Supply with Cognitive Behavior Therapy as First-Line Treatment in Patients with Obsessive-Compulsive Disorder

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Keywords
Obsessive-compulsive disorder · Supply and distribution · Germany · Exposure therapy · Cognitive behavioral therapy

Summary
Background: Cognitive behavior therapy (CBT) with exposure and response prevention represents first-line therapy for patients with obsessive-compulsive disorder (OCD). The aim of this study was to estimate the proportion of OCD patients that receive CBT with exposure and response prevention in Germany. Methods: In an observational study, data on treatment history from a sample of 369 patients with OCD (ICD-10 criteria) were analyzed. Results: Overall, 60\% of the patients reported that they had received CBT with exposure at least once, 37\% as their first treatment. 46\% of patients indicated having received CBT with exposure accompanied by a mental health professional at least once. The average time between the onset of OCD and the initial treatment was 6 years. Conclusions: Two fifths of the patients with OCD in our sample reported that they had never received CBT with exposure and response prevention, the state-of-the-art treatment for OCD. We discuss potential barriers from patients’ and mental health professionals’ perspectives as well as interventions that might help to improve the treatment situation.

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Schlüsselwörter
Zwangsstörung · Versorgung · Deutschland · Expositionstherapie · Kognitive Verhaltenstherapie

Zusammenfassung

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Background

Obsessive-compulsive disorder (OCD) is a common mental disorder with a lifetime prevalence of approximately 2% [Ruscio et al., 2010; Voderholzer et al., 2011]. According to the recent epidemiological study of Jacobi and colleagues [2014], 12-month prevalence rates of even 3.3% in men and 4% in women can be assumed. The leading symptoms comprise recurrent intrusive thoughts or impulses (obsessions) or repetitive behaviors (compulsions). If untreated, OCD frequently takes a chronic or recurrent course [Eisen et al., 2010; Skoog and Skoog, 1999] and is associated with a markedly diminished quality of life [Hertenstein et al., 2013; Koran et al., 1996; Moritz et al., 2005]. The direct and indirect costs induced by OCD in USA have been estimated at USD 8.4 billion in 1990 [Moritz, 2008].

A substantive body of evidence has demonstrated that cognitive behavior therapy (CBT) with exposure and response prevention, better exposure and response management (EX/RM), as well as pharmacological treatment with selective serotonin reuptake inhibitors (SSRIs) represent the most efficacious treatments for patients with OCD [Eddy et al., 2004; Hohagen et al., 1998; Rosalcaizar et al., 2008]. According to German treatment guidelines, CBT with EX/RM is the treatment of choice [DGPPN, 2013]. Treatment components of CBT in OCD include the establishment of a sustainable therapeutic relationship, the development of treatment motivation and of functional analyses, the planning and execution of EX/RM, and further, the utilization of cognitive techniques [Förstner et al., 2011]. While CBT with EX/RM is considered the first-line treatment, SSRIs are additionally recommended for patients primarily suffering from obsessions or comorbid depression [Hohagen et al., 1998].

As yet, relatively little is known about the implementation of CBT with EX/RM in routine care in Germany. However identifying potential discrepancies between guideline recommendations and their implementation in routine settings is a critical step to improve the health care situation [Garland et al., 2010].

Studies from both USA [Freiheit et al., 2004; Mancebo et al., 2011; Marques et al., 2010] and Germany indicate an undersupply in the treatment of patients with OCD. However, since crucial differences in the health care systems of the US and Germany make findings from both countries difficult to compare, the current work focuses on results regarding the treatment situation of OCD in Germany. A nationwide survey [Wittchen and Jacobi, 2004], conducted in 1998 on behalf of the German Ministry of Health, reported that only 44% of the investigated patients with anxiety disorders (including OCD) had received treatment within the past 12 months. The definition of ‘treatment’ included every contact with a mental health professional regardless of quality and duration. In a survey of 386 resident psychologists and psychiatrists in Germany, Külz et al. [2010] found that around 75% of the respondents treated 3 or less patients with OCD per year. Approximately 75% of the behavior therapists and 20% of the psychodynamic therapists found EX/RM to be effective. However, 25% also considered ‘thought stopping’ as helpful, despite the absence of evidence for this method. In another earlier survey of 138 German therapists with CBT training, 14% reported that they had never used stimulus confrontation techniques in the treatment of patients with OCD [Roth et al., 2004]. 17% of this sample only occasionally, rarely, or never used EX/RM for patients with OCD. However, it is not entirely clear whether all therapists in this sample regularly treated any patients with OCD. Böhm et al. [2008] examined the treatment experience of 57 patients with OCD who had formerly undergone psychotherapy and found that 83% of the treatments did not include EX/RM.

