Obsessive-Compulsive Disorder in the Community: An Epidemiologic Survey With Clinical Reappraisal

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Objective: To examine the prevalence of obsessive-compulsive symptoms and DSM-IV obsessive-compulsive disorder (OCD), the authors conducted a telephone survey of 2,261 adults in four regions of Canada. Method: Trained lay interviewers administered a modified version of the OCD section of the Comprehensive International Diagnostic Interview. A subsample of respondents with probable cases and probable subclinical cases of OCD was then blindly reinterviewed by research personnel experienced in the assessment of OCD, using the Structured Clinical Interview for DSM-IV and the Yale-Brown Obsessive Compulsive Scale, to confirm the diagnosis and gauge the severity of OCD. Results: The weighted 1-month prevalence of OCD in the entire sample according to the lay interviews was 3.1%. Upon clinical reappraisal, the 1-month prevalence estimate of OCD dropped to 0.6%; an additional 0.6% had subclinical OCD. The mean Yale-Brown Obsessive Compulsive Scale score of the individuals with OCD was 19.0 (SD=4.6, median=21); for those with subclinical OCD, the mean score was 15.4 (SD=2.4, median=14). Common reasons for overdiagnosis of OCD by the lay interviewers were inappropriate labeling of worries or concerns as obsessions and overestimating the degree of interference or distress attributable to obsessive-compulsive symptoms. Conclusions: OCD, while hardly a rare condition, may be somewhat less prevalent than had been believed on the basis of previous surveys. Additional studies are needed to substantiate these findings and to delineate precisely the extent of disability and reduced quality of life attributable to OCD (and OCD variants) in the community.

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Until the early 1980s, obsessive-compulsive disorder (OCD) was thought to be a rare disorder, although this notion was based largely on rates of OCD seen in psychiatric clinic samples. The Epidemiologic Catchment Area (ECA) study radically changed our views by finding a lifetime prevalence of OCD that ranged from 1.94% to 3.29% across the five ECA sites (1–6). Subsequently, surveys in other countries which used the same diagnostic instrument that was used in the ECA study—the National Institute of Mental Health Diagnostic Interview Schedule (DIS) (7, 8)—found similar rates of OCD, although some cross-national variability was found (9). The net effect of these findings has been to bring much-needed attention to the "hidden epidemic" (10) of OCD. Heightened awareness of OCD may be one factor that has led to the increased frequency of OCD diagnosis in recent years (11).

It has been 15 years since the completion of the ECA study and over 10 years since the findings were first reported (1–4). In the interim, two versions of DSM (i.e., DSM-III and DSM-III-R) have come and gone. A newer epidemiologic survey, the National Comorbidity Survey, has made available new data about the prevalence of mental disorders in the United States but, unfortunately, OCD was not among the disorders that were assessed (12, 13). To provide new data about the prevalence of OCD, we conducted a community survey using the OCD module (with some modifications) from the same instrument used in the National Comorbidity Survey (also with some modifications)—the Comprehensive International Diagnostic Interview (CIDI), Version 1.0 (14, 15).

A second aim of this project was to conduct a clinical

reappraisal of the lay interviewers' diagnoses. This aspect of the study was undertaken because of our suspicion that OCD might be a difficult diagnosis for nonclinicians to establish. This concern was underscored by several observations. 1) In the ECA study the temporal stability of the diagnosis of OCD over 1 year was remarkably poor (kappas ranged from 0.16 to 0.25, with the exception of the New Haven site, where kappa was 0.87 (16). 2) The reported 1-year rate for "new" OCD cases in the ECA study was 0.8% (17), which seemed remarkably high given the presumed early onset and chronicity of the disorder. Furthermore, 3) a study in Zurich that used the DIS found very low rates of OCD and poor longitudinal stability of the diagnosis (18). And finally, 4) a clinical reinterview study from the Baltimore site of the ECA study found that only a fraction of individuals diagnosed with OCD according to the DIS actually had this diagnosis when reexamined by a clinician (19). For all of these reasons, we felt it necessary to confirm our trained lay interviewers' diagnoses by means of a clinical reappraisal. This technique has been usefully applied to the study of other diagnoses (e.g., agoraphobia without panic) in the ECA study (20).

