

Helpseeking and access to mental health treatment for obsessive-compulsive disorder

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Objective: To identify predictors of helpseeking and use of mental health treatment for obsessive-compulsive disorder (OCD) using the behavioral model of health service use.

Method: Data were drawn from the 1996 National Anxiety Disorders Screening Day. Participants ($n = 14\ 860$) completed screening measures providing information about demographics, mental disorders, helpseeking, and treatment experiences for OCD.

Results: Previous use of mental health treatment was associated with comorbid panic disorder [odds ratio (OR) = 1.6 (1.3–1.98)], while minority racial status [OR = 0.7 (0.5–0.9)] emerged as a barrier to receiving care among individuals with OCD. Among those who had never received mental health care, comorbid panic disorder [OR = 2.0 (1.5–2.8)], post-traumatic stress disorder [OR = 1.7 (1.3–2.4)], and suicidal ideation [OR = 1.7 (1.2–2.3)] increased readiness to seek treatment while being employed [OR = 0.7 (0.5–0.9)], and feeling one could handle the problem on his/her own [OR = 0.5 (0.3–0.7)] decreased readiness to seek help for the first time.

Conclusion: These data suggest that access to treatment for OCD may not be equally accessible to all in need by revealing non-disease related factors (e.g. race, health beliefs) that have a significant impact on decisions to seek and use mental health treatment.

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Introduction

With a lifetime prevalence in cross-national studies of 1.9–2.5% (1, 2), obsessive-compulsive disorder (OCD) has consistently been underestimated in both prevalence, and scope (3). OCD is associated with severe social and occupational impairment, psychiatric comorbidity, increased use of medical health care services, and risk of suicide attempt (1, 2, 4–6). Over the past decade, significant progress in psychopharmacologic and psychotherapy research has resulted in the availability of several efficacious treatments for OCD (7). The availability of these treatments, and the factors that influence decisions about obtaining professional help among individuals with OCD in the community are issues that have attracted much less empirical attention.

Data from adult and adolescent community-based samples suggest that only a small minority

of individuals with OCD receive mental health treatment (8, 9). In 1990, Shapiro et al. (8) reported that less than 35% of those with OCD received specialized mental health treatment among adults in a community-based sample, and in 1984, Whitaker et al. (3) found similar results among a community-based sample of adolescents with OCD, only 35% of whom had experienced any treatment contact with a mental health professional. Other reports suggest that persons with OCD use more, specific specialty medical care services [e.g. more cardiologists and dermatologists (9)] compared with those with other anxiety disorders, or no anxiety disorder, but that few are properly diagnosed or treated in these settings (4, 5, 10). One study, using a community-based sample, found that only 28% of OCD sufferers had ever sought professional help for their symptoms, fewer than half of whom had seen a mental health specialist, and that the majority were seen by non-psychiatric physicians or clergy (5).

The determinants of access to care, and patterns of helpseeking, among those with OCD are unknown. It might be that only those with the most severe and debilitating or impairing cases of OCD use treatment services and that those whose symptoms are less distressing do not. In other words, access to treatment is determined by illness severity and need. It is also conceivable, however, that factors such as the stigma associated with mental illness (7) or limited health insurance coverage may prevent individuals from seeking needed professional services. The identification of the determinants of access to mental health treatment can facilitate the identification of those with unmet need in the community.

One method that can be used to evaluate whether and to what degree socio-demographic characteristics, health-related beliefs, and illness severity influence treatment-seeking behavior and service use is a behavioral model of health service use. One such model, the Behavioral Model of Health Service Use (10–12), identifies predictors of service use with a three-step model that includes predisposing characteristics, enabling resources, and perceived and evaluated need. Briefly, *predisposing characteristics* include demographic characteristics (age, gender, race, marital status, education). *Enabling factors* (i.e. income level, health insurance, quality of family relationships), are social and economic factors thought to play a role in access to care. *Perceived need*, or illness level, is the biological demand or perceived severity of illness and *evaluated need* is defined as professional judgment about patients' health status. This model has been used to evaluate the equity of access to health care among a variety of populations (11–15).

Aims of the study

The goals of this study are threefold. First, the study will determine the predictors of OCD in a community-based screening day sample. Second, the study will compare characteristics of those who have received treatment, compared with those who have never received treatment, among those with OCD. Third, the study will identify the factors that predict readiness to seek treatment among individuals who have never received treatment for OCD.

