Disability and Family Burden in Obsessive–Compulsive Disorder

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This paper reviews 2 aspects of obsessive–compulsive disorder (OCD): impairment in functioning and family burden associated with OCD. Impairment is evident from epidemiological and clinical studies in several areas, particularly in occupational and social maladjustment. Clinic outpatients show a range of impairment associated with OCD, while hospitalized patients exhibit consistently severe disabilities that rival those of patients with schizophrenia. Although behaviourally and medication-treated patients improve in adjustment levels, there is some evidence of persistent impairment, particularly in social and work functioning. Several studies support extensive family involvement and accommodation of OCD symptoms, as well as the considerable burden placed on families who reduce their social activities and increase their isolation and distress. Findings are equivocal regarding OCD and marital distress. Predictors of treatment outcome do not include marital dissatisfaction, but may include expressed anger and criticism. With regard to treatment, family support groups are popular but untested interventions, and family-assisted individual and group behaviour therapy have demonstrated good outcomes in limited trials.

(Key words: obsessive–compulsive disorder, disability, functional impairment, family burden)

Parts of the diagnostic criteria for defining OCD, according to both DSM-IV and ICD-10, are the presence of marked distress from symptoms, spending more than one hour per day on obsessional or compulsive behaviours, or significant interference with normal routine, occupational or academic functioning, social relationships, or activities (1). When obsessions and compulsions are clearly present, it is the degree of severity and the functional impairment that determines whether the person receives a clinical diagnosis or is classified as having subclinical symptoms.

Epidemiological and community studies make it clear that some individuals who meet both the symptom criteria and the distress and impairment criteria for OCD do not appear among treatment-seeking clinic samples. Instead, they prefer to keep their symptoms private, even secret, from others and may seek help for conditions caused by the OCD symptoms without identifying OCD as the problem. For example, 2 studies have reported the surprisingly high frequency of medical patients in dermatology clinics who exhibited contamination obsessions and washing compulsions that produced dermatitis: 15% to 36% met criteria for OCD and received scores typical of clinical patients on a standardized measure of OCD (2,3). In nearly all cases, the dermatologist was unaware of the psychiatric problem (3).

The literature review and discussion in this article focus on the extent and types of disability experienced by individuals with OCD, as well as the burden that OCD symptoms impose on families. In the first section, general disability findings are discussed, followed by information about specific impairments. The treatment literature pertinent to disability and to familial aspects is also presented with brief comments regarding the clinical implications of these findings. In this paper, the terms “interference with functioning,” “impairment,” “adjustment,” and “disability” are used synonymously, although they may have slightly different meanings depending on the context. Reference to monetary benefits for “disability” related to OCD is clearly noted. The second section about family burden begins with familial responses to OCD, particularly with regard to family accommodation and distress, marital relationships, and family impairment. Family involvement in support groups and

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behavioural therapy and family predictors of treatment outcome are included.

**Disability and Functional Impairment in OCD**

**Epidemiological Research Findings**

Some information about disability due to OCD is available from a recent Canadian survey and the United States (US) Epidemiological Catchment Area (ECA) study. A Canadian telephone survey studied OCD symptoms and diagnoses in 2661 adults in urban and rural areas (4). Within the entire sample, 1% to 2% were significantly impaired or distressed by obsessive or compulsive symptoms. Among the 0.6% who were diagnosed as having OCD within the past month, impairment and distress were experienced from obsessions by 26% and from compulsions by 22%.

The ECA study reported findings on employment and marital status which showed that OCD, which typically predated other conditions such as depression and schizophrenia, led to significant functional impairment (5). Individuals with OCD also had high mental health care utilization rates, second only to panic disorder among anxiety states: 35% sought mental health care from medical providers, 44% from specialty mental health clinics, and 36% from other human service settings. Kern and others (5) concluded that OCD was in the midrange with respect to the degree of mental health care seeking efforts. In a later report of ECA findings, Leon and others (6) noted that 22% of men and 13% of women with OCD were receiving disability payments. These percentages are 4 times higher than for individuals without an Axis I diagnosis. Women with OCD were more likely to be receiving welfare payments (14% versus 3% for men), so that overall, 25% to 30% of both men and women with OCD received some type of government financial assistance.

**Educational Functioning**

Few epidemiological studies have examined the educational functioning of those with OCD. Henderson and Polloward’s study (7) of 497 St. Louis residents did not find significant differences in education between those diagnosed with OCD and those without OCD, although there was some tendency for fewer of the former to complete college.

**Occupational Functioning**

According to ECA data, individuals diagnosed with OCD, especially men, were more often unemployed than those without the disorder, but this association was not specific to OCD (5,6). In Koran and others’ comparison of treatment-seeking OCD patients with normal samples, 22% of OCD patients were found to be unemployed (8), a figure that appears comparable to the 24% of OCD patients from the ECA study who had “low” socioeconomic status (9). Henderson and Pollard (7) did not find significant differences in income levels between adults diagnosed with OCD and those without the disorder, although those with OCD appeared more often in the under $10 000 range and less often among the over $40 000 group.

