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Patient Preferences for OCD treatment

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Abstract

Objective—To explore preferences for the treatment of obsessive compulsive disorder (OCD). We hypothesized that OCD patients will select a combination of medication and psychotherapy as their most preferred choice overall.

Methods—The authors designed a treatment preference survey using two health economics methods, forced choice and contingent ranking methods, to elicit preferences for OCD treatment available in mainstream care (Serotonin Reuptake Inhibitors [SRIs]), Exposure and Ritual Prevention [EX/RP], and their combination), and for novel treatments under development at OCD research clinics. This survey was given by telephone to 89 individuals with OCD who called the OCD research clinic at the New York State Psychiatric Institute between July 2008 and January 2009.

Results—Most participants chose combination treatment (43%) or EX/RP (42%) over SRI medication (16%). Participants ranked investigational psychotherapy as their most preferred novel treatment (endorsed by 48% of participants) and deep brain stimulation as their least preferred novel treatment (endorsed by 77% of participants). Qualitative data suggest that prior treatment experience, concerns about medications, and logistical and practical concerns about treatment regimens affect preferences.

Conclusions—Patients with OCD have identifiable treatment preferences. In this sample of convenience, most preferred either combination treatment or psychotherapy. Future studies should investigate prospectively what modifies these preferences and how these preferences affect treatment outcome.

1.0 Introduction

The two first-line treatments for OCD are pharmacotherapy with serotonin reuptake inhibitors (SRIs), and cognitive-behavioral therapy (CBT) consisting of exposure and ritual prevention (EX/RP) [1]. If a patient partially responds to one of these treatments, practice guidelines recommend adding the other [1]. EX/RP and SRIs are very different treatments. In EX/RP, patients are asked to confront their fears and to resist doing compulsions; the treatment is purposefully anxiety-provoking and requires a substantial short-term time commitment. SRIs do not directly confront patient fears, and treatment is less time-consuming. However, SRIs can have side effects, including sexual side effects. Thus, although EX/RP and SRIs are both efficacious treatments [1], patients with OCD might prefer one or the other, and these preferences might affect whether a patient will choose and initiate a particular treatment, adhere to the treatment procedures, or discontinue or switch to another treatment. In this study, we systematically assessed the treatment preferences of people with OCD for the first time.

Treatment preferences have been studied in non-clinical groups and in people with medical illnesses, [2–5] but have only recently been assessed for psychiatric disorders. In college students presented with trauma scenarios and treatment descriptions for PTSD, in victims of physical and sexual assault, and in depressed primary care patients, people demonstrate clear treatment preferences, with most participants preferring psychotherapy to medications [6–13]. Treatment preferences have also been shown to affect treatment adherence. For example, in depressed primary care patients, receiving treatment of one's preference is associated with the likelihood of entering and adhering to treatment [14–15], the receipt of guideline-concordant care, and the resolution of depressive symptoms [16]. Patient preferences also predict outcome in randomized antidepressant trials, particular when both medication and psychotherapy are involved. In particular, patients tend to dropout when randomized against their preferences [17–20].

We are unaware of any studies that have systematically examined treatment preference in OCD. However, in a randomized controlled trial comparing SRI medication, EX/RP, their combination, and pill placebo in OCD, 27 of 149 (18 %) patients dropped out after learning their randomization and before entering treatment [21]. Dropout rate for those who were randomized to monotherapy (SRI, pill placebo, or EX/RP) was higher (22%) than for those who were randomized to combination treatment (6%). Anecdotally, some expressed not wanting the monotherapy to which they were randomized. Thus, treatment preferences appeared to play a role in who entered OCD treatment. Given the potential for treatment preferences to affect outcome both in routine clinical practice and in randomized controlled trials, it is important to better understand the treatment preferences of OCD patients.

To begin to examine this issue, we studied a convenience sample of people with OCD seeking treatment at an OCD research clinic. We elicited treatment preferences using two methods: the choice experiment (termed “forced choice”) and the contingent ranking method (termed “rank –ordered preference”). These methods are similar to those used in the treatment preference studies reviewed above [7, 9–10] and are standard in social sciences and health economic research [22–25]. In the forced choice, we asked patients to choose between empirically supported treatments for OCD available in mainstream clinical mental health care (i.e., SRIs, EX/RP, or their combination). In the rank-ordered preference, we asked participants to rank their preference for novel treatments that are being developed and tested in research settings. Based on the literature reviewed above, we hypothesized that OCD patients will have strong preferences about SRIs and EX/RP and will select combination treatment (where they receive at least one of their preferred treatments) as their most preferred choice overall. We also explored demographic, clinical, and qualitative factors that influenced forced choice and rank ordered preferences.

