web site of the Center for Obsessive-Compulsive Treatment and Related Disorders clinic ([www.columbia-ocd.org](http://www.columbia-ocd.org)). This site includes information about the center, links to OCD resources, and descriptions of current research studies at the center that are recruiting participants. The advertisement recruited adults (18 and older) who self-identified as having OCD symptoms and used a self-report survey via [survey-monkey.com](http://survey-monkey.com). The Institutional Review Board of the New York State Psychiatric Institute approved the study.

### Survey Instrument

The 30-minute survey developed for the study asked participants about demographic information, treatment history, current OCD symptoms and severity, preferences for first-line treatment (EX/RP versus SRI medications) and augmentation treatment (EX/RP versus antipsychotic medications), acceptability of novel treatments, reasons for preferences, and suggestions to improve OCD services and treatments.

### Data

Participants were queried about sex, age, racial and ethnic background, marital status, income, education, employment status, and health insurance. Treatment history information included treatment status (currently receiving or not receiving treatment), type (SRIs, benzodiazepines, antipsychotic medications, EX/RP, and cognitive therapy, which was described as talk therapy to help the client overcome difficulties by identifying and changing dysfunctional thinking, behavior, and emotional responses), OCD support group, supportive or dynamic therapy, and overall experience (positive or negative) with medication or psychotherapy.

Participants self-reported whether they had ever received a diagnosis of OCD and by what type of health care professional (primary care physician, psychiatrist, psychologist, or social worker). In addition, participants completed the Obsessive-Compulsive Inventory-Revised (OCI-R) (19), an 18-item self-report questionnaire widely used in research with nonclinical samples to assess severity of OCD symptoms. Respondents rate the level of distress, on a scale of 0 to 4, of 18 common OCD symptoms that they encountered in the past month. The OCI-R has been validated against the Structured Clinical Interview for DSM-IV and the

Yale-Brown Obsessive Compulsive Scale. Severity of OCD is defined as mild (scores of 15–19), moderate (20–34), and severe (35). It has optimal cutoff scores of 21 (sensitivity 66% and specificity 64%) when distinguishing persons with OCD from nonanxious persons in a control group (19). A score of 21 was used as a cutoff to define clinically significant OCD in our sample; persons with a score of 21 may be more likely to seek treatment and discuss treatment preferences with a provider than those who score below the cutoff.

Preferences for first-line and augmentation treatments were framed in a forced-choice format as a recommended preference assessment technique to increase the number of survey responses for analysis and encourage respondents to respond (20). Descriptions of SRI and antipsychotic medication and EX/RP were derived from practice guidelines (16) and adapted to emulate how a clinician might present these treatment options for OCD in clinical practice. The description of each treatment provided background information along with procedures, typical duration, efficacy information, and possible side effects. Treatment descriptions were matched as nearly as possible with respect to sentence structure, wording and word count, grade level, and reading ease as determined by a readability formula commonly used to assess health education materials, the Simplified Measure of Gobbledygook (21). Each description was vetted by an expert in the pharmacological and psychological treatment of OCD. Participants were asked about their preferences among first-line treatment options for OCD (that is, treatment with an SRI or with EX/RP), referred to below as the “first-line treatments.” Only participants who reported residual symptoms while taking an SRI medication were queried about their preference for the addition of antipsychotic medication or EX/RP, referred to below as the “augmentation treatment.”

Rating scales were used to measure acceptability of novel treatments, given their ease of administration and because they assign a value or score to an item as opposed to a ranking, which asks respondents to list items in order of importance (22). We asked participants to rate overall acceptability of expert-vetted descriptions of each novel treatment by using an analog 5-point Likert scale (0, highly unacceptable, to 4, highly acceptable). Treatment descriptions were developed by using the same methods described above for forced-choice preferences. Each description was sent to an expert in each novel treatment for vetting the content and revision prior to inclusion in the treatment survey.

