A Review on Quality of Life and Depression in Obsessive-Compulsive Disorder

By Steffen Moritz, PhD

ABSTRACT

Quality of life (QoL) is increasingly recognized as a pivotal outcome parameter in research on obsessive-compulsive disorder (OCD). While the concept remains somewhat ill-defined, there is now little dispute that the patients' personal goals deserve foremost consideration during the course of treatment as the primary aim of treatment should be relief from individual despair, which is related but by no means synonymous to symptom reduction. Studies using generic (ie, illness-unspecific) instruments have confirmed poor QoL in OCD patients across a wide range of domains, especially with respect to social, work role functioning, and mental health aspects. Scores are sometimes as low as those obtained by patients with schizophrenia. Depression and obsessions are the symptom clusters that most strongly contribute to low QoL. Findings from a novel survey of 105 OCD participants point to multiple daily life problems, poor work status, and tense social networks in these patients. In order to achieve therapeutic success and improve QoL, functional problems at work and comorbid disorders such as secondary depression and physical impairments should be targeted. While successful treatment sometimes positively impacts well-being, in some studies symptom decline did not translate into improved QoL.

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Needs Assessment

Research on quality of life (QoL) is an important complement to conventional clinical exploration. It provides a subjective reality reflecting what matters to the patient and may be helpful for establishing a treatment hierarchy. QoL was found to be low in patients with obsessive-compulsive disorder (OCD) across various domains, most notably in mental health as well as in social and work functioning. This is corroborated by objective data on work and social status. Depression is the most frequent comorbid disorder and is present in one third to two thirds of OCD patients.

Learning Objectives

At the end of this activity, the participant should be able to:

- Define quality of life as it pertains to mental health.
- Describe the functional and social problems shared by many patients with OCD.

Target Audience: Psychiatrists

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INTRODUCTION

The Quality of life (QoL) construct has undergone a successful transition from being a mere catchword to its current role as a consensually acknowledged outcome parameter in treatment studies. While problems with defining QoL remain, the understanding that the patient is more than his or her symptoms has gained vast support over the years.[1] A comprehensive definition is provided by the World Health Organization (WHO), which describes QoL as the individual's perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. A common denominator of health-related QoL scales is the individual's perspective on multiple dimensions including functional (eg, work), physical, psychological, and social aspects.[2] As will be discussed more thoroughly below, expert-rated illness severity is related to QoL but does not represent a one-to-one reflection of subjective well-being in accordance with the *International Classification of Diseases*, 10th Edition definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."[3] To illustrate, while many patients in the obsessive-compulsive disorder (OCD) spectrum, especially those with cognitive compulsions (eg, counting, cognitive rituals) are seemingly inconspicuous and uncompromised in daily life, many of them are in fact severely troubled: The maintenance of a normal facade is achieved at the cost of great resistance and active avoidance of social and other activities, eventually leading to exhaustion. In contrast, some OCD spectrum patients who present severe and overt obsessive-compulsive symptoms are less impaired in their pursuit of happiness. For example, patients with obsessive personality disorder or hoarding compulsions often show relatively normal subjective well-being as the symptoms to some extent provide both a burden and a mission/meaning in life. Urge for change may therefore constitute an important variable in the equation.

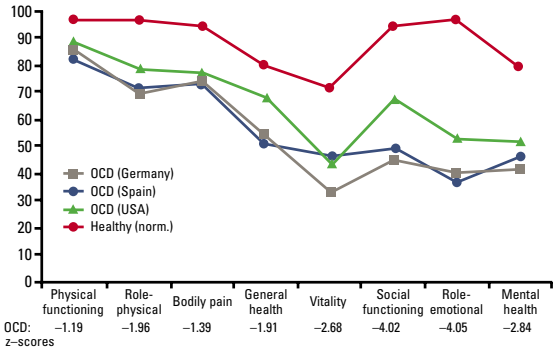
The first part of this review will deal with results from QoL studies in OCD using generic (illness-unspecific) instruments. These data will be complemented by objective data on the economic and social situation of OCD patients. The author will then turn to specific correlates and contributors to QoL in OCD. Subsequently, novel results will be presented from a survey conducted with 105 OCD patients, which was set up with the help of the German and Swiss Societies for Obsessive-Compulsive Disorders (DGZ, SGZ). The article closes with a section on major depression, the most prevalent comorbid disorder in OCD.