Although several epidemiologic studies of OCD in adolescents and/or children have recently appeared (21–24), to the best of our knowledge, this study is the first North American community survey of OCD in adults to have been conducted in the past 15 years.

METHOD

The data we report were collected as a coordinated effort through the 1994 Winnipeg Area Study and the 1994 Alberta Survey in Canada. The goal was to interview approximately 2,000 respondents over a 1-month period—1,000 respondents in the city of Winnipeg, Manitoba, and at least 1,000 respondents in the province of Alberta (approximately one-half from two cities, Calgary and Edmonton, and the remainder from rural Alberta). Winnipeg is a city of approximately 650,000 inhabitants, with a stable economy and population base, located in the Canadian midwest. Calgary and Edmonton are western Canadian cities with populations of approximately 600,000 and 550,000, respectively. The remainder of Alberta has approximately 1 million residents.

The sampling was conducted independently for the Winnipeg and Alberta surveys. Both surveys used a two-stage sampling frame to obtain 1) a probability sample of households from Winnipeg and Alberta based on random-digit dialing and 2) a randomly predesignated selection of an adult respondent within each household to ensure an equal representation of male and female participants. Past experience in our studies indicates that women are more likely than men to answer the phone. If the person answering the phone was of the specified gender, only that person could be interviewed. If the person was not of the specified gender, that person was asked if someone of the appropriate gender was in the household. If there was no one of the specified gender living there, the respondent was designated only as the person who answered the telephone. If a person of the designated gender was living there, the interviewer asked for this person or for the oldest if there was more than one. The oldest was selected because he or she is more likely to be a head of household. If the respondent was not at home or for some other reason was not available, every effort was made to set up another appointment. No substitution was permitted if the eligible respondent refused. Additional selection criteria were that the respondent had to be 18 years of age or older, and the dwelling unit had to be his or her usual place of residence. Calls were made between 9:00

a.m. and 9:00 p.m. In order to reach the designated respondent, up to 10 callbacks were made at varying times and days (the modal number of callbacks was two). All interviews were conducted over the telephone, either at the respondent's residence or occasionally at another telephone number. The response rates for the survey were 72% of eligible households in Winnipeg and 73% in Alberta. The average length of an interview was 31 minutes (SD=10, range= 13–118). All respondents gave their informed verbal consent to participate in this study. The study was approved by the respective faculty committees on the use of human subjects in research at the University of Manitoba and the University of Alberta.

The study personnel were professional interviewers who had extensive experience with population surveys. Anticipating that the elucidation of obsessive-compulsive symptoms would be difficult for lay interviewers, we provided them with an educational session about the nature of these symptoms and the clinical syndrome of OCD. In this educational session, interviewers were informed about the often secretive nature of OCD, about the need for tact and empathy in order to overcome respondents' possible reluctance to disclose their obsessions and compulsions, and about the form and conduct of the modified CIDI OCD module itself. After a pilot test, 10 professional interviewers in Winnipeg and 24 in Edmonton spent 9 hours practicing for this project with the help of an instruction handbook written specifically for this version of the survey. This handbook contained clinical examples of the various types of obsessions and compulsions, which the interviewers were instructed to use to prompt subjects who were unable or unwilling to generate unprompted responses to the probes. Following the pretest, two of the clinicians involved with this study (M.B.S. and J.R.W.) reviewed all of the specific examples of obsessions and compulsions given by the respondents, and additional feedback was provided to the interviewers about their classification of particular symptoms.