Participants were asked the following open-ended questions: “Why did you choose this as your preferred treatment?” (regarding their forced-choice preferences) and “Please tell us, in your own words, about any comments or suggestions on how to improve treatment and services for people with OCD.”

### Quantitative Analysis

Statistical analyses were performed with IBM SPSS Statistics for Windows, Version 23.0, and the library poLCA (23) in the Foundation for Statistical Computing’s statistical software R version, 3.1.2. Analyses were performed of data from participants who reported that they had OCD and who had an OCI-R score of 21 or higher (N=216). Descriptive statistics were used to describe demographic characteristics, treatment history, OCD symptom severity, and forced-choice preferences, as well as ratings of novel treatment acceptability. In addition, to examine associations between demographic, clinical, and treatment variables and

preferences, we conducted chi-square tests for categorical variables by using a collapsed dichotomous variable for race (white versus other) or Fisher's exact tests as appropriate. Ordinal variables were compared by using nonparametric Wilcoxon tests, and t tests were used for quantitative responses. An alpha of .05 was used as the criteria for significance; no corrections were made for multiple testing.

To discover whether subgroups of our participants had similar characteristics and responses and to create profiles of such groups, LCA was performed (24) that used all demographic, treatment history, and OCD and severity variables described above. The Bayes information criterion (BIC) was used to choose the optimal number of classes. Each of the two chosen classes was then described in terms of the percentage of persons with high or low values on the survey questions. The derived classes were then used as predictor variables for the treatment preferences by using the statistical methods described above.

### Qualitative Analysis

Open-ended question data were abstracted by using an inductive process suggested by Hill and colleagues (25). Two coders (SRP and MBK) each developed a preliminary list of themes by independently reviewing the open-ended question data. The coders met and iteratively modified themes by comparing and discussing the data until consensus was met on themes that were reported by at least 10% of the sample.

## RESULTS

### Sample

Of the 370 online surveys started, 304 (82%) were completed. Our final sample included respondents who self-reported clinically significant OCD symptoms (N=216, 71%) as determined by a cutoff score of 21 on the OCI-R. Table 1 presents characteristics for the final sample (N=216). Overall, many participants were white (89%), college educated (55%), middle-aged (mean age of 34), and female (73%). Most earned \$55,000 or less per a year (59%), and most had private insurance (75%). About half were single and had never been married (59%), and about half were employed (53%). The mean±SD score on the OCI-R was 48.614.2 (range 24–84), which indicates severe OCD symptoms. Most respondents self-reported receiving a diagnosis of OCD (85%), the largest portion by a psychiatrist (N=112, 52%), followed by a psychologist (N=55, 26%) and a primary care physician (N=36, 17%). Slightly more than half of the 216 survey respondents were receiving SRI treatment (57%), and about a third were receiving cognitive therapy (31%).

### Preferences for First-Line and Augmentation Treatments and Related Factors

The clinical characteristics of the 198 participants who provided their preferences for first-line OCD treatments are presented in Table 1. Of the 198 participants, 108 (55%) reported preferring EX/RP to SRIs, and 90 (45%) preferred SRIs to EX/RP. No factors (demographic, clinical, or treatment) were significantly associated with EX/RP preferences. Some factors were significantly associated with preferences for SRIs. Those who preferred SRIs were in treatment at the time of the survey ( $p=.011$ ), were receiving SRIs as their treatment ( $p<.001$ ),

and reported a positive experience with treatment overall (58%,  $p=.043$ ) and with medications (61%,  $P<.001$ ).

The clinical characteristics of the 111 participants experiencing ongoing residual symptoms while on medications are also shown in Table 1. More than half of this sample preferred EX/RP to SRIs ( $N=76$ , 68%;  $\chi^2=14.4$ ,  $df=1$ ,  $p<.001$ ). Compared with those who preferred antipsychotics, those who preferred EX/RP were younger ( $42.0 \pm 15.0$  and  $31.0 \pm 13.2$ , respectively;  $p<.001$ ), more likely to be female (63% and 83%, respectively;  $p=.021$ ), and more likely to be taking benzodiazepines (11% and 24%; respectively,  $p=.050$ ).