To acquire greater clarity in routine care of patients with OCD is thus a timely step to further determine potential treatment barriers and to improve the mental health situation.

The aim of the present study was to evaluate the treatment situation of patients with OCD in Germany. The following questions were addressed: i) How much time passes, on average, between the onset of OCD and the initiation of the first treatment?; ii) How many patients receive CBT with EX/RM?; iii) Do patients who receive EX/RM perceive their treatment as more helpful in comparison to patients who receive other treatments?

Methods

Participants

A total of 525 patients participated in the survey. One subsample was recruited online via the German OCD society and filled in an online version of the survey (270 participants). Another subsample of 255 participants was recruited either in 1 of 3 German medical centers (University hospital of Freiburg, Department of Psychiatry and Psychotherapy; University hospital of Leipzig, Department of Psychotherapy and Psychiatry, Schoen Klinik Bad Bramstedt) which provide disorder-specific treatment for patients with OCD (207 participants), or in outpatient units in Germany specialized in the treatment of OCD (48 participants). The survey was referring to the experience of previous treatments, not to the current treatment during which patients were recruited. Written informed consent for participation in the study was obtained from all participants.

The analyzed sample consisted of 369 patients with OCD. Diagnoses were established by experienced mental health professionals in a specialized institution or, in case of the online sample, the participants identified themselves as having been diagnosed with OCD by a psychologist, psychiatrist, or neurologist. 78 patients were excluded due to missing symptom severity data (no Y-BOCS Scale), 78 patients were excluded because they had only been diagnosed by their general practitioner or by themselves.

Data were collected between October 2009 and August 2010.

Questionnaire

Data were derived from the ‘Patient Survey on Obsessive Compulsive Disorder’ developed by the authors of the present paper. It contained the following questions:

(1) Age (in years)
(2) Gender (male or female)
(3) Employment status (student, employed, unemployed, homemaker, retired, other)
(4) Partnership status (with partner, no partner)
(5) How long have you been suffering from symptoms of OCD? (in years)
(6) Which type of OCD do you suffer from? (primarily obsessions, primarily compulsions, mixed type)
(7) If you suffer from obsessions, which type of obsessions do you suffer from? (contamination, somatic, aggressive, sexual, repeating, religious)
(8) If you suffer from compulsions, which type of compulsions do you suffer from? (cleaning/washing, checking, counting/repeating, ordering, hoarding, mental rituals)

(9) Do you suffer from another mental disorder? If yes, which disorder do you suffer from?

(10) How much time passed between the onset of OCD and your first treatment?

(11) If you have already received psychiatric or psychotherapeutic treatment, please complete the following questions for each treatment you received (currently ongoing treatment should not be evaluated):

• Did you receive behavioral therapy?
• Did you receive exposure treatment? If yes, did you participate in therapist-guided exposure sessions?
• How helpful was this treatment for you? (rated on a Likert scale from 1 (very helpful) to 6 (not at all helpful))
• Did you ever receive medication for the treatment of your OCD? If yes, which medication? (name of drug, dosage)

Additionally, the Yale-Brown obsessive compulsive scale self-rating (Y-SR) is the widely used self-rating version of the clinician-administered Y-BOCS [Goodman et al., 1989]. The interview and the self-rating scale are highly correlated with each other and can thus be considered as equivalent with respect to the measurement of severity [Schaible et al., 2001].

Statistical Analysis
All statistical analyses were carried out using SPSS version 17.0. Means, standard deviations (SD), absolute frequencies and percentages were computed for descriptive purposes. To test difference hypotheses t-tests, χ²-tests and ANOVAs were conducted. The level of significance was set at \( p < 0.05 \) for all analyses.