Material and methods

Study design and procedure

The National Anxiety Disorders Screening Day (NADSD) survey was designed to screen for

anxiety disorders in community health care settings. The NADSD takes place on one day each year in all 50 states in the United States. Advertisements about the 1996 screening were posted in various media outlets and participants were volunteers who presented themselves for screening on the appointed day. Participants were asked to complete a screening questionnaire after first viewing a video that dramatizes the symptoms of panic disorder (PD), post-traumatic stress disorder (PTSD), generalized anxiety disorder (GAD), obsessive-compulsive disorder (OCD), social phobia (SOP), and major depression (MDD). After completing the questionnaire, participants met with a mental health professional who was instructed to inquire whether the participants' symptoms were distressing or resulted in functional impairment. This professional determined whether further evaluation was necessary and if so, gave the participant a referral for mental health treatment.

Participants

Participants were obtained from the total sample of 15 606 individuals who attended the 1996 NADSD. The sample was 56.7% female, 85.2% White, 6.2% Black, and 3.7% Hispanic. About 40.4% of participants were employed full-time, 13.2% part-time, 16.3% were retired, approximately one in five (19.8%) had completed college, and 39.3% had completed high school. Over half of participants were married (53.1%) and almost one in five (19.5%) were never married and 16.1% were separated or divorced. Further details of the NADSD sample have been described previously (16–18).

Measures

The 1996 NADSD questionnaire was designed to identify individuals with anxiety disorders. Items query about symptoms occurring during the past month and are based on diagnostic criteria in the DSM-IV (19). The screening questionnaire included two OCD items, one cognitive and one behavioral, with a 1-month reference period: 'Did you have persistent, senseless thoughts you could not get out of your head, such as thoughts of death, illnesses, aggression, sexual urges, contamination or others', 'Did you spend more time than is necessary doing things over and over again such as washing your hands, checking things or counting things?' For the purposes of this study, individuals who endorsed both of these symptoms are grouped as having OCD; those without OCD endorsed only one or neither of these symptoms.

The screening questionnaire included socio-demographic characteristics (age, sex, race, or ethnicity, education, employment status, and geographic location), whether the person had used mental health treatment, readiness for treatment, and the extent to which anxiety symptoms interfered with daily living. Interference in daily life and readiness for treatment were rated on six-point Likert scales. Participants were asked to indicate their level of readiness for treatment with endorsements ranging from 'not even thinking about getting help' to 'ready to get help now.' For the purposes of the subsequent analyses, 'readiness for treatment' was defined by the participants endorsing items indicating that he or she was ready to get help now. Items describing interference in daily life ranged from 'not at all' (0%) to 'almost all of the time' (90–100%). Interference in daily life was operationally defined by participants' endorsement of a statement indicating that their anxiety symptoms interfered with daily life 'about half the time' or more (40–60% of the time). The questionnaire also had a checklist of eight potential barriers to treatment, which were asked only of those participants who had never been previously treated for anxiety. These included the belief that he/she does not have an anxiety disorder, was afraid of what others would think, was afraid to take medication, did not have insurance, did not know where to go for help, could not afford treatment, did not think treatment would help, or believed he/she could handle it on his/her own.

The NADSD screening questionnaire diagnoses have been shown to have excellent internal consistency (16). Factor analysis of the questionnaire diagnoses demonstrated factorial invariance across racial/ethnic groups (16). Questionnaire diagnoses were compared with diagnoses made by experienced clinicians using the Structured Clinical Interview for DSM-IV (19, 20) on a sample of 203 individuals from two anxiety disorders clinics. Comparisons of screening and diagnostic outcomes revealed fair to moderate levels of agreement. The sensitivity and specificity for participants with a positive screen for OCD were 50 and 91, respectively. The sensitivities and specificities for other diagnoses were: PD 0.87, 0.72; GAD 0.89, 0.55; SOP 0.64, 0.85; PTSD 0.62, 0.94 and MDD 0.80, 0.72.

Analytic strategy

First, the socio-demographic characteristics, psychiatric morbidity, and social functioning of those with OCD ($n = 3069$), compared with those without OCD ($n = 11\,791$), were examined using Pearson's chi-square tests. Next, the same method

was computed to identify the differences in socio-demographic characteristics, psychosocial issues, comorbid mental disorders, and suicidal ideation between those with treated ($n = 1472$) and untreated OCD ($n = 1241$). Third, a multivariate logistic regression model was employed to identify predictors of readiness for treatment among all participants with OCD following the Behavioral model of Health Service Use (11–13). Potential predictors were entered in three steps. In the first step, predisposing characteristics (demographics) were included. Enabling factors (employment status, readiness for treatment, health service use-related beliefs) were entered in the second step. Comorbid mental disorders and suicidal ideation were entered in the third and final step. Odds ratios (with 95% confidence intervals) were calculated for the association between each predictor (a binary variable) and readiness for treatment (binary). Fourth, another multivariate logistic regression model was used to identify the predictors of readiness for treatment among participants with OCD who had never received mental health treatment ($n = 1241$). Finally, descriptive data on the reasons for not seeking help were provided for participants who had never received treatment.