**Marital Status**

According to ECA findings, 21% of OCD-diagnosed respondents were single (9). These epidemiological figures do not differ from national norms which indicate that 26.8% of men and 19.4% of women do not marry (US Bureau of Census, 1996). Using the same data, Karno and others (5) noted that OCD occurred more often among divorced or separated respondents, although, as for other impairments previously discussed, marital disruption was not specific to OCD. In contrast to these findings from the community, most clinical studies have indicated much higher nonmarriage rates that ranged from 37% to 60% (8,10–12), with rates as high as 72% for inpatients (13,14). These rates did not differ from anxiety disordered (12) or depressed (14) patients, indicating that OCD may not produce more heterosexual difficulties than other psychiatric disorders. Higher rates of nonmarriage for OCD patients compared with community samples and for inpatients compared with outpatients is likely due to differing severity and chronicity, with more severe OCD symptoms impairing social and sexual skills and, consequently, the likelihood of marriage. Men may be especially prone to remaining single: several studies reported that up to three-quarters of male patients with OCD were unmarried, compared with half this number for women (13,15,16). This disparity may be related to the earlier onset age of OCD in males, who typically experience symptoms in early adolescence, compared with females, whose onset usually occurs during the late teens or early 20s (17).

**Findings From Clinical Treatment Studies**

Much of the data pertaining to functioning levels in clinical studies of OCD derive from baseline measures in treatment outcome studies or from psychometric studies of instruments to assess OCD symptoms and their effects. In the findings reported below for individuals who experienced sufficient suffering to seek treatment, it is not surprising that the type and extent of impairment recorded in these studies is somewhat higher than similar findings from epidemiological studies. The degree of general disability is described first, followed by categories of educational, occupational, social, and family functioning.

**Rates of General Impairment**

Among measures of OCD symptoms specifically, 2 clinician-administered instruments contain information about patient functioning: the Yale–Brown Obsessive Compulsive Scale (Y–BOCS) (18) and the Leyton Obsessional Inventory (LOI) (19). In the Y–BOCS, 2 of 10 items assess interference of obsessions and compulsions with functioning. Unfortunately, only a few studies have reported findings for these individual item scores, rather than only summed scores. Goodman and others (18) assessed 42 OCD outpatients entering a medication trial. Scores on both obsessional and compulsive interference with functioning ranged from 0 (none) to 4 (extreme), with mean scores in the midrange of 2.2 to 2.3 and with one-quarter to one-third of the patients
scoring 3 (moderately severe). These findings indicated moderate to significant interference in general functioning for most treatment-seeking individuals with OCD, with compulsions slightly more problematic than obsessions.

Kim and associates (20) reported a 63% agreement between the Y–BOCS and the LOI regarding the degree to which OCD symptoms interfered with functioning. The total Y–BOCS severity score showed a moderate relationship (r = 0.43) with interference on the LOI: as might be expected, more severe OCD symptoms provoked more interference in functioning. Furthermore, both Y–BOCS interference items were strongly associated with their respective subscales, indicating a strong association of functioning with obsessional and compulsive symptoms (21,22). Calvocoressi and colleagues (23) noted that inpatients with severe and usually comorbid OCD present unique symptoms and functional impairments which require specialized management strategies within the hospital setting. Of 455 applicants for treatment of primary OCD, 17% required hospitalization for disability-related problems, including disruption of the home environment, poor self-care, and possible self-injury. Understandably, disability in this sample was considerably higher than in outpatient or community samples. According to their report, routine activities (sitting in chairs, using the telephone, eating) were often disrupted because of contamination fears and extensive cleaning rituals. Primary obsessional slowness, a relatively rare condition, occurred more often in this sample, making completion of all routine motor tasks painfully time-consuming. Some patients exhibited poor hygiene and medical complications secondary to their compulsions. Global Assessment of Functioning (GAF) scores for 55 inpatients averaged 40 (major impairment in several areas), with a range from 15 to 61. This contrasts with more typical GAF scores of 50 to 60 in our own outpatient samples.

In Calvocoressi and colleagues’ inpatient sample (23), mean Y–BOCS scores before treatment were 27.6, higher than usual outpatient means of 20 to 25. Multimethod interventions over an average of 3 to 4 months included medication (often with augmentation strategies), staff-assisted modified behavioral regimens, and stress management. These methods reduced OCD symptoms to a mean of 18.3 on the Y–BOCS, still 2 points above the usual clinical cut-off score of 16 required for treatment entry. Calvocoressi and associates (23) noted that these patients often behaved disruptively on the ward, interfered with other patients’ routine needs, such as bathroom use, and provoked staff conflict and inconsistent treatment. Prior to discharge, most of these patients required extensive discharge planning that included referral to social and vocational rehabilitation, disability benefits, continued intensive outpatient treatment, case management, and structured residential placement. In its severe form, OCD can clearly produce very substantial impairment equivalent to that seen in chronic mental illness, such as schizophrenia.