GENERIC QUALITY OF LIFE IN OCD

QoL in OCD has most often been assessed with the 36-Item Short Form (SF-36),[1] which was originally derived from the Medical Outcome Study.[4] It captures eight domains: physical functioning, role limitations due to physical health problems (role-physical), bodily pain, general health, vitality, social functioning, role limitations due to emotional problems (role-emotional), and mental health. The raw scores range from 0 to 100, with 0 representing the worst and 100 representing the best possible QoL status. The Figure compiles data from different QoL studies that will be addressed in more detail below. In recent years, some research on QoL also employed the WHO-QoL,[5] which is a short scale containing four subscales: physical, psychological, social, and environment.

The interest in QoL in OCD was sparked by a seminal paper published by Koran and colleagues[6] in 1996. With few exceptions, investigations on acute OCD populations have reported diminished scores on social and work-role functioning and mental health aspects of QoL.[6-9] In a study conducted by my group, Moritz and colleauges,[10] z-scores of the OCD sample were 2–4 standard deviations lower than those of a healthy subsample on the role-physical, general health, vitality, social functioning, role-emotional, and mental health subscales of the SF-36.

FIGURE.
Short Form-36 subscale scores for three OCD samples (US,[6] Spain,[9] Germany[10]) and a healthy sample (healthy participants of the German norm study[1])



z-scores refer to OCD patients of the German study.

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Unlike other studies, the results revealed diminished QoL scores on the physical well-being (z-score: -1.19) and bodily pain (z-score: -1.39; Figure) SF-36 subscales. For the three physical variables, two out of five patients showed impairments. Half to three-quarters of the OCD patients displayed marked decrements of QoL either at admission or discharge in the other SF-36 subscales. Conversely, a large OCD subgroup did not report problems with QoL which accords to data from Sorensen and colleagues.[11] Of the 219 patients with OCD participating in their survey, 36% asserted that they were satisfied or particularly satisfied with life.

Inconsistent data have emerged for physical well-being which likely reflects differences in choice of control subjects. For example, several studies compared OCD subjects against a normative SF-36 sample, which is older and also comprises patients with somatic problems. In any case, physical well-being seems to be less affected in OCD relative to other disorders.

Evidence asserting poor psychosocial QoL variables fits well with data indicating that one third[6,12] to >50%[13] of OCD patients do not have a partner, often due to their illness, or have problems in their partnership. According to Hollander and colleagues,[14] 62% have fewer friends or difficulty maintaining friendships. Low self-esteem is estimated in 92% of OCD patients.

Notwithstanding average to sometimes above-normal intellectual abilities in many patients, most of them either lack behind in their academic achievements[15] or are unemployed.[11,14] One third[16] to half of the patients[14] have problems fulfilling work duties. Confirming prior research,[17] a recent study[18] found that 38% of the sample were unable to work due to psychiatric reasons according to self-assessment, and 42% of these subjects received disability payments; the overall unemployment rate in the sample was 50%. Even more dramatic are the statistics provided by the aforementioned Danish study.[11] Here, only 43.4% of the participants were employed and ~4 out of 5 of those considered themselves impaired in their ability to work. Certainly, these figures are not universally true and are dependent on regional job opportunities and the national unemployment rate, which in several countries of the European Union is markedly higher than in the United States. For example, in a study conducted in the US,[6] only 15% of the patients were unemployed due to their psychiatric condition (self-report, entire rate: 22%) which, however, still considerably exceeded the overall unemployment rate of 6% at that time. Risk factors for occupational disability in patients were the severity of OCD and depression symptoms, as well as lifetime substance abuse.[6] The economic burden inflicted by OCD was estimated at $8.4 billion US in 1990,[19] whereby indirect costs (eg, work loss, early retirement) exceeded direct costs (eg, hospital care, medication) by far. Lifetime indirect costs due to lost wages were estimated as high as $40 billion in the US.[14]

Several studies compared QoL across different disorders. Traditionally, conditions formerly subsumed under the umbrella term "neuroses" are regarded as less grave and disabling than psychosis/schizophrenia. While the prognosis for OCD is indeed better than for schizophrenia and successful treatment frequently persists, in some studies QoL was comparable for OCD and schizophrenia patients for some aspects.[20] Stengler-Wenzke and colleagues[7] even reported decreased scores in OCD relative to a sizable sample of schizophrenia patients on two out of four QoL domains (psychological well-being and social relationships). Accordingly, lower scores in OCD patients relative schizophrenia patients on disease-unspecific symptom rating scales such as the Brief Psychiatric Rating Scale or the Global Clinical Impression should not mislead the clinician to assume less despair. Many symptoms are actively suppressed or denied because of embarrassment (eg, sexual intrusions, obsessions relating to the therapist) or fear of being misdiagnosed as psychotic. Relative to patients with post-traumatic stress disorder[21] but not to other anxiety disorders,[22] QoL in OCD is higher. In comparison to depression, results are equivocal.[6,8,9,23] When controlling for sociodemographic differences, patients with depression and OCD performed almost equal to depressed patients on mental health scales, but achieved elevated scores for general and physical health in one study.[6] Bobes and colleagues[20] found that OCD patients had lower scores on QoL than heroin addicts and this was also true for mental health related QoL when comparing OCD patients with patients suffering from somatic problems.