The modified OCD module of the CIDI in its entirety is available from the first author but is summarized here. After an introduction describing the nature of the survey, the modified CIDI 1.0 questions for OCD were posed. There are three notable differences between our modified interview and the original CIDI 1.0 OCD questions. First, whereas the CIDI 1.0 poses the questions on a lifetime basis (i.e., "Have you ever had . . . ?") and later asks about recency of the symptoms, we posed all questions on a past-month basis (i.e., "In the past month, have you had . . . ?"). Second, whereas the CIDI 1.0 asks a yes/no question (once for obsessions and once for compulsions) about whether the symptoms did "interfere with your life or work, or cause you difficulty with your relatives or friends, or upset you a great deal," we posed four separate questions, with scaled response options of 1 (not at all) through 7 (a great deal), about interference in the past month with 1) work outside or inside the home, 2) social activities with friends, family, or neighbors, 3) educational activities, and 4) the extent to which the person was bothered by unpleasant repeated thoughts or actions. Third, we included five probes for obsessions and five for compulsions, including two for specific types of obsessions not explicitly covered by the CIDI 1.0: 1) wanting to have things arranged in a particular way or in a particular order and 2) doubts that an activity has been performed correctly. The impact of these modifications on the properties of the CIDI 1.0 is unknown, and so we caution that our results should not be interpreted to reflect results that might have been obtained if the original instrument (or its successor, the CIDI 2.0) had been used.

To meet the DSM-IV disability and/or distress criterion for OCD, respondents needed to endorse either that their obsessions or compulsions took up at least 1 hour per day or that their obsessions or compulsions caused substantial (operationalized as a rating of 6 or 7 on the 7-point scale described above) interference with occupation, social activities, or education or caused personal distress.

Funding constraints limited our reinterview endeavors; we decided to contact only a representative sample of respondents from Winnipeg, where our research group was situated. We attempted to contact for reinterview all Winnipeg subjects who had a diagnosis of OCD according to the modified OCD module of the CIDI (N=27). We also interviewed a convenience sample (N=25) of persons in Winnipeg who fell short of meeting these criteria by having at least one obsessive or compulsive symptom *and* stating that they had only mild to modest levels of disability/distress. (Subjects with no obsessive-

TABLE 1. Demographic Characteristics of 2,261 Persons in a Community Survey of Obsessive-Compulsive Disorder[a]

Characteristic	N	%
Gender		
Male	1,127	49.8
Female	1,134	50.2
Age (years)		
18–29	586	26.0
30–44	866	38.4
45–64	523	23.2
≥65	278	12.3
Education (years)		
0–11	527	23.3
12	499	22.1
13–15	1,113	49.3
≥16	120	5.3
Income ($/year)		
0–19,999	850	42.7
20,000–39,999	623	31.3
40,000–69,999	373	18.7
≥70,000	146	7.3

[a]All data are weighted to be proportionate with respect to gender and the population size of the regions that they represent, according to Statistics Canada. The N for different categories varies because of missing data.

compulsive symptoms or subjects who reported no disability/distress in the telephone interview were not reinterviewed.)

For the clinical reappraisal interviews, the following customized modules derived from the Structured Clinical Interview for DSM-IV (SCID) (25) were administered: lifetime and current (past 12 months) OCD, current major depressive disorder (past 12 months), and lifetime psychosis. In addition, a series of questions was asked pertaining to current and previous treatment for OCD or other mental disorders, treatment preferences, and current level of functioning. Finally, the Yale-Brown Obsessive Compulsive Scale (26) and the Center for Epidemiologic Studies Depression Scale (27) were administered, the former after the subject had been cued about possible obsessive-compulsive symptoms with the use of the Yale-Brown Obsessive Compulsive Scale checklist (26).

Diagnoses of OCD were made according to the following conventions. If the person met the full criteria for OCD according to the OCD module of the SCID, then a diagnosis of OCD was applied. If the person met the full criteria with the exception that the disability or distress was judged to be below the diagnostic threshold, then a diagnosis of subclinical OCD was applied. Specifically, if the interviewer was unable, after a thorough survey of a wide range of educational, occupational, and social spheres, to document more than insignificant impairment or minimal distress, then the subclinical label was applied.