2.0 Method

Participants

Individuals with OCD who called the Anxiety Disorders Clinic (ADC) at the New York State Psychiatric Institute/Columbia University between July 2008 and January 2009 were asked to participate in this study. Callers were responding to newspaper or internet-based advertisements about various OCD studies (including a brain imaging study, medication and psychotherapy clinical trials, mindfulness meditation, and transcranial magnetic stimulation [TMS], all modalities they were being asked about in the survey), word-of-mouth referral, or a recruitment mailing (i.e., they had previously received treatment in the ADC and gave permission to be re-contacted regarding future treatment opportunities). All participants met criteria for OCD based on the telephone screening evaluation. Reliability for OCD screening diagnosis by telephone and for OCD diagnosis made by a MD or PhD- level clinician in a face-to-face interview was assessed in over 50% of the sample and yielded 100% agreement.

Procedure

All callers, with their consent, underwent a telephone evaluation by trained OCD screeners. This evaluation included questions about current symptoms, medical history, and treatment history. Before discussing treatment opportunities in the ADC, the screener asked callers if they would like to participate in a study about treatment preferences for OCD. If they provided verbal consent, participants were then administered the treatment preference survey. This Institutional Review Board of the New York State Psychiatric Institute approved the study.

Survey Instrument

Developed by the authors (SRP and HBS), the survey elicited treatment preferences using forced choice and rank ordered methods [See Appendix A]. In the forced-choice section, the interviewer reads written descriptions of the treatments to the participant. Descriptions of SRI medication, EX/RP, and their combination were derived from practice guidelines [1] and adapted to emulate how a clinician might present these treatment options for OCD in clinical practice. Each description provided background information along with procedures, typical duration, efficacy information, and possible side effects for each treatment. SRI, EX/RP and combination treatment rationales were matched when 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 SMOG (Simplified Measure of Gobbledygook) [26–27]. After providing these treatment descriptions, screeners asked participants to choose the treatment they most preferred. In an open-ended format, participants were also asked the reason for their choice: “What factors influenced your choice?”

In the rank ordered section, interviewers presented participants with five types of treatments currently under development and investigation for OCD. These treatments were: Investigational Medication, Investigational Psychotherapy, Alternative treatments (e.g., meditation, yoga, or herbal remedies), Deep Brain Stimulation and Transcranial Magnetic Stimulation. Following each type of investigational treatment, the interviewer provided a general lay description (developed by authors) of each treatment. Participants were then asked to rank them in order of preference, with #1 being most preferred and #5 the least preferred. In an open-ended format, participants were also asked “What makes your #1 most preferred treatments and your #5 least preferred treatment?”

Lastly, in an open-ended format, participants were asked, “I would like to ask you if you have any comments or suggestions on how to improve treatment and services for people with OCD. We are very interested in learning from you about this.”

3.0 Analysis

Quantitative

Data analyses employed the Statistical Package Social Sciences, version 16.0. Descriptive statistics were used to describe demographics, treatment status (treatment naïve, treatment experienced), treatment type (currently receiving medication, psychotherapy, combination treatment, or no current treatment) as well as forced choice and rank ordered preferences. Chi-square analyses, using collapsed dichotomous variables for employment (not working versus working), race (Caucasian versus Other), and marital status (single/never married versus married), and Pearson correlations were used to examine associations between demographic and treatment variables and forced choice and rank-ordered preferences. Due to the exploratory nature of the study, an $\alpha=.05$ was used as a measure of significance.

Qualitative

Qualitative data were abstracted using an inductive process similar to that suggested by Hill, Thompson, and Williams [25]. Two coders (SRP and HBS) each developed a preliminary list of domains by independently reviewing the qualitative reasons for preferences given by all participants. The coders then met and iteratively modified these domains by comparing the data and the derived domains and discussing to consensus until core domains emerged. For the forced choice and rank ordered open ended questions, we present the domains that were reported by at least 10% of the sample.

4.0 Results

Of 148 telephone evaluations, 89 individuals (60%) gave verbal consent and participated in the treatment preferences study. Reasons most often cited for refusing were lack of time and lack of interest. Table 1 presents demographic and treatment status and type for the study sample. Most participants were middle-aged Caucasian females who were single/never married, equally employed or unemployed, with a mean education of 16 years, earning up to \$60,000 a year. Of the sample, 13% were treatment naïve, 87% reported a history of some form of treatment, and 65% were currently receiving treatment (any type of medication [35%], any type of psychotherapy [8%], or their combination [22%]).