While the present article is primarily concerned with QoL in those afflicted with OCD, it should also be brought to the readers' attention that the disorder negatively impacts on the QoL of close relatives. A recent study[24] reported decreased QoL in relatives in three out of four measured domains which mirrors results from other psychiatric populations. Relatives of OCD patients face special burdens and daily hassles. Many relatives are actively involved in the patients' rituals and, for example, have to aid with cleaning and checking stoves or locks etc. They may also have to consistently reassure the patient

of various things—for example, that he/she has not committed a serious crime. Often they are forced to obey idiosyncratic rules. Negligence or failure to comply may result in aggressive outbursts. Koran[15] cites evidence that the burden on the family is comparable to that of major depression and schizophrenia. Integration of relatives in the treatment process is in many cases crucial to break the "OCD system."

CORRELATES OF POOR QUALITY OF LIFE IN OCD

An increasing body of research has turned to the correlation between QoL and depression, OCD symptom severity, and illness subtype (eg, washing, cleaning). Studies generally converge on the inference that depression is the best predictor of low QoL in OCD,[6,8,13,25,26] although some compromised QoL remains when controlling for depression.[6]

Evidence is less consistent regarding the impact of obsessions and compulsions on QoL. Compulsions, as the most striking feature of OCD to the outside observer, are strongly correlated with QoL in some studies[10,12,26] but not in others.[25] Compulsions have been found to promote physical exhaustion[10] and in the case of washing compulsions often result in secondary skin problems.[27,28] These are sometimes overlooked or misdiagnosed as neurodermatitis by practitioners. Many studies detected a substantial relationship with obsessions.[12,13,25] This comes as no surprise: Notwithstanding that OCD, unlike psychotic patients, acknowledge that their thoughts are absurd, aggressive impulses (eg, worry to harm one's own children) and fear of contamination (ie, fear of contaminating party guests with HIV by handshake even though the patient knows that this is scientifically impossible and that he is unlikely to be HIV-positive), in particular, are extremely bothersome. The aggressive interpersonal content and sometimes embarrassing sexual thoughts make it hard for many patients to disclose them even to significant others. Accordingly, one of the most fundamental positive experiences shared in OCD self-help groups is to learn that other persons are pre-occupied with similar thoughts, which reduces loneliness and estrangement.[29]

Apart from their content, the excessive length of many rituals and frequency of obsessive thoughts are troubling and decrease QoL. When remained untreated, compulsions in particular tend to worsen and prolong over time.[30] At a certain point compulsions cannot be kept secret anymore and cause conflicts at work (eg, due to obsessional slowness and checking compulsions), which in turn avalanche other problems. In our study,[10] washers were found to have poorer QoL relative to non-washers for the following domains: social functioning, general health, physical functioning, and role-emotional. In contrast, patients with checking compulsions showed lower QoL only for mental health and role-emotional aspects compared to non-checkers.

TREATMENT-RELATED QUALITY OF LIFE

A further important area of research explores QoL during the course of treatment. Conventionally, treatment success in OCD is defined as a symptom decline of at least 35%[31] on the Yale-Brown Obsessive Compulsive Scale (Y-BOCS), the gold standard for assessing the severity of OCD symptoms. Adopting this criterion, many patients clinically considered responders still display disabling symptoms at discharge. While some reviews report success rates up to 80%,[32] response rates may fall to as low as 50%[33-35] when drop-out rates are taken into account (eg, discharge against clinical advice). To achieve comprehensive treatment success, it is recommended to complement classical behavioral strategies such as response prevention treatment with cognitive approaches, for example association splitting.[36] For some patients, partial symptom reduction may allow them to re-participate in social life and pick up their former work. For others, however, a decreased but still marked symptomatic burden may bring little relief in everyday life.[37]

Tentative evidence suggests that QoL improves somewhat over the course of treatment.[23,38,39] Diefenbach and colleagues[37] investigated an OCD sample undergoing cognitive-behavioral therapy. They found symptom-correlated changes in QoL on social and family functioning. However, some increase in QoL seems to be independent of symptom improvement.[38] For example, Tenney and colleagues[39] found that responders and non-responders showed equal improvement in QoL which was interpreted as a "non-specific treatment effect." Likewise, our study[10] found improved QoL in all patients. Increments in QoL at discharge could not be reliably predicted by baseline characteristics. Responders exceeded non-responders only on the SF-36 vitality subscale. Another study[40] reported a decline of QoL at the follow-up period, despite continued symptom improvement, further suggesting that QoL is not directly tied to OCD symptom severity. Recently,[41] subsamples with heterogeneous outcome patterns were described as follows: a group exhibiting strong symptom reduction accompanied with very good QoL gains, a second group with significant symptom reduction but less robust QoL improvements, and a third group with limited symptom gains and

even decrements in QoL.