Two studies have assessed the disability-related phenomenon of quality of life (QOL) experienced by individuals with OCD. Elizondo and others (24) described 17 outpatients who exhibited significant impairment on a standardized measure, the Quality of Life Inventory, such that mean scores were lower (worse) than 93% of nonclinical adults, although patients’ scores ranged widely. Despite substantial reductions in Y–BOCS scores after intensive behavior therapy, QOL scores improved only slightly. The sample size at posttest, however, was too small to determine whether change in OCD symptoms led to change in QOL. Koran and colleagues (8) compared health-related QOL for 60 patients with OCD with published norms and with scores of patients with depression and diabetic health problems. According to a standardized self-rated health survey form, role impairment and social functioning in OCD were substantially worse than population norms and were also worse than in subjects with diabetes. More severe OCD symptoms were associated with lower social (but not role) functioning, regardless of level of current depression. Physical health was comparable across groups, except with diabetic patients, suggesting that mental health impairment due to OCD is not associated with poorer physical health (25).

**Comparisons With Other Groups**

There is some disagreement in findings regarding functioning levels of OCD clinic patients compared with other Axis I disorders. In our earlier research, 75 OCD outpatients appeared to be more functionally debilitated than 65 patients with social phobia, simple phobia, agoraphobia, or generalized anxiety disorder (12). In particular, they were poorer and less frequent (31% versus 68%). Chakrabarti and others (25), however, found no differences between OCD outpatients compared to dysthymic and GAD samples on overall dysfunction; all 3 scored in the moderately dysfunctional range. Likewise, Chambless and others (26) found that OCD outpatients assessed using the GAF were similar to panic and agoraphobic patients on functioning.

As noted earlier, patients with OCD had relatively low current GAF scores, averaging in the low 40s, comparable to inpatients with major depression and somewhat higher than those with schizophrenia (27). Only 29% were able to achieve a moderate level of overall functioning compared with 46% of patients with schizophrenia and 69% of those with an affective disorder. Fenton and McGlashan’s brief report (28) on 7 patients with OCD accompanied by “obsessive psychosis” identified these patients’ premorbid social functioning as the poorest of any diagnostic group in their follow-up study. Occupational skills were comparable to patients with schizophrenia, and long-term follow-up after hospitalization indicated that the severe disability evident in this sample was chronic, particularly for work and social functioning.

This research makes it clear that there is a substantial range of general functioning, even in clinical samples with OCD, relative to community and subclinical samples. Impairment can be minimal, permitting full functioning in work, social, leisure, and family activities and relationships, or it can be
severe, requiring inpatient intervention and extensive care. Specific domains of functioning are described below, typically derived from studies that used Likert-like scales to rate patients’ work, social, and family capabilities.

**Occupational Functioning**

Independent assessor ratings from several studies have indicated that, on average, OCD patients entering Exposure and Response Prevention (ERP) and medication trials scored in the moderate to severe range in work functioning (29–32). Hollingsworth and others’ follow-up report (33) of children followed 6.5 years after treatment indicated that all 7 who were over 16 years of age were employed, but 2 had difficulty keeping a job, and most had taken positions where OCD symptoms could be managed. Calvocoressi and colleagues’ comparison (27) of OCD inpatients to schizophrenic and depressed inpatients indicated that only 13% of OCD patients had consistent employment, and 88% were supported by others, percentages comparable to those for schizophrenic patients. Both of these groups had worse employment histories, lost more time from work, and performed activities of daily living worse than depressed inpatients. Thus OCD patients who required hospitalization were severely occupationally impaired and required extensive vocational rehabilitation services.

**Social Functioning**

Hollingsworth and others’ follow-up study (33) of adults who had been treated when they were children indicated that all who were over 16 years of age had problems with their social lives, and only 30% had ever dated. Assessor-rated social functioning was moderately impaired in most outpatient samples studied (29,30,32,34), although patients rated themselves as slightly less impaired that did independent assessors. Self-report assessment, however, according to the more detailed Social Adjustment Scale, Self-Report version (SAS-SR), showed marked difficulty (mean scores were 2.84) (35). On the QOL issue of social functioning, OCD outpatients scored considerably lower than normal and diabetic samples, but slightly better than depressed patients (8). Compared to schizophrenic and depressed inpatients in general, severely symptomatic OCD inpatients did not differ in amount or quality of social relationships; all of these inpatient groups had, in general, fair to very poor levels of friendship (27). Thus, as for general functioning, social adjustment ranges from mild to severely impaired.

OCD patients’ social functioning appeared to be associated with the presence of personality disorders (PD) in general and, especially, the bizarre cluster and avoidant PD, which may partly identify social anxiety (36). This link to personality did not apply to family, work, or general functioning assessed in the SAS-SR. Using the same measure to study parental traits in patients’ upbringings, Chambless and colleagues (26) noted that poor social adjustment was related to low levels of parental care and high levels of overprotection in a mixed outpatient sample with OCD and agoraphobia. There is no way to determine from these cross-sectional data whether worse functioning led to negative recall of parental upbringing (blaming parents for current failures; crediting parents with current successes) or whether inadequate parental care led to worse functioning.