Forced choice

When forced to choose among SRI medication, EX/RP, or combination treatment, 43% (n=38) chose combination treatment, 42% (n=37) EX/RP and 16% (n=14) SRI medication (Table 2). No significant associations were found between forced choice and demographic (including age, gender, marital status, education, income, employment and race), treatment status (treatment naïve, treatment experienced), or treatment type variables (currently receiving medication, psychotherapy, combination treatment, or no current treatment); all p values > .30). As shown in Table 2, participants who were not currently receiving treatment and those who are naïve to treatment endorsed similar patterns of forced choice preference as those currently receiving any type of treatment and treatment experienced participants with one exception: the former choose psychotherapy more frequently than combined treatment as their forced choice, although this was not a statistically significant difference, (Not currently receiving treatment $r = -.21$, $p = .052$; Treatment naïve: $\chi^2(2, 89) = 5.29$, $p = .77$).

Qualitative analysis of reasons

Of the 38 participants who preferred combination treatment, about 40% reported that a prior positive experience with combination treatment influenced their choice (e.g., “The medicine helps me get through the therapy.”). Some (24%) believed that combination treatment would optimize their outcome (e.g., “Hammering it from both angles is most effective”). A smaller group (11%) had the impression that scientific evidence proved combination treatment was the most effective treatment for OCD (e.g., “Medical research shows that the combo is most effective”).

Prior treatment experience also influenced participants who chose EX/RP, although in the opposite direction. Specifically, of the 37 participants who chose EX/RP, 33% reported that a negative experience with medications (e.g., weight gain, sexual side effects, lack of efficacy, increased symptoms and anxiety) influenced their choice (e.g., “Having taken medication in the past, I know that the physical side effects are pretty extreme”; “I’ve been on a lot of medications and none of them seemed to really work. My experience is that medication makes my symptoms worse”). Others (30%) expressed a lack of belief in medication as an acceptable treatment (e.g., “I just do not believe in taking medication for

psychological problems”; “I am really uncomfortable with putting a pill in my body to fix my head.”). Some (17%) who chose psychotherapy did so based reading about treatment for OCD (e.g., “I have read Edna Foa's book that has really helped me.”)

Of the 14 participants who chose SRI medication, 23% cited lack of time for other treatment (e.g., “If I take medication, I'll have more time for my own life.”). Some (23%) also believed that treatment course is easier with medications (e.g., “If I had a choice-- I want a magic pill! It would be easiest to take a pill and know I'll get better.”).

Rank ordered preferences

Among investigational treatments (Table 2), a new psychotherapy was the preferred treatment, ranked first by 48% (n=42) of participants. Deep Brain Stimulation was endorsed as least preferred by 77% (n=68) of the participants. The modal rank number for each investigational treatment was: Investigational psychotherapy (mode=1); Alternative treatments (mode=2); Investigational medication (mode=3); Transcranial Magnetic Stimulation (mode=4); and Deep Brain Stimulation (mode=5).

We examined associations between demographic and treatment variables and participants' most and least preferred treatments among the five rank ordered options. This procedure avoids a tendency to over interpret middle ranking positions [9, 28]. Results indicate that younger participants were more likely than older patients to rank psychotherapy as their most preferred treatment ($r = -.28, p = .008$) and females were more likely than males to rank Deep Brain Stimulation as their least preferred treatment $\chi^2(1, 89) = 5.24, p = .02$. Participants who were on medications $\chi^2(1, 89) = 4.47, p = .03$ and combination treatment $\chi^2(1, 89) = 4.55, p = .03$ at the time of the survey were less likely than those who were not on medication or combination treatment to rank Deep Brain Stimulation as their least preferred treatment. All other comparisons were not significant (all p values > .20), with the exception of females ranking psychotherapy $\chi^2(1, 89) = 3.49, p = .06$ as their most preferred treatment more often than males.

Qualitative analysis of reasons

Of the 42 participants who ranked investigational psychotherapy as their preferred treatment, 42% reported that a prior positive experience with therapy influenced their ranking (e.g., “Therapy I have had in the past has been helpful [more so than medication]”). Some participants (27%) believed that the process of talking is most helpful (e.g., “I think that talking it out is better than just taking a pill that is going to dissolve in your body and magically cure you”). Some (14%) opined that psychotherapy is safest and least invasive, while others (11%) expressed specific concerns about medication (e.g., “I don't want to be on medication my whole life and therapy would be the best way to help me”, “I would prefer to be as free from medication and surgery as possible”).