INTERNET SURVEY ON DAILY HASSLES AND DISTURBANCES RELATING TO OCD

While providing a valuable overview for global QoL, studies relying on generic QoL scales such as the SF-36 and the WHO-QoL are almost silent on disorder-related concerns of patients. To shed more light on specific problems in OCD, our group has undertaken an Internet survey for the purpose of this review. We deliberately chose an Internet survey over a conventional study for various reasons. Firstly, OCD is correctly nicknamed the "hidden disorder": A large group of patients does not speak openly about their problems and never seeks professional help. There is evidence that patients seeking treatment have a better prognosis per se and differ on some QoL aspects[42] from those who abstain from treatment, thus making it difficult to extrapolate from inpatients to the entire population. Second, while anonymous surveys have been criticized in terms of diagnostic reliability,[43] results are less distorted by confounding influences such as social desirability that hamper data obtained from direct interviews.

This survey was conducted with the help of the German as well as the Swiss Societies for Obsessive-Compulsive Disorders, and with the support of two other self-help forums. These forums are dedicated to knowledge translation and exchange among patients. A total of 105 patients with a reliable diagnosis of OCD took part in the survey (authenticity of diagnosis was confirmed with multiple criteria, several redundant questions were provided to affirm validity). Patients were asked to fill out the Y-BOCS in its self-report form (M=18.47, SD=6.90). Approximately two thirds of the participants were female (68%), and the mean age was 34 years (SD=11.49; range: 16–61 years). Items were compiled following discussions with experts in the field on common daily problems due to OCD. Cookies prevented ratings from being made more than once by the same person.

The Table shows the areas where patients reported the greatest problems (ie, endorsed by at least 40% of the participants). We also present the overall percentage of patients describing the problem as very or extremely bothersome. In accordance with the aforementioned sections, many patients reported impairments at work, mood disturbances, and problems relating to social relationships. In addition, more specific problems were disclosed. Many patients share financial problems, difficulty speaking about the illness with others, and feelings of shame. Sexual problems and interpersonal aggression/tensions also emerged as a result of the disorder. A subgroup of patients was also severely troubled by medication side effects. Concerning physical well-being, two out of five patients reported chapped hands because of excessive hand-washing (notably, as not all patients were washers, the figures for washers are likely higher). The main reasons not to talk to others about their disorder were fear of rejection (40%), shame (30%), and fear of being considered "mad" or "crazy" (37%) or dangerous (13%). A total of 21% endorsed that they are satisfied with their life despite having OCD, and another 42% affirmed that this was partially true.

Almost two thirds of the patients were worried that they might become "mad" or psychotic. While the fear of developing schizophrenia is in most cases unfounded according to longitudinal studies, the worry of being misdiagnosed as psychotic is not. Because many patients with schizophrenia display rituals reminiscent of OCD behavior, and some OCD patients show over-valued ideas that mimic delusional preoccupation, inexperienced clinicians sometimes confuse the two disorders. However, OCD symptoms are characterized by ego-dystonic thoughts. The ideas are regarded as strange, but patients usually acknowledge that these thoughts arise out of their own mind and are not inserted by an external source. Moreover, problems with ego boundaries (eg, thought broadcasting) and voice-hearing are not found in OCD. Even though some patients affirm that their obsessions share an acoustic quality, they are acknowledged as self-generated. Typical themes of delusions, such as the idea of persecution and self-reference, are not found in OCD.

DEPRESSION IN OCD

Depression is the most common comorbid disorder in OCD and the best predictor of low QoL in OCD according to most studies (see above). Between one third[44,45] and two thirds of OCD patients[46] are clinically depressed. Apter and colleagues[47] found that almost 50% of adolescent OCD patients display scores of >30 on the Beck Depression Inventory, which equates to very severe depression. The pathogenetic relationship between depression and OCD is complex and not yet fully elucidated. For example, obsessions and depressive symptoms are highly correlated[30] and OCD worries and depressive ruminations are often almost inseparable. While most depressive symptoms are secondary to OCD, the opposite, primary depression and later onset of OCD, have also been described. An older study[45]

estimated that 37% of their OCD sample showed secondary depression while 29% had OCD symptoms that followed a primary depression. Twenty-one percent did not suffer from depression and for 13% no decision was possible.