### LCA and Preferences

We used LCA with several values for the number of classes and found that the two-class model had the best fit as measured by the BIC (BIC [ $k=2$ ]=7,589 versus BIC [ $k=3$ ]=7,801 and BIC [ $k=1$ ]=9,522; goodness-of-fit test  $\chi^2=2,913,800,702$ ,  $df=2$ ). By using the LCA-predicted class probabilities, the sample was divided into two distinct classes (Table 2). Compared with those in latent class 1 ( $N=96$ ), those in latent class 2 ( $N=120$ ) were significantly more likely to have higher income, private insurance, and a diagnosis of OCD and to be currently receiving treatment for OCD. They were also significantly more likely to prefer SRI medications to EX/RP (SRI medications,  $N=64$ , 55%; EX/RP,  $N=51$ , 44%;  $p=.001$ ). Latent class membership was not associated with preferences for EX/RP as a first-line treatment or with preferences for augmenting treatment with EX/RP or antipsychotic medication.

### Acceptability of Novel Treatments

As shown in Table 3, acceptance and commitment therapy was rated as an acceptable treatment by a significantly higher proportion of respondents (73%) than the next-most-acceptable treatment, Kundalini yoga (58%) ( $\chi^2=8.02$ ,  $df=1$ ,  $p=.005$ ). The least acceptable treatments were gamma knife surgery (24%) and deep brain stimulation (21%).

### Reasons for Preferences and Suggestions to Improve Treatment and Services

Common themes related to reasons for preferences emerged and are shown in Table 4, along with sample quotes illustrating each theme. They include positive and negative beliefs about treatment, ideas about how treatments work, past experiences with treatments, and their efficacy. Two themes emerged for how to improve OCD treatment and services: educating the public about OCD and its treatments and increasing access. Illustrative quotes for each theme are reported in Table 4.

## DISCUSSION

This study examined treatment preferences and acceptability in a large sample of individuals with self-reported OCD and severe OCD symptoms. There were four main findings. First, although the finding was not statistically significant, EX/RP was somewhat more preferred as a first-line treatment for OCD compared with SRIs. However, EX/RP was significantly preferred to antipsychotic medications when used to augment SRI response. Second, age, gender, income, and treatment experience were associated with treatment preferences. Third,

among novel OCD treatments, behavioral interventions (for example, acceptance and commitment therapy and Kundalini yoga) were rated as more acceptable than medical procedures (for example, deep brain stimulation and gamma knife surgery). Finally, beliefs or concerns about treatments, how they work, and their efficacy seemed to influence preferences, and respondents called for increasing awareness and reducing stigma surrounding OCD, as well as increasing access to preferred treatments.

Although not statistically significant, the finding that adults with OCD were more likely to prefer EX/RP over SRIs as a first-line treatment is consistent with our results from a smaller sample in which participants preferred EX/RP with or without medications over medications alone (11). Our new finding that individuals with OCD who were taking SRIs but who were still experiencing symptoms also preferred EX/RP over SRIs adds to the literature. This recurring preference for psychotherapy over medications is consistent with prior research indicating that individuals with depression and PTSD prefer psychotherapy to medications at a rate of three to one (18). However, our finding is in contrast with nationwide treatment utilization data demonstrating that office-based physicians more commonly treat OCD with medications than with psychotherapy (26). Given EX/RP's efficacy, both as monotherapy (27) and as a strategy to augment SRI response (28), and our finding that individuals preferred EX/RP whether or not they were taking SRIs, efforts to increase access to this treatment are warranted. Our qualitative data highlight the need for rapid availability of EX/RP. Ways to achieve this goal include training more providers in EX/RP and developing treatment models that harness technology to deliver Internet- or mobile-based treatments. Such programs have recently been shown to be effective (29) and may help meet the needs of many more individuals with OCD.