Of the 68 participants who ranked Deep Brain Stimulation as their least preferred treatment, 58% felt that surgery was too extreme (e.g., “Putting a stick in my brain is the last resort”) or undesirable (e.g., “It's super scary! There could be side effects, also irreversible and permanent”). Others (16%) noted that not knowing much about the procedure influenced their rank ordered preference (e.g., “Just because I'm scared of it and don't know anything about it”).

Improving treatment and services for OCD

Fifty one percent (n=45) of the sample made recommendations for improving services and treatment for OCD. Examples of domains and quotes are presented in Table 3. These included improving treatments currently available such as tailoring treatments to individual

needs and developing medications with fewer side effects and creating more awareness about OCD, forums for group support and accessibility to treatments.

5.0 Discussion

Our data demonstrate that patients with OCD have identifiable treatment preferences. Confirming our hypothesis, most participants chose combination treatment over SRI medication alone. However, participants choose EX/RP almost as often as combination treatment, and many fewer were interested in SRI medication alone. We thought that this finding may, in part, reflect that 35% of this convenience sample was already taking SRI medications alone (n=31), whereas only 8% (n=7) was already receiving psychotherapy alone (and only 2 of these 7 were receiving EX/RP). However, current treatment type was not associated with treatment preference in our analyses. Future research in a larger random sample is warranted to confirm this finding and examine if those currently receiving EX/RP endorse a reverse preference for SRIs.

Our results are consistent with the literature on treatment preferences for PTSD in clinical and non-clinical samples [6–11] and major depression [12–13] in which most participants prefer treatment with psychotherapy over medications, although these other studies did not include combination treatment as an option. Exploratory analyses suggested that treatment naïve participants were more likely to choose EX/RP than combined treatment, and younger age was associated with ranking psychotherapy as the preferred treatment, although the small subsample renders these findings tentative.

Qualitative analyses suggest several factors that may influence participant preferences. One is prior experience. Participants chose combination treatment if they had had a positive experience with combination treatment in the past. Those with a prior negative experience with medications (e.g., due to side effects or lack of efficacy) chose psychotherapy. Another factor is the complexity of the treatment procedures: those who chose medications were influenced by the logistical ease of medications compared to EX/RP. Lastly, self-education appeared to be an important factor that influenced preferences for combination treatment and psychotherapy. However, it was notable that knowledge about the treatments was not always accurate (e.g., that combination treatment is clearly superior to monotherapy, that EX/RP is a type of therapy where you “talk it out,” that medications can magically cure OCD, that OCD is a psychological problem and thus can't be helped by medication).

Several studies found that discussing treatment preferences facilitates treatment negotiation and better uptake of treatment recommendations [14–16]. Thus, it is reasonable to hypothesize that clinicians who treat OCD will likewise facilitate treatment alliance and uptake if they not only offer their treatment recommendation but also discuss with their OCD patients their treatment preferences [29–30]. Our data suggest that important areas for discussion include: 1) past and current treatment experiences, including existing knowledge about OCD treatments; 2) beliefs or concerns about treatments, especially with medications; and 3) logistical and practical concerns about treatment regimens such as time commitment, availability, and access to trained OCD providers. Future studies will need to examine whether such discussions facilitate treatment negotiation and better adherence to treatment recommendations in OCD.

Participants' preferences and opinions about novel treatments can also help to inform and guide the OCD treatment research community. This sample of patients articulated a desire for medications with an improved side effect profile. In addition, they stressed the difficulty of finding trained OCD specialists, underscoring the need to disseminate evidence-based treatments for OCD and to expand opportunities for clinicians to train in EX/RP. Of interest

to patient advocacy groups, several participants underscored the importance of educating the public about OCD and its treatment.

This study is the first to assess systematically stated treatment preferences for both mainstream and investigational treatments in a sample of people diagnosed with OCD. Borrowing methods commonly used in health economics research, we used the choice experiment and the contingent ranking procedure and collected qualitative data on participants' reasons for choosing treatments and ranking preferences. Future development of the survey will address existing limitations including vetting the investigational treatment descriptions through experts in each area of treatment development [7, 9–10], and more rigorous matching of SMOG readability grades for all treatment descriptions. Unlike previous studies assessing treatment preferences, we explored the relationship between treatment status and type on choice and preferences.