Results

Socio-demographic characteristics of the sample

About ($n = 3069$) of the sample of 14 860 met screening criteria for OCD. Participants with OCD were younger, more likely to be male and White, less likely to be married and more likely to be never married compared with those without OCD (see Table 1). There were no significant differences in education between those with and without OCD.

Mental health treatment

Overall, people with OCD who had received mental health treatment were older, more likely to be Caucasian, and more likely to have been divorced or separated, compared with those who had not (see Table 2). Individuals who have never been married were less likely to have been treated. There was no association between gender or education and treatment.

Individuals with current OCD who had received treatment were significantly more likely to have comorbid PD, GAD, or PTSD compared with those who had not been treated (see Table 2). There was no statistically significant difference in prevalence of major depression or suicidal ideation

Table 1. Socio-demographic characteristics of the sample

	No OCD (%) n = 11 791	OCD (%) n = 3069
Age*		
Under 21	3.0	3.9
21–34	22.9	28.5
35–44	23.6	26.3
45–54	19.6	18.8
55 and over	30.9	22.5
Gender†		
Male	26.2	31.0
Female	73.9	69.0
Race‡		
White	86.9	83.1
African American	6.1	8.2
Hispanic	3.8	5.2
Asian	1.4	1.5
Native American	0.8	1.0
No answer	1.1	1.0
Marital status§		
Married	56.7	49.3
Widow	7.9	6.1
Separated	3.7	4.4
Divorced	13.0	15.3
Never married	18.7	24.9
Education¶		
Grade school	3.6	5.9
High school	42.7	48.1
Trade school	10.6	10.8
2-year college	14.9	13.9
4-year college degree	18.4	15.1
Graduate degree	9.7	6.1

*Mean = 104.4, df = 4, $P < 0.0001$.

†Mean = 22.7, df = 1, $P < 0.0001$.

‡Mean = 34.0, df = 5, $P < 0.0001$.

§Mean = 34.9, df = 4, $P < 0.0001$.

¶Mean = 5.5, df = 5.

between those with OCD who had and had not been treated.

Correlates of mental health treatment

Older age and female gender increased the likelihood of mental health treatment use when the model included only predisposing factors (i.e. socio-demographic characteristics) (data not shown). After enabling characteristics were entered into the model, the associations between age and gender remained significant and being Caucasian increased likelihood of treatment, though employment status had no effect. Perceived need (readiness for treatment and interference of anxiety symptoms in daily life), which was entered in the next model, predicted treatment and the association between age (older) and ethnicity (Caucasian) persisted; however, the effects of gender and interference in daily life were no longer significant. When evaluated need was entered on the final step, comorbid PD emerged as the strongest predictor of

Table 2. Characteristics of those with treated and untreated obsessive-compulsive disorder

	No. treatment (%) n = 1241	Treatment (%) n = 1472
Age***		
Under 21	6.2	2.4
21–34	34.2	25.1
35–44	24.0	27.9
45–54	16.4	21.1
55 and over	19.2	23.6
Gender		
Male	33.6	29.8
Female	66.4	70.2
Race***		
White	9.4	6.3
African American	80.5	86.6
Hispanic	6.1	4.2
Asian	2.1	1.0
Native American	0.9	0.9
No answer	1.0	1.0
Marital status***		
Married	48.3	51.5
Widow	4.9	5.4
Separated	4.1	4.4
Divorced	12.2	17.5
Never married	30.4	21.3
Education		
Grade school	5.0	6.2
High school	48.1	48.1
Trade school	9.9	11.5
2-year college	14.0	13.4
4-year college degree	17.0	14.8
Graduate degree	6.1	6.0
Psychosocial factors		
Employed full-time*	40.0	36.1
Significant interference in daily functioning related to anxiety**	91.9	94.7
Ready for treatment***	40.2	50.2
Psychiatric comorbidity		
Major depression	75.5	77.4
Panic disorder*	64.2	75.3
Social phobia	81.7	82.3
Generalized anxiety disorder**	87.9	91.6
PTSD*	31.0	35.0
Suicidal ideation	27.8	27.9

*** $P < 0.001$; ** $P < 0.01$; * $P < 0.05$.

treatment. Age, race, and readiness for treatment continued to predict treatment, though the relationship between treatment use and interference in daily life was no longer significant.