Our findings that age, gender, and treatment experience influenced preferences for psychotherapy over medication replicates our previous findings in a smaller sample of individuals with OCD, as well as findings from studies of persons with depression and PTSD (3,6,9–12). LCA results extend this research and indicated that individuals with higher income, private insurance, and a history of an OCD diagnosis and medication treatment preferred SRI medications. Given their resources for care, individuals in this group may have received high-quality psychiatric care that afforded them the time and attention to discuss and resolve concerns about medication. Our study also found that persons who were taking SRIs and who were taking benzodiazepine preferred to add EX/RP rather than antipsychotics to augment SRI response. This may reflect the desire to avoid additional psychiatric medication and to try EX/RP.

Our study is the first to use rating methods to assess acceptability of novel treatments for OCD. Behavioral interventions, such as acceptance and commitment therapy and Kundalini yoga, were rated as more acceptable, and medical procedures, such as gamma knife surgery or deep brain stimulation, were rated as least acceptable. This is consistent with our ranking data in a previous study (11). Behavioral interventions, such as therapy and yoga, are more familiar than specialty medical procedures and thus may be perceived as more acceptable. Indeed, there were high ratings of uncertainty for more invasive treatments, which may reflect a lack of evidence and of public awareness of these treatments. Furthermore, a

gradient in acceptability ratings was noted, with the least invasive treatments rated as more acceptable and the more invasive treatments as least acceptable.

Data for the open-ended questions indicated that treatment experience and beliefs influenced preferences. The same has been found in studies of depression, where a discussion of treatment preferences has resulted in better engagement and outcomes (30,31). Furthermore, participants in our survey called for increasing awareness of OCD and its treatments and destigmatizing the illness. Public health campaigns related to stigmatized illnesses, such as HIV, may serve as a model for these efforts (32).

Several study limitations deserve consideration. First, inherent sampling bias may exist because the online survey was accessible via the Web site of an academic research center for OCD treatment research. Therefore, the sampling method would be less likely to recruit individuals who were not seeking information or treatment resources for OCD, have responded well to treatment, have poor insight about their OCD symptoms, have low motivation to complete questionnaires, and do not have access to a computer. Second, the respondent sample was predominantly white and female. Third, our survey relied on self-reported OCD diagnosis, with the OCI-R as the only independent self-report assessment of OCD symptoms. We did not have independent confirmation of the OCD diagnosis or information about the presence or severity of comorbid disorders, which may also affect preferences for treatment.

## CONCLUSIONS

Our findings highlight the importance of patient-level characteristics, beliefs about treatment, and past experience as factors that influence preferences for OCD treatment. Future studies should examine the impact on clinical care of discussing treatment preferences, consider treatment acceptability as part of the treatment development process, and explore strategies to decrease stigma regarding OCD.

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**TABLE 1.** Characteristics and responses of 216 persons surveyed about preferred treatments for obsessive-compulsive disorder (OCD), by preferences for first-line and augmentation treatments

Characteristic	First-line treatment (N=198)						Augmentation treatment (N=111)					
	Total (N=216)		Prefers EX/RP <sup>d</sup> (N=108)		Prefers SRI <sup>b</sup> (N=90)		Prefers EX/RP <sup>d</sup> (N=76)		Prefers antipsychotic (N=35)			
	N	%	N	%	N	%	N	%	N	%		
Age (M±SD)	34±13		32±12		36±13		31±13		42±15			
Female	157	73	84	78	63	70	63	83	22	63		
Education												
High school	17	8	8	7	8	9	5	7	4	11		
Some college	79	37	43	40	31	34	29	38	11	31		
4-year college degree	120	55	57	53	51	57	42	56	20	57		
Marital status												
Single	124	59	65	63	48	53	46	60	15	43		
Married or living with partner	75	35	33	32	35	39	22	29	16	46		
Divorced, separated, or widowed	12	6	5	5	7	8	5	7	4	11		
White race	193	89	94	87	88	98	1	1	1	3		
Non-Hispanic ethnicity	197	91	95	88	84	93	69	91	34	97		
Employment												
Employed	120	53	59	55	55	61	43	57	23	66		
Student	36	21	17	16	14	16	15	20	2	6		
Unemployed	60	35	32	30	21	23	18	24	10	29		
Income												
<\$25,000	45	24	25	28	18	21	12	16	6	17		
\$25,000-\$55,000	66	35	33	37	30	36	24	32	10	29		
\$55,001-\$85,000	29	15	14	16	12	14	13	17	4	11		
>\$85,000	49	26	18	20	24	29	13	17	13	37		
Insurance												
Private	162	75	78	72	71	79	61	80	28	80		
Public	27	13	15	14	10	11	9	12	15	145		
None	27	12	16	15	9	10	6	8	2	6		