However, our study should be viewed as preliminary given several limitations. First, our sample consisted of a convenience sample of primarily treatment-seeking patients; therefore, we do not know whether the results generalize to all individuals with OCD. The sample is biased by the likely exclusion of patients who are satisfied with their current treatment. Second, our sample size limited our ability to fully examine demographic (e.g., racial and ethnic differences) and treatment status variables and their influence on treatment preferences. Third, we elicited treatment preferences and reasons for choices at a single time. Preferences could change with passage of time, education about treatment options, cost of treatments, access to care, therapeutic discussion with a clinician, and actual treatment experience. Understanding the impact of preferences on the treatment process and learning what affect these preferences is important because the data will have implications for educational campaigns about OCD treatment, patient-provider communication in the clinical encounter, and the design and conduct of OCD clinical trials.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographic and treatment status variables for sample (N=89)

Patient characteristics	N (%)
Demographics	
Sex	
Male	38 (43%)
Female	51 (57%)
Age (mean, sd)	41 (13.7)
Race	
Caucasian	68 (77%)
African American	10 (11%)
Asian	3 (3%)
Other	7 (8%)
Ethnicity	
Hispanic	9 (10%)
Non-Hispanic	80 (90%)
Marital status	
Single/Never married	16 (73%)
Married/living w/ partner	56 (45%)
Divorced/separated/widowed	53 (42%)
Religion	
Protestant	17 (21%)
Catholic	32 (39%)
Jewish	23 (28%)
Muslim	1 (1%)
Other	7 (8%)
Income	
\$9,999–19,999	10 (12%)
\$20,000–59,999	27 (33%)
\$60,000–99,999	9 (11%)
100,000+	11 (13%)
Education (mean, sd)	15.7 (2.4)
Employment status	
Employed	34 (40%)
Student/Homemaker/Retired	22 (26%)
Unemployed	22 (18%)
Disabled	6 (7%)
Treatment Status	
Treatment naive	12 (13%)
Received treatment in the past	77 (87%)

Patient characteristics	N (%)
Currently in treatment	58 (65%)
Medications	31 (35%)
Psychotherapy	7 (8%)
Combination	20 (22%)
Currently not in treatment	31 (35%)

Table 2

Forced choice and rank ordered preferences by treatment variables

Samples	Forced choice			Rank ordered	
	EX/RP	SRI	Combination	Investigational Psychotherapy ranked#1	Deep Brain Stimulation ranked #5
Entire sample (n=89)	37 (42%)	14 (16%)	38 (43%)	42 (48%)	68 (77%)
Treatment naïve (n=12)	6 (54%)	2 (18%)	4 (33%)	7 (58%)	11 (92%)
Treatment experienced (n=77)	31 (40%)	12 (16%)	34 (44%)	39 (51%)	19 (25%)
Currently not receiving treatment (n=31)	18 (58%)	5 (16%)	8 (26%)	15 (48%)	25 (81%)
Currently on medication (n=31)	10 (32%)	5 (16%)	16 (52%)	15 (48%)	28 (90%)
Currently in psychotherapy (n=7)	3 (43%)	1 (14%)	3 (43%)	3 (43%)	4 (57%)
Currently in combination treatment (n=20)	6 (30%)	3 (15%)	11 (55%)	10 (50%)	12 (60%)

Table 3

Qualitative data on improving treatment and services for OCD (n=45)

Improving treatment and services for OCD	Domains	Quotes
Treatment	Tailoring treatments to individual patient needs	"You know, everyone is different and should be treated based on their specific symptoms."
	Developing medications with fewer side effects	"I'd like a medication without the side effects, like the sleepiness, over-eating, and irregular periods."
	Exploring the biological basis for OCD	"If I were a researcher, I would try to find the OCD gene. I'm not a doctor, but if there is an OCD gene or way to learn about the physical part of OCD I would love that."
Services	Educating the public about the disorder and its treatment	"I don't know much about OCD, but I think that there should be more focus on educating the public about the disorder and possible avenues for treatment."
	Improving accessibility of qualified OCD specialists familiar with cutting edge treatments	"There should be more doctors and therapists available who know how to treat OCD. Psychiatrists just experiment and most therapists don't know how to do cognitive behavioral therapy. And none of them take insurance."
	Providing group forums where patients can share their experiences with each other	"I'm glad there is a name for the condition, but it's not cocktail party conversation. I'd like to discuss it with other people with OCD and read about what other people have gone through."