A recent factor analysis on a sample of OCD patients[48] has shown that depression, assessed with the Hamilton Rating Scale for Depression, falls into four dimensions: core depressive symptoms, sleep, anxiety, and somatic problems. In that study, aggressive obsessions were related to core depressive symptoms which is in line with earlier studies.[49] Anxiety symptoms were associated with excessive rituals. More than one third of all patients in this study displayed definite symptoms of depressed mood, and one third of these patients were severely compromised regarding work activities. Feelings of guilt are also very common and displayed by approximately one out of four OCD patients. Substantial genital symptoms, sleep problems (especially early insomnia), or general somatic complaints occurred in approximately one fifth of all patients. In that study, suicidal ideas were reported by only 2.5% of the patients, which is below the figures published by others who found suicidal ideation in half of the patients. Sorensen and colleagues[11] detected suicidal ideas even in as many as two thirds of their patients. This inconsistency could be due to methodological differences. Some patients choose not to disclose symptoms or concerns during a direct interview.

TABLE.
Results From an Internet Survey: Percentage of Everyday (Illness-Specific) Problems and Degree of Despair

	Yes (%)	*Rated as Very or Even Extremely Bothersome (% From Total)*
Life is hard due to OCD	96.2	68.6
I feel tired and exhausted	90.5	59.1
I cannot relax	78.1	27.6
I am often overpowered by strong feelings	78.1	28.6
I have problems talking to others about my illness	76.2	29.5
I believe something is not right with my brain	74.3	40
I conceal OCD at work	72.4	21.9
I am suspicious of other people	72.3	29.5
Pleasant activities are in many cases impossible due to OCD	70.5	49.6
My family suffers because of my OCD	68.6	34.3
I have left behind my possibilities	67.6	23.8
I am ashamed of being mentally ill	67.6	41
I feel as though I am a burden to others	64.8	35.3
I fear that I will become "mad"	63.8	37.2
I take medication	63.8	15.3
Compulsions occur frequently at work	61	29.5
I feel socially left out	61	33.3
I cannot concentrate at work because of OCD symptoms	60	23.8
I am often alone because of OCD	60	35.2
OCD leads to tensions in my partnership	59.1	33.3
I have little contact with other people due to OCD	58.1	32.4
I have sexual problems because of OCD	58.1	33.3
I involve my partner in rituals/OCD	56.2	25.7
I avoid body contact due to OCD	56.2	31.4
There are tensions if my partner/family does not participate in my OCD rituals	54.3	37.1
I am aggressive toward my partner/ family because of OCD	53.3	29.5
I have problems approaching other people	52.4	23.8
I have forgotten how to feel joy	51.4	27.6
I have high costs (eg, water, electricity) because of OCD	50.5	24.7
My partner/family say I have to pull myself together with regard to OCD	50.5	25.7
I am not able to manage household/ children by myself	49.5	23.8
I feel an inner distance toward friends	47.6	20.9
I cannot sleep due to obsessions	47.6	28.5
I suffer from medication side effects	45.7	20.9
I fear I may fail as a parent	41.9	21.9
I cannot make any enterprises due to OCD	41.9	26.6
I have chapped hands due to excessive washing	41	21.9
I cannot make longer journeys due to OCD	41	26.6
I have financial problems due to OCD	40	20.9

N=105 OCD patients.

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Estimates of actual suicide attempts have varied, ranging from 3%[6] to 10%,[47] 11%,[11] and 13%.[14] Somewhat counter-intuitively, one study[47] found that depression in OCD patients who had previously attempted suicide was lower than in those who had not.

The close relationship between QoL in OCD and depression mirrors results from other patient groups.[8] Depression, however, is not the only contributor to low QoL, and social functioning seems to remain impaired in OCD after controlling for depression.[6]

CONCLUSION

OCD patients display low QoL that in some studies matches or even falls below scores obtained from chronic and disabling conditions such as schizophrenia. QoL is most consistently associated with depression, a disorder which is present in ~50% of these patients. To a lesser degree, QoL correlates with obsessions, and in some studies also with compulsions. Our Internet survey shows that patients have multiple social and work-related problems associated with OCD. While our study mainly involved adults, similar problems have been reported among children and adolescents.[50]

Reasons for low QoL are multidimensional and may largely vary across subjects. Initiation of treatment is often started at a point in time where the illness has progressed and important resilience factors and resources (eg, social support and employment) have already been compromised. ***CNS***

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