All diagnoses were made by the principal investigator (M.B.S.) on the basis of clinical reinterviews carried out over the telephone by a psychiatric clinical research nurse (G.A.) who had 5 years of experience in the diagnosis and assessment of OCD in a research setting, including use of the SCID and the Yale-Brown Obsessive Compulsive Scale. The clinical reinterviewer met weekly with the principal investigator, an experienced research psychiatrist, who reviewed in detail all diagnostic material that had been elicited and assigned the final diagnosis. When necessary, additional diagnostic information was obtained from the respondent by subsequent interview(s) until diagnostic clarity was achieved to the satisfaction of the principal investigator. In cases where an unequivocal diagnosis was not apparent, a final diagnosis was assigned in consensus between the principal investigator and a senior research psychologist (J.R.W.). All of the personnel involved in diagnostic assignment were blind to the status of the persons being interviewed (i.e., whether they had OCD or subthreshold OCD according to the modified CIDI).

Data were weighted for gender and region (e.g., rural versus urban Alberta) in order make them proportional to the populations they represent. We dealt with refusals or missing clinical reappraisals by

making the assumption that noninterviewed persons would be representative of the sample as a whole; we then imputed rates of OCD and subclinical OCD from the subsample that was interviewed. Similarly, we imputed rates of disorder in the Alberta sample by making the assumption that the findings from the clinical reappraisal data for the Winnipeg sample (i.e., the proportion of people with OCD on the initial interview who proved to have OCD on clinical reappraisal) would apply. Rates are reported as means with 95% confidence intervals. We generated frequency tables of the characteristics of subjects in the relevant response categories. Sample sizes vary for different questions because of differences in the number of responses that could be evaluated.

RESULTS

The total sample consisted of 2,261 respondents: in Winnipeg, N=1,002; in Edmonton, N=415; in Calgary, N=428; and in rural Alberta, N=416. The demographic characteristics of the combined sample are shown in table 1.

Many respondents endorsed having obsessions (N=592, 26.2%) or compulsions (N=502, 22.2%). The distribution of the types of obsessions and compulsions is shown in figure 1. The most common obsession was pathological doubting (14.4%), followed by the desire for orderliness (10.9%). The most common compulsion was checking (15.1%), followed by repeating (11.3%). The majority of persons with symptoms had only one obsession and/or one compulsion (figure 2). Of the 793 respondents (35.1%) with at least one obsession or compulsion, 290 (36.6%) had obsessions alone, 201 (25.3%) had compulsions alone, and 302 (38.1%) had both obsessions and compulsions.

Although obsessive and compulsive symptoms were very common, only a minority saw these as unreasonable or excessive, even fewer indicated that these were truly repetitive or recurrent, and fewer still endorsed these as being time-consuming (≥1 hour per day) or associated with substantial impairment or distress (figure 3). Accordingly, there was a steep drop-off from the level of symptoms (26.2% of persons in the community with obsessions; 22.2% with compulsions) to the level of diagnosis (1.9% of persons in the community with obsessions that warranted a diagnosis of OCD; 2.1% with compulsions that warranted a diagnosis of OCD).

In total, 69 persons (3.1%) in the combined sample met the DSM-IV criteria for OCD according to the modified OCD module of the CIDI. Of these, seven (10.1%) had obsessions only, two (2.9%) had compulsions only, and 60 (87.0%) had obsessions and compulsions.

As mentioned in the Method section, clinical reappraisal interviews took place only in Winnipeg. We were able to reinterview 25 (92.6%) of the 27 persons in the Winnipeg sample who had OCD according to the modified OCD module of the CIDI. Of these, only six (24.0%) were proven to have DSM-IV-defined OCD according to the clinical reappraisal interview; an additional five persons (20.0%) were found to have subclinical OCD (i.e., they met all of the DSM-IV criteria with the exception of the disability/distress criterion). The mean Yale-Brown Obsessive Compulsive Scale score was 19.0 (SD=4.6, me-

dian=21) for the persons with OCD and 15.4 (SD=2.4, median=14) for those with subclinical OCD. None of the 25 reinterviewed persons with subthreshold OCD according to the modified CIDI met the DSM-IV criteria for OCD or our operational criteria for subclinical OCD.