Results

Demographic and Clinical Characteristics of the Sample

Demographic characteristics of the sample are presented in table 1. The subsamples did not differ in gender, age, and relationship status. Of note, there were significant differences in employment status, i.e. there were more unemployed patients in the internet sample.

Clinical characteristics of the sample are listed in table 2. The subsamples differed only with regard to time between onset of OCD and treatment and the proportions of patients who suffered from contamination fears. The results indicate that the period of time between onset of OCD and first initiation of treatment as well as the proportion of participants suffering from contamination fears was significantly larger in the facility subsample than in the online subsample.

According to the current global score of the Y-BOCS, 6.2% of the total sample had subclinical OCD (Y-BOCS 0–7 points), 27.4% mild (Y-BOCS 8–15 points), 37.1% moderate (Y-BOCS 16–23 points), 26.3% severe (Y-BOCS 24–31 points), and 3% extreme OCD (Y-BOCS 32–40 points).

48% (n = 177) of the total sample stated that they suffered from one or more comorbid disorders. The most frequent comorbidity was depression (31%), followed by anxiety disorders (15%), personality disorders (5%), eating disorders (3%), attention deficit hyperactivity disorder (2.4%), substance-use disorders (1.6%), bipolar disorder (0.8%), and psychotic disorders (0.8%).

Treatment Situation

The average time that had passed between onset and first treatment was 5.9 years (SD 8.1 years) for the total sample (see table 2). 37% indicated that they had received CBT with EX/RM as their first treatment. 24% had conducted EX/RM in their first treatment in attendance of a therapist. 60% reported that they had received EX/RM at least once. In 46% of cases the exposure was also accompanied by a mental health professional. Figure 1 visualizes the ab-
solute frequencies and percentages of patients with OCD who re-
ceived EX/RM or treatment without EX/RM. Additionally, figure 1
delineates patients’ subjective satisfaction with different treat-
ments. In figure 2 the cumulative percentage of patients who re-
ceived EX/RM in 4 consecutive treatments is outlined. The com-
putation of χ²-tests did not reveal any significant dif-
ferences in any of the 4 surveyed treatments regarding the frequen-
cy distributions of utilisation of 'treatments with EX/RM', 'treat-
ments without EX/RM' and 'no treatments' depending on method
of data collection (facility vs online). Likewise, with respect to
mode of exposition (therapist-guided vs not therapist-guided), χ²-
tests did not yield significant differences for both first and all 4
treatments together depending on the sample. Therefore, results
are only reported for the total sample.

The proportion of patients who had been treated with EX/RM
at least once were comparable in the subgroups of patients with
clinically relevant vs. less severe OCD (table 3). For the first ther-
apy, patients who had received EX/RM rated their treatment as
significantly more helpful than those who had not (table 4). The
performance of a 2-way ANOVA did not show any significant
differences regarding satisfaction with treatment with or without
EX/RM in dependence on method of data collection (facility vs
online). Hence, findings on patient-rated usefulness of treatments
are only reported for the total sample.

In terms of pharmacological treatment, 74.3% (n = 274) of the
total sample reported that they had received medication to treat
their OCD. 58.9% (n = 216) had received SSRIs. Two χ²-tests ex-
amining differences in the frequency of medication and SSRIs
intake (yes vs no) did not yield any significant differences in the
subsamples either. Figure 3 illustrates frequencies of intake of
different medications in OCD treatment.

## Discussion

This survey yielded 2 major findings: First, we found an average
delay of 6 years between the onset of OCD and the initiation of the
first treatment. Second, a large proportion of patients stated that
they had not been treated with CBT with EX/RM. More specific-
ally, 40% of the examined patients treated for OCD in Germany had

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<td>Received EX/RM at least once, % (n)</td>
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n = absolute frequency, m = mean, SD = standard deviation, Y-BOCS = Yale-Brown Obsessive Compulsive Scale (self-rating),
EX/RM = exposure with response management, t = test value of t-Test for independent samples, p = level of significance.
All percentages are given as valid percentages.
*Significant differences.
χ².
t-value.
never received CBT with EX/RM and 63% had not received CBT with EX/RM as first treatment. Even if patients had received exposure, more than half of them had not received a therapist-guided exposure. These findings appear particularly important since CBT with EX/RM, in accordance with the guidelines, was reported by the subjects to be significantly more helpful than treatments without EX/RM.