**Family Functioning**

Ratings of family functioning on global scales have indicated mild to moderate problems in outpatient samples (29–32). Similar or slightly worse results were evident on the SAS-SR, which showed moderate to marked difficulty (mean = 2.26) in extended family relationships (35). According to Calvocoressi and associates (27), 67% of OCD inpatients appeared to have fair to poor family relationships, a percentage comparable to other inpatient groups with schizophrenia or major depression. Satisfaction in marital relationships is discussed in the section about family burden.

**Sexual Relationships**

Global ratings of sexual functioning in studies by Marks and colleagues (31,32,34) and by Foa and Goldstein (29) generally indicated moderate to mild disturbance. In Freund and Steketee’s sample of 44 outpatients (15), some degree of sexual dysfunction occurred in 39% of these patients, and 73% were dissatisfied with their sex lives, primarily due to the absence of a partner and relationship difficulties. Consistent with the lower rates of marriage in OCD, patients appeared to have had less dating experience, fewer steady heterosexual relationships, and less sexual experience during their teenage years, which probably contributed to later sexual dissatisfaction. It also appeared likely that contamination fears associated with bodily secretions constituted part of the interference of OCD symptoms in sexual functioning. Staebler and others (37) also examined sexual relationships in 108 outpatients with OCD compared to patients with panic disorder and depression. Fifty-nine percent of OCD patients were dissatisfied sexually, but they did not differ from other patients on sexual satisfaction, age at first sexual intercourse, and perceived quality of marital relationships. It appears that the sexual histories and relationship quality of OCD patients are not unique among clinical samples, though there appears to be greater impairment than for nonclinical adults.

**Influence of Comorbid Conditions on Functioning**

The relatively limited information about the influence of comorbidity on functioning suggests that certain comorbid conditions may further reduce functioning, but only to a limited extent. For example, OCD patients with concurrent psychiatric disorders had poorer quality of life than those without other psychiatric disorders, but only in the mental health domain (8). They did not exhibit poorer social or role functioning. Greater depression, though not necessarily an affective disorder diagnosis, was associated with more family dysfunction, according to the Sheehan Disability Scale (38). Likewise, more self-reported personality traits (but not diagnoses) were modestly predictive of poorer social adjustment after treatment (36). A comparison by Stein and others (4),
however, indicated that OCD patients with Tourette’s syndrome (TS) showed significantly less interference on the LOI compared with OCD patients without TS. Not surprisingly, however, both groups scored substantially worse on interference in functioning than a nonclinical sample. Jenike and colleagues (39) note the very high failure rate of OCD patients who also have schizotypal personality disorder, but they do not assess functioning capacity, except clear social isolation that is part of this diagnosis. Thus the influence of comorbid conditions is not uniform, but tends in the direction of worse functioning.

Effect of Treatment on Functioning

Unfortunately, relatively few treatment outcome studies have assessed change in functioning. The relatively limited findings are discussed below. General interference in functioning assessed by the LOI improved significantly for 20 OCD patients treated intensively with ERP (31). Bolton and colleagues (40) reported outcome on social adjustment for 14 adults treated 9 to 14 years previously as adolescents using behaviour therapy and, in some cases, clomipramine. Social adjustment estimated on a 3-point scale from interviews and case records was good in only 43% of the sample with one-third “definitely” and another third “severely” maladjusted. Somewhat surprisingly, good social adjustment at follow-up was not related to severity of OCD symptoms at follow-up, suggesting that current OCD symptoms do not always account for functioning difficulties. Disability may be caused by other problems or, if functioning was impaired seriously early in life, symptomatic improvement may not enable patients to recover lost ground easily.

Trials by Marks and colleagues (31,32) and by Foa and colleagues (29,30) have examined outcome on assessor and patient-rated Likert scales assessing work, leisure, sex, and family adjustment after ERP, with and without the addition of serotonergic medications. In most studies, treatment led to modest gains in functioning, and these benefits persisted at follow-ups that ranged from months to several years. In a later trial, Marks and others (32) reported that mean impairment scores were generally reduced, after 10 weeks of clomipramine (CMI) or ERP, from moderately severe (scores of 5 to 6 out of a possible 8) to mild to moderate (2 to 4), with CMI-treated patients most often averaging in the 1 to 2 range. Work and social or leisure functioning were most impaired and improved most in some cases (29,31,34), but showed some persistent disability in others (32). In these studies, the least benefit occurred in patients treated with medication only, without the addition of exposure treatment (34). Other studies have also confirmed the benefits of behaviour therapy and other serotonergic medications, including fluvoxamine, for improving obsessive and compulsive (OC) symptoms and functioning after treatment and at one-year follow-up (41; Rasche-Rauchle and colleagues, unpublished observations).