These data translate to a weighted 1-month prevalence rate for DSM-IV-defined OCD in Winnipeg of 0.7% (95% confidence interval=0.2%–1.1%); the corresponding rate for subclinical OCD in Winnipeg is 0.6% (95% confidence interval= 0.1%–1.0%). Applying the clinical reappraisal rates from Winnipeg to the combined (i.e., Winnipeg and Alberta) sample yields weighted 1-month prevalence rates of 0.6% (95% confidence interval=0.3%– 0.8%) for DSM-IV-defined OCD and 0.6% (95% confidence interval=0.3%–0.8%) for subclinical OCD. In aggregate, the rate for *either full or subclinical* OCD is 1.1% (95% confidence interval=0.8%–1.5%).

Only approximately one in four persons with OCD according to the modified CIDI was assessed as meeting the DSM-IV criteria for OCD upon clinical reappraisal with the SCID. We reviewed all discordant cases in the Winnipeg sample in an attempt to discern what the primary sources of disagreement might be. We judged that the majority of discordant diagnoses were due to one of two factors.

First, the respondents labeled ordinary sources of worry, concern, preoccupation, or interest as obsessions, and the lay interviewers lacked the clinical background to determine whether these were truly obsessions. An example is someone who mentioned being "obsessed" with the possibility that her boyfriend was having an affair. When the clinical interviewer questioned this individual further, it became clear that this was a realistic concern about a wayward boyfriend.

Second, a systematic type of error pertained to the difficulty in assessing the degree of disability or distress with a few brief questions on the initial interview. Even though some persons would report a great deal of disability or distress in the initial interview, when the clinician was able to probe about these domains in greater detail, many persons were found have a subclinical status, in the sense that their level of distress was patently less than "marked," the level of interference with

FIGURE 1. Percentages of Persons in a Community Sample (N=2,261) Who Had Specific Types of Obsessions or Compulsions
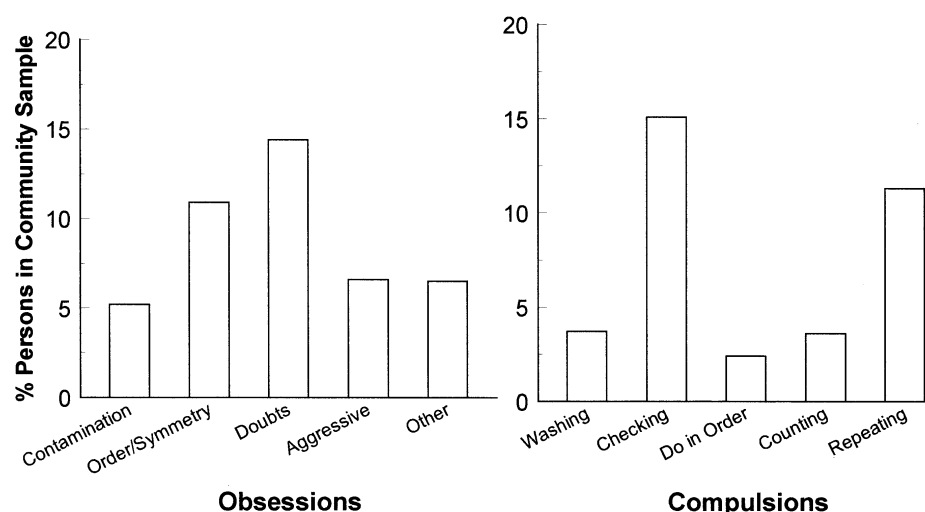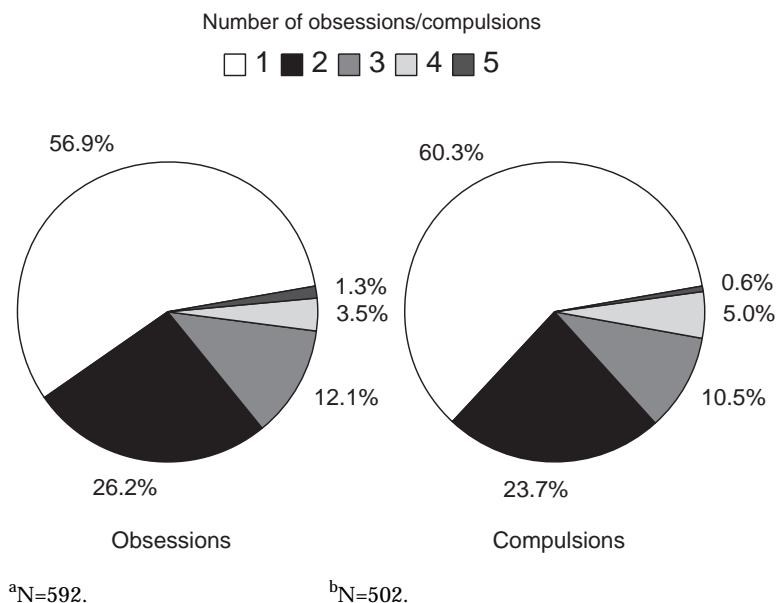