Characteristic	Total (N=216)				First-line treatment (N=198)				Augmentation treatment (N=111)				
	N	%	N	%	Prefers EX/RP <sup>d</sup> (N=108)	%	Prefers SRI <sup>b</sup> (N=90)	%	Prefers EX/RP <sup>d</sup> (N=76)	%	Prefers antipsychotic (N=35)	N	%
Has a diagnosis of OCD	184	85	89	82	80	89	69	91	31	89			
OCD-R (M±SD and range) <sup>c</sup>	48±14	24-84	50±15	26-84	47±13	24-76	50±15	26-84	45±11	27-72			
Receiving treatment <sup>d</sup>	124	57	51	47	70	71*	68	78	30	86			
SRI <sup>b</sup>	124	57	47	43	70	78*	68	90	30	86			
Benzodiazepine	30	14	18	17	12	13	18	24	4	11*			
Antipsychotic	19	8	8	7	10	11	7	11	9	26			
EX/RP <sup>d</sup>	20	9	13	12	6	7	10	13	2	6			
Cognitive therapy	67	31	37	34	29	32	32	42	12	34			
OCD support group	9	4	5	5	4	4	3	4	2	6			
Supportive/dynamic therapy	23	11	10	9	12	13	12	16	5	14			
Experience with treatment													
Positive overall	76	49	32	41	42	58*	33	43	13	37			
Positive with medications	69	44	20	27	47	61*	32	42	15	43			
Positive with therapy	83	57	39	54	41	59	38	50	12	34			

<sup>a</sup>Exposure and response prevention

<sup>b</sup>Serotonin reuptake inhibitor

<sup>c</sup>Obsessive-Compulsive Inventory-Revised. Possible scores range from 24 to 84, with higher scores indicating more severe illness.

<sup>d</sup>For variables related to treatment, responses about first-line treatment were received from 198 participants and responses for augmentation treatment were received from 111 participants.

\* p=.05, for association with first-line and augmentation treatment preferences

**TABLE 2.**

Characteristics of survey respondents with significant symptoms of obsessive-compulsive disorder, by latent class membership (in percentages)

Characteristic	N responding	Latent class 1 (N=96)	Latent class 2 (N=120)	p
Age (range) <sup>a</sup>				.953
Low	118	60	58	
Medium	60	29	31	
High	21	10	11	
Race				.060
White	177	83	94	
Black	8	6	2	
Asian	9	6	3	
Other	5	4	1	
Non-Hispanic ethnicity	183	91	92	.788
Marital status				.471
Single	115	62	53	
Married	68	29	39	
Divorced, separated, or widowed	11	6	5	
Education <sup>b</sup>				.674
Low	16	8	8	
Medium	74	41	33	
High	62	28	34	
Employment status				.149
Employed	110	50	60	
Unemployed	34	16	18	
Student	56	34	22	
Income				.032
Low	43	25	18	
Medium	89	49	40	
High	44	14	30	
Insurance				<.001
None	27	23	4	
Private	141	59	82	
Public	26	14	12	
Private and public	6	4	2	
OCI-R score <sup>c</sup>				.204
Low	92	40	52	
Medium	78	43	35	
High	31	18	13	
Diagnosis of OCD	168	72	96	<.001
Receiving treatment	145	47	98	<.001

<sup>a</sup>Low, 12.9–36.0 years;medium, 36.1–59.0 years;high, 59.1–82.1 years

<sup>b</sup>Low, <12 years;medium, 12–15 years;high, 16 years

<sup>c</sup>Low, 17.9–40.0;medium, 40.0–62.0;high, 62.0–84.1. Possible scores range from 17.9 to 84.1, with higher scores indicating more severe illness.