In these ERP and medication trials, family and sexual functioning, which was less impaired at the outset of treatment than occupational or social adjustment, also improved (29,31,32,34). Riggs, Hiss, and Foa (42) noted that marital distress also improved significantly following intensive ERP. Cobb and others (43) compared the effects of marital therapy for patients with OCD with those of ERP treatment. Marital treatment improved marriages, but did not affect OCD symptoms, whereas ERP improved both problems. When obsessions were specifically focused on marital fidelity (labeled “morbid jealousy,” which may have been a form of paranoia), however, a broader spectrum of treatment that included ERP, marital, cognitive, and skills training elements led to more benefit (44).

Interestingly, in a trial by Marks and others (32), the largest functional improvement occurred in their highly depressed subsample, but it appeared that this might have been due to their greater impairment at pretest, which permitted more improvement. Patients whose depressed mood persisted after treatment showed more functional impairment after treatment and at follow-up (35; Rasche-Rauchle and others, unpublished observations). It seems quite likely that significant depressed mood will accompany serious impairment and that these aspects of OCD will interact causally and reciprocally. That is, depression will impair functioning, and reduced functioning will lower mood.

Van Noppen and others (38) noted that both group and multifamily ERP interventions led to significant improvement in overall functioning ability on the Sheehan Disability Scale after treatment and at a one-year follow-up. Family functioning, however, assessed using a standardized self-report questionnaire, did not show significant improvement, although multifamily treatment helped subjects to achieve healthier role functioning within the family, and more OCD patients scored in the healthy range on family functioning a year after group or family treatment. Interestingly, patients whose families were more dysfunctional at the start of treatment were more generally disabled after therapy.

Because of the infrequent assessment of functioning domains, most metaanalyses aggregating findings across pharmacological and behavioural therapy investigations have not reported treatment effects on functioning (45–47). One exception is the comprehensive metaanalytic report by van Balkom and others (48). As might be expected from individual studies reported earlier in this paper, posttest effect sizes for treatments indicated that serotonergic antidepressants, ERP, and their combination had generally large effects (Cohen’s $d = 0.70$ to 1.51) on social functioning. These did not appear to differ noticeably across treatment methods, particularly when studies of ERP alone were combined with those of ERP plus placebo medication. Unfortunately, there is insufficient information about the effect of cognitive therapy alone or combined with other methods on social adjustment.

Functioning as a Predictor of Treatment Outcome

This section will focus on work and social impairment predictors of outcome; family and marital predictors are...
discussed in the following section on family burden. Some have suggested that extensive involvement in OC symptoms may also serve the purpose of avoiding social and work challenges (49). This assertion partly accords with clinical lore among behaviour therapists experienced in treating OCD that patients who do not quickly replace time spent on symptoms with the compelling distractions of work or other functional activities will have less motivation to improve and be more likely to relapse shortly after the end of therapy. Thus pretreatment level of functioning may be an important predictor of immediate outcome, and posttherapy return to social and occupational activities may predict long-term outcome. Unfortunately, few studies have examined these effects specifically for functioning capacity, despite widespread assumptions of their truth.

Bolton and others (40) found no evidence to support their hypothesis that pretreatment social adjustment of adolescents treated with ERP would be related to long-term gains on OCD symptoms 9 to 14 years later. Their small sample, however, left them with little power to detect such relationships. In another study of 43 outpatients who received ERP for OCD (11,35), several measures of pretreatment social and work functioning were not consistently associated with follow-up outcome. On the other hand, when posttreatment functioning was used to predict relapse, poor work (or family) functioning reduced treatment gains independent of one’s mood. Surprisingly, assessment of social skills by patients and by close informants had no relationship to outcome in this outpatient sample, although some research has pointed to potential benefits of social skills training added to ERP for some patients (50). In view of the serious social skills deficits often seen in inpatient samples (23), findings about the influence of social skills on outcome might be different for an inpatient sample.

Family Burden Associated With OCD

Family Reactions to OCD

Most reports about the burden imposed by OCD symptoms on family life have been anecdotal. For example, one patient’s sister described a life in which her sister had confined herself to the family living room refusing to allow any family members or outsiders to enter for the past 4 years because of contamination fears. Urinating and defecating into tin cans to avoid using the toilet produced a “vile” odor. The sister had sought help, fearing eventual violence between her mother and sister, whom she described as very controlling. As several writers have noted, OCD symptoms often provoke family members to engage in illness-related behaviours that can dominate family life and provoke intense disagreements among family members about how to respond to the patient’s symptoms (19,51).

Coping with a family member with OCD appears to be quite different than coping with a family member’s physical illness. As Cooper noted, “Grief responses in OCD families are unique because their losses are partial and incomplete. The family member survives, but with marginal abilities and ongoing deterioration” (52, p 306). Marital discord, substance abuse, grief, depression, guilt, blame, and social stigma are anecdotally reported results of the stress that OCD puts on family members. At least moderate guilt in nearly half of family members has been reported (53,54), probably especially among parents who fear that their child-rearing practices may have contributed to the patient’s OCD. Saddled with the patient’s needs and feeling blamed and burdened, family members may withdraw from usual social activities and become increasingly isolated themselves.