FIGURE 2. Percentages of Persons in a Community Sample (N=2,261) With at Least One Obsession[a] or at Least One Compulsion[b] Who Had One to Five Obsessions or Compulsions
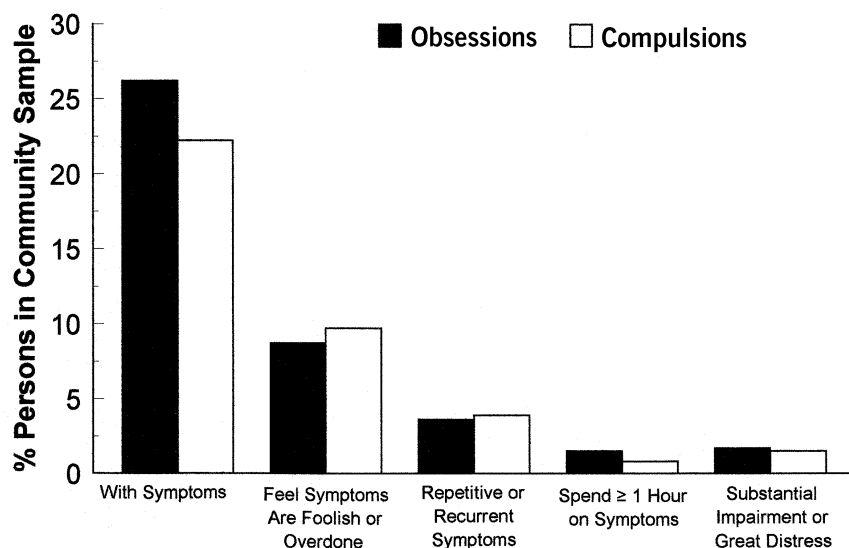

[a]N=592. [b]N=502.

various aspects of their lives was minimal, and the actual time spent obsessing or dealing with compulsions was less than 1 hour per day.

DISCUSSION

This is the first study in 15 years to examine rates of OCD in a sample of North American adults. It is also the first, to the best of our knowledge, to apply DSM-IV criteria for OCD to a community sample, although these criteria have been evaluated in a clinical setting as part of the DSM-IV field trial (28). We found rates of

FIGURE 3. Percentages of Persons in a Community Sample (N=2,261) With Obsessive or Compulsive Symptoms and Certain Characteristics

prevalence of OCD in the community will need to incorporate confirmatory reinterviews by experienced clinicians.

The second implication of our findings flows directly from the first. Given that previous population estimates of the prevalence of OCD were based on lay interviews, it is likely that there is considerably less OCD in the community than we have come to believe. This fact does not diminish the importance of identifying and treating persons with OCD. Even if the rate is as low as 0.6%, this still translates to over 1 million Americans who suffer from this disorder. Given the reduced quality of life (notably, impaired instrumental role functioning) associated with serious cases of OCD (34), the public health implications of untreated OCD in the community are enormous, even with our attenuated prevalence estimates.

OCD that approximate those found in the ECA study and in a similar OCD telephone survey (29) where the lay interviewers' assessments were examined in isolation. However, when we applied the information obtained through clinical reappraisal by experienced clinical research personnel, the rate dropped severalfold to provide a 1-month prevalence estimate of approximately 0.6%.