The treatment latency of 6 years between onset of OCD and first treatment identified in our sample was markedly shorter than in various samples of patients with OCD from USA, which reported 10 years [Marques et al., 2010], 14 years [Cullen et al., 2008], and 17 years [Pinto et al., 2006]. It is plausible to assume that patients with OCD in Germany seek treatment earlier than patients in USA, possibly due to differences in the health care systems. This hypothesis is supported by the notion of Marques et al. [2010], stating that 57% of patients reported being worried about the health care costs and that 38% had concerns about their insurance coverage. However, a number of methodological differences (e.g., regarding...
sample characteristics, types of recruitment, and surveys) might also account for these discrepancies.

Our result that a large proportion of patients did not receive CBT with EX/RM is in accordance with previous studies indicating a potential undersupply of CBT with EX/RM for patients with OCD in Germany [Böhm et al., 2008; Külz et al., 2010; Roth et al., 2004] and in USA [e.g., Marques et al., 2010]. The finding that this treatment was rated significantly more helpful in our sample than treatments without EX/RM is in line with a large body of research that bolsters the efficacy of this treatment in reducing OCD symptoms and improving the associated quality of life [e.g., Foa et al., 2005; Moritz et al., 2005; Rosa-Alcázar et al., 2008]. However, in this regard, it must be pointed out that even if the treatments without EX/RM were rated as significantly less helpful, the treatments involving EX/RM were merely rated as moderately useful. In the subsample which received EX/RM as a first treatment, the proportion of patients who rated this therapy as good or very good was in fact comparable to the proportion of patients who rated it as unsatisfactory or not helpful at all. The low treatment satisfaction in this sample might result from the retrospective data collection; it is theoretically possible that the majority of the patients benefitted from EX/RM in the short, but not in the long-term, which could have led to a more negative rating in retrospect. This hypothesis is supported by Eisen and colleagues [1999], who found a 48%-probability of relapse in patients with OCD within 2 years after remission [for contradictory findings, see Rufer et al., 2005]. Another possible explanation for the reduced treatment satisfaction is that some patients in our sample might have received EX/RM treatment which was not always performed according to best practice guidelines. Possible mistakes in the treatment of patients with OCD with EX/RM include, e.g., an inadequate preparation of the patient for the exposure, conducting exposures over short time intervals, and not addressing cognitive avoidance during exposure sessions [Gillihan et al., 2012; Hand, 2011; 2013].

Our study did not investigate reasons why some patients of our sample did not engage in CBT with EX/RM. Thus, we can only speculate about conceivable reasons for not initiating treatment. Külz et al. [2010] state, however, that the vast majority of therapists in their study rarely or never treated patients with OCD. In addition, some of the therapists who actually treat OCD patients with CBT presumably do not provide EX/RM [Hillebrand and Niedermeier, 2014], often due to difficulties in integrating EX/RM into the daily routine care of private practices and the associated financial losses (e.g., caused by insufficiently compensated travel time to the exposure treatments) [Hillebrand and Niedermeier, 2014; Külz et al., 2010]. Considering the aforementioned aspects, then, it is possible that at least some patients may have difficulties finding a therapist who offers CBT with EX/RM. Furthermore, Mancebo et al. [2011] found that one quarter of the patients who had received a recommendation for CBT did not initiate the treatment and that 31% of those who had started CBT terminated the treatment prematurely. These results direct attention to barriers on the patients’ sides. The temporarily anxiety-provoking nature of EX/RM is probably one reason why patients do not wish to enroll in this treatment or drop out prematurely. Further potential barriers to the initiation of treatment are scheduling problems and financial concerns, stigma and shame as well as the perception that treatment will not be helpful [Mancebo et al., 2011; Marques et al., 2010].