Livingston-Van Noppen and colleagues (51) speculated about family responses to OC symptoms based on extensive clinical experience. They hypothesized that families fall on a continuum ranging from giving in and assisting in OCD symptoms to resistance and overt opposition. They proposed that “enmeshed” families lie on the accommodating end of the spectrum, showing a lack of boundaries, poor limit setting, and avoidance of conflict in an effort to keep peace and reduce the patient’s anxiety. “Antagonistic” families are rigid, demanding, intolerant of symptoms, and highly critical. “Split” families are inconsistent in their responses, with one family member antagonistic, while another may be understanding and indulgent. They proposed that most families fall in the middle of the continuum, responding in various ways depending on the OCD symptom severity and functional impairment, as well as their own level of anger and frustration. Regardless of the family response pattern, both patient and family often feel confused and anxious. Findings reported below provide some validation for this perspective.

Systematic investigations of the accommodation and burden experienced by families of patients with OCD have emerged in recent years. Calvocoressi and others (55) interviewed 37 patients with their family members and found that nearly one-third frequently reassured the patient, participated in the patient’s compulsive behaviours, and assumed responsibility for activities usually completed by the patient. Up to 40% of family members modified family activities to accommodate the patient. These activities were not associated with the severity of OCD symptoms (Freshman and others, unpublished observations), but appeared to be efforts to help manage the patient’s distress and anger, as evident from the moderate to severe anxiety and anger reactions shown by 40% of patients (54). Family involvement, however, also led to distress for nearly 60% of family members, which was associated with greater depression and anxiety in relatives (Freshman and others, unpublished observations). In a similar report, Shafran and others (53) obtained self-reported reactions of 98 family members (two-thirds spouses or partners and the remainder parents, children, or siblings) of volunteers who scored high on OCD symptoms, but may not have received this diagnosis. Of these relatives, nearly 60% were involved in conducting or observing rituals, such as checking and giving reassurance or in avoiding feared situations. Interestingly, 40% felt some responsibility for their relative’s difficulties. Only 10% of respondents described no interfer-
ence from the OCD in their lives, and 20% reported severe interference. Most family members wanted information, counselling, and discussion with other relatives of individuals with OCD.

Cooper (56) surveyed a large sample of 181 family members (50% parents and 32% spouses) of adults with OCD to identify symptoms that disturbed them, types of distress experienced, and resources sought by family members. The most troublesome symptoms causing the greatest concern, in descending order of frequency (expressed by 51% to 70%), were ruminations, unemployment, rituals, noncompliance with medication, depression and associated withdrawal from social and family contact, lack of motivation, and excessive arguing. Somewhat fewer family members (20% to 50%) expressed concern about manipulative behaviour, self-involvement, involving the family in rituals, inconsiderateness, collecting behaviours, poor handling of money, breaking things, and poor grooming. More than 80% reported personal disruption in the life of a family member who bore the main burden of care. Approximately half the sample reported “great” interference in family social activities leading to loss of friendships, marital discord, financial problems, and hardship on siblings. Among the concerns of these relatives were worry about who would care for the person with OCD when they could not, managing their own anger, and grief about the loss of functioning of the OCD family member.

A study in India also examined family burden for 30 patients with OCD (66% of family members were spouses), comparing findings with families of patients with dysthymia and generalized anxiety disorder (GAD) (25). Interviews with family members indicated that the greatest burden was felt for disruption in family routine and leisure activities, with lesser burden also felt for family interaction and financial matters. The degree of family burden was essentially comparable for the other patient groups. The most frequent problems reported for all groups are not dissimilar to those reported by Cooper (56) in an American sample: inconvenience because of the patient’s unemployment (57% of OCD patients were unemployed), lack of help with or disruption of housework, loss of leisure time, financial costs of treatment, neglect of children or other family members, and arguments. As in the Cooper study, the principal caregiver was the main sufferer, experiencing depression and worry about the patient’s future. Married women experienced more burden than other relatives.

These responses from family members clearly indicate that living with OCD often leads relatives to try to alleviate some of the patient’s fear and anxiety. It also results in feelings of frustration, anger, and guilt, as well as financial worries and loss of family social activity.

**Marital Relationships and OCD**

Research findings differ regarding whether marriages of patients with OCD are more distressed than nonclinical samples and whether this might be due to OCD symptoms specifically. Both European and American studies have indicated that approximately half of married OCD sufferers reported experiencing marital distress (57,58). Mean scores in several studies are somewhat below the normative cut-off scores on standard measures (15,37,42). At least one European study, however, has reported that OCD patients and their partners do not differ significantly from the general population in marital satisfaction (59). The frequency of dissatisfaction is similar to that reported for major depression (60), but considerably higher than the 20% of the general population rate reported for subjects with agoraphobia (61). According to research conducted in India, married patients sought treatment later than unmarried ones (16), perhaps because marriage provided emotional support that enabled some patients to delay therapy, or clients who were able to marry were less impaired or had less severe symptoms. Partly supporting this view, Riggs and others (42) demonstrated a link between marital distress and severity of OCD avoidance behaviour, though not with obsessions and compulsions per se.