There are two principal implications of these findings. The first—which echoes findings from DIS clinical reinterview studies (19, 30)—is that interviews designed to be administered by lay interviewers are at risk of substantially overdiagnosing OCD. In making this comment, we wish to underscore that our instrument was a modified version of the CIDI 1.0, and we are unable to say to what extent its performance mirrors that of the original CIDI 1.0 in this regard. Although a computer-administered version of the CIDI 1.0 demonstrated excellent interrater reliability for OCD in comparison with a clinician interview (kappa=0.81) (31), this was in the setting of an anxiety disorders clinic where the severity of cases of OCD would be expected to be high. In an epidemiologic sample, the CIDI was shown to have excellent reliability for the majority of psychiatric diagnoses in the community (32, 33), but to the best of our knowledge, OCD was not among the diagnoses examined. Although future refinements (e.g., CIDI, Version 2.0, World Health Organization, unpublished) or newer diagnostic instruments may ultimately prove superior to the modified instrument we used here, we believe that there are definite limitations to the diagnosis of OCD by nonclinicians. OCD is a disorder in which subtle distinctions from other disorders (e.g., generalized anxiety disorder) abound, and the concept of obsessions and compulsions is neither easy to define nor possible to account for in a finite list. For all of these reasons, we believe that future efforts to determine the

Our study had a number of limitations. First, it is possible that our particular diagnostic instrument might have been insensitive to OCD and that our rates might be low as a result. Although none of the persons with subthreshold cases according to the telephone interview were found to have OCD upon clinical reappraisal, our sample of reinterviewed subthreshold subjects was too small (N=25) to rule this out. It is also possible that the rates of OCD might have been higher if an in-person interview, rather than a telephone interview, had been used. The extant data, however, suggest that this is unlikely (35). In fact, one could argue that the relative anonymity of a telephone interview might *facilitate* the disclosure of sensitive, potentially embarrassing obsessive-compulsive symptoms.

Another limitation of the study was its reliance on a single diagnostic interviewer for the clinical reappraisals. We attempted to compensate for this by having the narrative and additional diagnostic highlights from each interview reviewed in detail by an experienced research psychiatrist, by providing the opportunity for clarification reinterviews when necessary, and by resolving diagnostic dilemmas through consensus with an experienced research psychologist. Still, it would have been preferable to have several interviewers involved in order to ensure that systematic biases in the elicitation of information did not occur. We plan to implement this methodologic improvement in future studies.

Other limitations of our study include the focus on past-month prevalence of OCD, rather than on lifetime prevalence, as well as the exclusive focus on OCD itself, without reference to comorbidity. Sampling limitations also apply—most notably, our failure to include institutionalized individuals and those without telephones. Furthermore, we lack data about rates of OCD among

persons who refused to participate in the survey. These sampling inequities suggest that the true rate of OCD in the community may be somewhat higher than our purported estimates.

When we consider rates of OCD in the community, should we include people with subclinical OCD? The present study is consistent with others in showing that many persons have obsessive-compulsive symptoms that fail to meet conventional diagnostic thresholds (22, DSM-IV, ICD-10). It may well be that these persons have meaningful levels of distress or impairment despite failing to meet full diagnostic criteria, but this is at present unknown. Future epidemiologic studies of OCD should attempt to address this possibility by permitting several thresholds for diagnosis and by carefully assessing limitations in quality of life imposed by obsessive-compulsive symptoms.

Future investigators would also be well-advised to expand the scope of their studies to include so-called OCD spectrum disorders, such as trichotillomania, Tourette's disorder/chronic motor or vocal tics, and perhaps others (e.g., compulsive shopping, compulsive gambling, body dysmorphic disorder) (36–40). These studies, which should seek to incorporate state-of-the-art measures of functional impairment and quality of life (e.g., the Medical Outcomes Study Short Form-20 or Short Form-36) (34, 41, 42), will provide us with a comprehensive picture of the extent and severity of OCD and possible OCD variants in the community. This and similar advances in research methods will improve the field's ability to determine accurately the extent of service needs and, ultimately, will provide more accurate data, which will be used to shape public policy about OCD and other mental disorders.

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