The present study includes some limitations. First, it must be acknowledged that the exact extent of an undersupply of CBT with EX/RM in patients with OCD can only approximately be determined due to the fact that all data were based on retrospective self-reports. Administering retrospective self-ratings in the present study has potentially led to receiving limitedly valid information on (1) whether a CBT has been utilized, (2) whether expositions have been performed, and (3) whether these have been therapist-guided, since patients often might have been unable to recall or had not been aware of the kind of treatment they had received in the first place [Stobie et al., 2007]. Another related reason is that we do not know for certain whether EX/RM in general, and specifically therapist-guided EX/RM (as the first treatment), was indicated for every single patient included in our study. As described in the S3 guidelines for OCD [DGPPN, 2013], therapist-guided exposures are the treatment of choice. Still, there may have been some cases in which other approaches had been indicated. For example some might have suffered from severe comorbid disorders which needed to be treated prior to OCD or which constituted a contraindication to EX/RM. However, only a minor percentage of our sample indicated that they suffered from severe comorbidities, such as substance dependence, bipolar disorder, or psychosis. Thus, we assume that our results can in fact be interpreted as an indicator of an undersupply, at least with respect to EX/RM.

Another limitation of the current study is that no structured diagnostic instrument was administered. However, we only included patients who were diagnosed with OCD in a specialized institution or who reported that they had been diagnosed by a psychologist, psychiatrist, or neurologist. Contrary to Marques and colleagues [2010], we did not exclude patients with a subclinical Y-BOCS score because we wished to include treatment responders.

The restricted representativeness of the sample must be pointed out as another limitation of the current study. Although the present
sample size is relatively large (N = 369) it only corresponds to less than 1% of the 60,000–310,000 individuals that are actually affected by OCD every year in Germany (0.7–3.8%) [Adam et al., 2012; Wittchen and Jacobi, 2012]. This indicates a limited generalizability of our findings, also concerning the low motivation to change of the ones affected. Moreover, the generalizability has been impaired by the fact that we have only included patients who had completed all measures and who had been diagnosed by an expert. Finally, our procedure of recruitment might have led to a sample less representative of patients with OCD in Germany. For example, it can be assumed that patients from behavioral therapy facilities generally have utilized CBT with EX/RM more often and have rated them differently than participants from community samples.

Several questions have not been addressed in our questionnaire and might be the subject of further research. Of interest are, e.g., the identification of the period of time between outset of diagnosis and first treatment, the question of whether patients received an adequate dose of psychotropic drugs, the exploration of reasons why evidence-based treatment was not initiated, and the investigation of the frequency and perceived effectiveness of treatment elements which are closely related to EX/RM, such as ‘case formulation’ and ‘cognitive restructuring’. In addition, the collection of qualitative aspects of EX/RM (e.g., motivational support, frequency, and duration of exposition-sessions) as well as their evaluation would be interesting. These would yield a more accurate picture of the treatment supply situation for OCD in Germany and would presumably also have a considerable impact on the ratings of EX/RM and the treatment in general.

Conclusions

Although efficacious treatments for OCD do exist, many patients with OCD are not treated according to current German treatment guidelines [DGPPN, 2013]. Even though the exact extent of undersupply is not entirely clear due to the methodological limitations of our study, our results still point out obstacles on the part of many therapists and patients in the use of CBT with EX/RM. Possible interventions which might work positively in removing patients’ barriers include imparting information about OCD and its treatment through the media and anti-stigma work as well as the implementation of low-threshold treatment offers, such as evidence-based self-help and internet-based interventions. Potential actions aiming at reducing reservations regarding CBT with EX/RM from a therapist’s view include the improvement of the financial conditions of practitioners (e.g., by increasing the compensation for travel time) and conveying ideas which improve the integration of exposition-treatments into the daily routine care of mental health professionals without causing financial impairments [Hillebrand and Niedermeier, 2014]. The implementation of these actions could lead to an expansion of CBT with EX/RM and, therefore, possibly to an improved treatment supply for patients with OCD.

Authors’ Contributions

UV, AKK, MR, TH, BO, KS, LI, and SM contributed substantially to the conception and design of the study and the acquisition of the data. SS, AKK, NT, EH, CS, NH, and CN conducted the data analysis. All authors were involved in the interpretation of the data. SS, AKK, NT, EH, and CS have been involved in drafting a first version of the manuscript. AD has revised the entire manuscript for publication. All authors gave final approval of the version to be published.

Disclosure Statement

The authors report no conflicts of interest.

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