**Family Functioning and OCD Symptoms**

Consistent with the previous comments, some research demonstrates that families with an OCD member have difficulty functioning effectively. Livingston-Van Noppen and others (51) asked each family member of 50 OCD patients to complete the Family Assessment Device (FAD), which measures problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control, and global functioning. Patients and family members generally agreed in their assessment of the family, and their scores were averaged consistent with other FAD research. In this sample, 61% of patients were living with a spouse or partner, and 39% of patients were living with parents. Compared with control families, families of OCD patients had a higher percentage of unhealthy scores on all dimensions of family function except communication. The worst scores were on affective responsiveness and roles, with problem solving and behaviour control also problematic. This study indicates that OCD often occurs in families with a significant degree of unhealthy functioning, and findings by Freshman and others (unpublished observations) link FAD-assessed affective responsiveness, behaviour control, and general functioning to relatives’ and patients’ depression and anxiety, but not to patients’ OCD symptoms.

There is some evidence that expressed emotion (EE), comprised of critical comments, hostility, and emotional over-involvement of relatives, may be applicable to understanding OCD and developing treatment approaches with patients and family members. Hibbs and colleagues (62) reported that 46% of fathers and 76% of mothers of 49 children with OCD symptoms exhibited high levels of EE, rates that were 2 to 3 times higher for parents of OCD children than for parents of nonpsychiatric controls. Parents with high EE ratings had more psychiatric diagnoses, as well as more family conflict and marital discord (62,63). Our own recent findings with an adult sample do not show a link between
pretreatment OCD symptoms and EE-relevant variables, but some aspects associated with EE appear to adversely affect treatment outcome at follow-up (Steketee and Chambless, unpublished observations).

Marital and Family Predictors of Treatment Outcome

Although published studies have not yet examined the effects on treatment outcome of continued accommodation to patient OC symptoms, a small amount of research does shed light on the effects of marital discord and the climate of the familial environment on treatment gains and maintenance. The paucity of available data may be due to the fact that many OCD patients are not married and etiological theories about OCD have not usually included interpersonal explanations. Marks (64) has suggested that the presence of serious marital problems is not a contradiction for ERP, an assertion that has been supported by studies in which improvement from ERP treatment did not depend upon pretreatment marital satisfaction (42,57). Furthermore, ERP improved OCD symptoms without provoking marital dissatisfaction in patients or partners (57) and also led to improved marital satisfaction. This research supports earlier findings on very small samples that exposure-based treatments for OCD and phobic conditions accompanied by marital distress improved both the anxiety targets and the marital problems (41). There appears to be little support to suggest that marital quality is pertinent to treatment outcome, although it is difficult to know whether this will hold true in cases where marital problems are severe.

Good pretreatment role functioning and communication within the family predicted more immediate gains in OCD symptoms, and role functioning also predicted outcome after one year (38). Steketee (11) reported that poor family functioning and household interactions characterized by anger and criticism, as reported by the patient before therapy, were associated with fewer benefits on OCD symptoms at 9-month follow-up. Emmelkamp, Kloek, and Blaauw (65) also observed that EE ratings at posttest, combined with avoidant coping style, life events, and daily hassles, significantly predicted relapse. Interestingly, in light of family treatment studies reported above, Emmelkamp and colleagues (65) recommended involving spouses or family members in empathic listening skills and communication training and employing group interventions particularly for the OCD clients who had problems with social interaction.

Family Involvement in Treatment

From the above predictors and models of family roles, it is reasonable to wonder what role family members might play in therapy. We refer mainly to behavioural therapy since medications do not routinely require family participation, except with regard to education about OCD, medication use, and compliance. Unfortunately, family participation in medication-based interventions has not been studied.

Support Groups

Several researchers have reported on the benefits of combined patient and family or family only support groups, which include psychoeducation about OCD and its treatment and support of group members (52,54,66). Family support groups offer social support and shared strategies for managing difficult problems, such as reassurance seeking and requests to participate in OC behaviours. Although no outcome data have been reported, satisfaction with such groups has been high.

Family-Assisted Treatment

Several researchers have examined the potential benefits of behaviour therapy that include family assistance. Efforts to reduce relatives’ involvement in OCD symptoms were applied in an inpatient treatment program that combined ERP with the training of relatives to monitor patient behaviour and encourage self-exposure in a noncritical manner (67). Forty-five patients, most of whom suffered from OCD, experienced a 45% decrease in symptoms at discharge, and 22 of the patients who were available at 6-month follow-up demonstrated a 60% reduction with concomitant improvement in functioning. Such gains constitute good success for this severe inpatient population who scored in the extreme range on disability from OCD symptoms.