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Acceptability of novel treatments among survey respondents with significant symptoms of obsessive-compulsive disorder

**TABLE 3.**

Treatment	N	Acceptable		Uncertain		Unacceptable	
		N	%	N	%	N	%
Glutamate modulating medications	179	92	51	67	37	20	11
Acceptance and commitment therapy	178	130	73	33	18	15	8
Kundalini yoga	177	103	58	45	25	29	16
Gamma knife surgery		42	24	58	33	78	44
Deep brain stimulation	177	37	21	67	38	73	41
Transcranial magnetic stimulation	177	77	43	71	40	29	16

Themes emerging from responses to open-ended questions about treatment preferences and services for obsessive-compulsive disorder (OCD) by survey respondents with significant symptoms of OCD<sup>a</sup>

Domain	Theme	Sample quote
Preferences	Belief in treatment, treatment mechanism, and efficacy	For EX/RP: "To know that I was the one changing my behaviors (with the help of a therapist) is more reassuring and satisfying than completely relying on a medication that I either may not want to believe is working or will want to believe is working—so I psychologically determine the resulting behaviors." For SRI medication: "Medication is always better because it attacks the chemicals head on."
	Concerns about treatment, treatment mechanism, and efficacy	For EX/RP: "I fear EX/RP would overwhelm me and I would simply obsess about what I had been exposed to instead of engaging in an appropriate response." "EX/RP requires going outside with a therapist or sitting in there acting out scenarios, and I feel very awkward." For SRI medication: "I do not want to take and become dependent on an SRI. I believe in medication but am worried about possible addiction."
	Negative experience with treatment	For EX/RP: "EX/RP took my OCD from bad to worse. I went from a mostly functioning individual to being completely unable to leave my house except to go to school, where I had additional problems." For SRI medication: "I am tired of being medicated and observing not that much of a change." "Medication causes me to gain in excess of 40 pounds. I have tried several types of medication, and all seem to affect me in the same way." "Antipsychotic medication: [I've had] extremely negative responses to all antipsychotics that I've been tried on in the past. I experience hypersomnia, at even the lowest dose, slurred speech, unable to function at all."
Services	Educate the public about OCD and its treatment	"I suffer from sexual- and harm-related OCD. I think many people like me are scared to seek out treatment because they are afraid their therapist or physician will not understand. For people that have intrusive thoughts related to things like pedophilia, there is a real concern that speaking to a mental health professional could get them into legal or personal trouble. Public perception of OCD tends to focus on things like hand washing and lock checking, but people are less aware of harm or sexual obsessions. Because of this it can be hard to both find appropriate health care providers and it can be hard to explain your OCD symptoms to the people in your life. If there were more pamphlets about this aspect of OCD in physicians' and mental health professionals' offices, I think you would have a lot higher treatment rates. If I had read a flyer about this kind of OCD at my primary care physician's office, I would have immediately spoken to him about treatment. I started having OCD symptoms when I was 12, but I didn't understand anything about it until I read about OCD on an Internet forum when I was 22."
	Increase access to care	"More people—therapists included—need to be educated that OCD cannot typically be treated with traditional talk therapy. Additionally, we need more therapists properly trained to treat the unique problems of a patient with OCD. More treatments should be more readily available as quickly as possible." "The disparity in quality of treatment for OCD seems vast. For such a paralyzing disorder it seems cruel that some practitioners don't offer evidenced-based treatment."

<sup>a</sup>EX/RP, exposure and response prevention;SRI, serotonin reuptake inhibitor