Correlates of readiness for treatment

Younger age was the only socio-demographic characteristic that increased the likelihood of being ready to seek help when only demographic characteristics were entered into the model (see Table 3). After enabling factors were included, higher education emerged as a predictor of

Table 3. Predictors of readiness for treatment among those never treated (odds ratios with 95% confidence intervals)

Determinants	Predisposing factors	Predisposing and enabling factors	Predisposing, enabling, and perceived need factors	Predisposing, enabling, perceived and evaluated need
Predisposing factors				
Age (continuous)	0.98 (0.97–0.99)*	0.99 (0.98–0.99)*	0.99 (0.98–0.99)*	0.99 (0.98–0.99)*
Gender (1 = male)	0.8 (0.6–1.0)	0.88 (0.74–1.1)	0.9 (0.8–1.1)	0.8 (0.6–1.1)
Race (1 = caucasian)	1.1 (0.8–1.5)	1.0 (0.8–1.3)	1.1 (0.9–1.3)	0.9 (0.6–1.4)
Marital status (1 = not married)	0.98 (0.87–1.1)	1.01 (0.86–1.2)	0.98 (0.8–1.2)	1.01 (0.86–1.2)
Education (1 = HS+)	1.1 (0.9–1.5)	0.78 (0.7–0.9)*	0.8 (0.7–0.96)*	1.2 (0.9–1.6)
Enabling factors				
Employed (1 = employed full-time)		1.02 (0.9–1.2)	1.0 (0.9–1.2)	0.7 (0.5–0.9)*
Don't have an anxiety disorder (1 = yes)		0.25 (0.2–0.3)*	0.4 (0.3–0.5)*	0.9 (0.5–1.6)
Afraid of what others would think (1 = yes)		1.1 (0.9–1.4)	1.0 (0.8–1.3)	1.0 (0.7–1.5)
Afraid to take medications (1 = yes)		0.8 (0.6–0.98)*	0.7 (0.6–0.9)*	0.9 (0.6–1.4)
No insurance (1 = yes)		1.5 (1.2–2.0)*	1.4 (1.1–1.8)*	1.3 (0.85–2.0)
Not sure where to go (1 = yes)		2.0 (1.7–2.4)*	1.8 (1.5–2.2)*	1.7 (1.3–2.0)*
Can't afford treatment (1 = yes)		0.9 (0.7–1.2)	0.9 (0.7–1.1)	0.8 (0.6–1.2)
Treatment won't help (1 = yes)		0.66 (0.45–0.99)*	0.6 (0.4–0.9)*	0.5 (0.3–1.0)
Handle on my own (1 = yes)		0.35 (0.3–0.4)*	0.35 (0.3–0.4)*	0.5 (0.3–0.7)*
Perceived need				
Interference in daily living (1 = yes)			3.8* (2.9–4.9)	1.6 (0.9–3.1)
Evaluated need				
Panic disorder (1 = yes)				2.0 (1.5–2.8)*
Major depression (1 = yes)				1.4 (0.9–2.0)
Generalized anxiety disorder (1 = yes)				1.0 (0.6–1.7)
Social Phobia (1 = yes)				1.3 (0.8–1.9)
PTSD (1 = yes)				1.7 (1.3–2.4)*
Suicidal ideation (1 = yes)				1.7 (1.2–2.3)*

*P < 0.05.

readiness for treatment and several enabling factors increased the likelihood of being ready for treatment. These include: thinking one does not have an anxiety disorder, being afraid of taking medication, not having insurance, not knowing where to go for help, and thinking that treatment would not help. After perceived need factors were entered into the model, the statistical significance of several of these associations disappeared and perceived need (interference in daily life) emerged as a significant predictor.

When evaluated need was entered on the final step, PD, PTSD, and suicidal ideation emerged as significant predictors of readiness for treatment. ‘Not being sure where to go for help’ continued to increase readiness for treatment while older age,

being employed full-time, and thinking one can handle it on one’s own decreased the likelihood of being ready to get help.

Health care belief attitudes

A closer examination of the helpseeking attitudes revealed that the most common reason for not seeking treatment was ‘not knowing where to get help’, which was endorsed by almost 40% of those who had never been treated (see Table 4). The next most frequent reason was the feeling that one could ‘handle it on one’s own’ (28.4%). About one in four respondents said the reason they did not go for help was that they were unable to afford it (24.9%), and about one-fifth (20.5%) said they did not go because they were afraid of what others might think. A much smaller percentage (5.7%) endorsed the statement ‘did not think treatment would help.’