Including family members has produced somewhat mixed results in larger controlled trials. Emmelkamp and colleagues’ 2 studies compared spouse assistance during ERP with individual behaviour therapy (57,68). Overall, spouse-aided exposure made no difference either after treatment or at follow-up, despite improvement in marital satisfaction in the spouse-aided group. Contrasting findings, however, were reported by Mehta (69) in India who compared 15 OCD patients who were assisted in exposure therapy by family members with 15 patients who received unassisted behaviour therapy. Patients aided by family members benefitted significantly more than the comparison group and were more likely to maintain their gains. Nonanxious, firm family members proved especially helpful. The discrepancy in these study findings could be due to the greater intensity of treatment in Mehta’s trial (24 sessions 2 times a week versus 8 sessions in 5 weeks), possibly, to fewer critical reactions to OCD symptoms, and, perhaps, to Mehta’s inclusion of family rather than only spouses in the therapy. It is apparent that more research is needed to determine whether family involvement in individual ERP treatment is useful and for which patients and families.

Van Noppen and colleagues (38) conducted a preliminary uncontrolled trial of the benefits of multiple family behavioural treatments (MFBT) that combined elements of family support groups and family-assisted behaviour therapy, which was described earlier. In vivo demonstrations of exposure and response prevention during group sessions were followed by homework assignments that required behavioural contracting between the patient and family members during group sessions. Nineteen patients and their families treated with MFBT experienced significant reductions in OC symptom severity.
and improvement in family functioning. A comparable group of patients, who received group ERP without family involvement, also benefitted on OC symptoms, but not on family variables. More of the MFBT patients were clinically significantly improved (scoring in the nonclinical range on OCD symptoms) at posttest (47%) and at one-year follow-up (58%) compared with group-treated patients (31% at posttest and 43% at follow-up). Poorer initial family role functioning and communication skills predicted less benefit on OC symptoms and more disability. Thus multiple family involvement in treatment produced positive outcomes that appeared comparable to, or better than, nonfamily ERP, but since the trial was not controlled, it is not clear that the benefits exceeded those from individual ERP.

Implications for Practice

The previously mentioned studies of disability, family burden, and family emotional and behavioural responses to OCD indicate a wide range of behaviours that encourage routine assessment of patients’ functioning capacities and of family involvement in symptoms and emotional reactions to the patient. There may be some benefit of including specific intervention efforts directed at occupational and social difficulties, if these are prominent problems for the patient, since such problems were particularly troublesome among OCD disabilities. Including family members in ERP and, possibly, in medication interventions may be advantageous to educate and advise family members about OCD symptoms, their effects on functioning, and how best to respond to the patient. This may be especially useful for families with extensive participation in OCD symptoms and for OCD patients whose marital and family relationships are seriously impaired. Very critical or hostile family members, however, may prove problematic in such treatments. Recent research on multifamily intervention makes this an attractive and potentially cost-effective alternative for clinical settings in which such groups can be mounted.

Clinical Implications

- OCD produces moderate to severe social and occupational disability, especially in severe and comorbid cases.
- Behavioural and pharmacological treatments improved functional capabilities to a moderate extent.
- Many family members extensively accommodate OCD symptoms, leading to family distress and negative mood.

Limitations

- Whether poorer functioning is associated with particular OCD symptom types is unknown.
- Few treatment studies assess outcome with respect to functional impairment.
- Family participation in behavioural treatment produced greater benefit in some studies but not in others.

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References


Résumé

Le présent article examine 2 aspects de la névrose obsessionnelle, à savoir les difficultés de fonctionnement et le fardeau familial associés à la névrose obsessionnelle. Ce dysfonctionnement ressort clairement des études épidémiologiques et cliniques menées dans plusieurs domaines, notamment sur l’inadaptation professionnelle et sociale. Les patients traités en externe présentent un éventail de dysfonctions associées à la névrose obsessionnelle, alors que les patients hospitalisés manifestent des incapacités graves qui rivaalisent avec celles des patients souffrant de schizophrénie. Bien que le niveau d’adaptation s’améliore chez les patients traités à l’aide de médicaments et par thérapie comportementale, une certaine dysfonction persiste, en particulier au niveau social et professionnel. Plusieurs études font état de la grande participation exigée des familles et de leur adaptation aux symptômes de la névrose obsessionnelle et reconnaissent l’énorme fardeau qui pèse sur les familles qui doivent réduire leurs activités sociales et chez qui l’isolement et la détresse augmentent. Les conclusions au sujet des liens entre la névrose obsessionnelle et les difficultés conjugales sont équivoques. Les prédicteurs de l’issue du traitement n’incluent pas l’insatisfaction conjugale, mais peuvent inclure la colère exprimée et la critique. En ce qui a trait au traitement, les groupes de soutien familiaux s’avèrent des interventions populaires, mais non éprouvées, alors que la thérapie comportementale individuelle et de groupe assistée par la famille ont donné de bons résultats lors d’essais limités.