Table 4. Potential barriers to treatment among those never treated

	Affirmative response (%)
Don't have an anxiety disorder	4.5
Afraid what others would think	20.5
Afraid to take medication	14.7
No insurance	16.7
Not sure where to go	39.8
Can't afford treatment	24.9
Treatment won't help	5.7
Can handle it on own	28.4

Discussion

This study is the first to identify correlates of mental health service use and helpseeking among individuals with OCD in a large screening day sample. Fewer than half (40.4%) of adults with OCD in this screening sample had ever received

treatment for their anxiety disorder, though the majority experienced significant interference in daily functioning associated with their symptoms, approximately one-fourth had current thoughts of suicide, and more than three out of four had concurrent major depression and/or another anxiety disorder.

Contrary to our hypothesis, psychiatric morbidity was not the only significant predictor of treatment among those with OCD. The finding that comorbid PD is the strongest predictor of use of services among individuals with OCD is consistent with previous reports demonstrating a consistent association between PD and heavy utilization of health care services (11–14). The results of the final regression model, however, suggest that access to treatment for OCD is also heavily influenced by predisposing factors (age, gender, and race) indicating that access to mental health care is not equitably distributed in the community. In other words (female) gender, (older) age, and (Caucasian) race were stronger predictors of having received some form of mental health treatment than interference in daily life, comorbid major depression, or suicidal ideation. While readiness for treatment was a consistent and significant predictor of treatment, these data suggest that race and age are just as powerful determinants of access to care.

These analyses reveal several noteworthy associations between readiness for treatment and help-seeking attitudes. About 40% of this population stated that a reason they had not sought treatment in the past was lack of knowledge of where to find help. In effect, lack of knowledge of where to find treatment was a stronger barrier than not having the funds to do so. Also, it might be that not knowing where to go for help increased readiness for help, possibly because those who are ready but do not know where to go are untreated for longer as they are looking for treatment. In contrast, not knowing where to get help was associated with not having used treatment in the past. These data are profound in their implications to identify areas of unmet need and inform public education programs aimed at improving accessibility of mental health services in the community. Of interest, all of the helpseeking-related statements were endorsed by approximately 20% of the sample. The clear exception to this was the ‘treatment won’t help’, endorsed by only 5.7% of the sample. Belief that treatment would not help is by far the least common reason for not getting mental health treatment, with these other barriers being much more prominent obstacles to seeking care. As it appears that at least nine out of 10 participants

believe that treatment would be helpful, these results suggest that these beliefs may indeed keep people from seeking help.

Limitations

Limitations of this study are numerous and the results should only be interpreted within their context.

First, these data should not be considered representative of the general population, as they were self-selected into participation at the screening day, not a randomly selected community sample.

Second, the assessment of OCD and other mental disorders was performed using a screening instrument, rather than a structured clinical interview or full-length epidemiologic survey assessment tool. Future investigations of this type that use a more rigorous diagnostic assessment instrument are needed to replicate these data, though screening diagnoses were validated against a subsample who were given structured diagnostic interviews by trained clinicians (19, 20).

Third, these data do not provide great detail in describing the specific symptoms that prompted distress or motivated the decision to seek help. Such information would be a useful focus of future, more in-depth investigation, as it would provide clues as to which factors might be most important to target for future interventions.

Fourth, information on the type and duration of treatment, satisfaction with treatment experiences, and how previous experience with mental health treatment influenced decisions to seek help in the future might shed more light on factors that would improve access to, and the effective delivery of care.

Fifth, some of the significant results could be because of the large sample size (e.g. the significant effect of age on mental health service use), therefore replication in community-based samples is needed.

Our study is the first to identify the predictors and barriers to mental health treatment within a large, geographically diverse screening day sample of individuals with OCD using a behavioral model of health service use. While it must be noted that our sample cannot be considered representative of the community, the results of our analyses suggest that access to treatment is heavily influenced by sociodemographic and health care seeking-related attitudes. These data are unsettling in the apparent racial and age-related discrepancies in access to treatment. From a public health perspective, however, this information could help in the identification of targets for intervention to improve access to mental health treatment among those

with OCD in the community. For instance, these data suggest that changes in insurance coverage (increasing coverage for mental health treatment) and efforts to provide the public with more information about where to seek help for mental health-related conditions should have an impact on access to treatment. This use of the behavioral health model provides valuable information for clinicians and policy makers who are interested in improving the equity of access to mental health treatment for all who are in need. As the burden of OCD extends beyond direct costs to the indirect costs associated with unemployment and work loss [i.e. one community based survey found that 45% of men with OCD were unemployed (12)], efforts to improve access to mental health treatment for those with OCD are critical not only in alleviating suffering for the individual, but will likely benefit society as a whole.

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