

Editorial

Original version accepted in English

The importance of epidemiological studies on obsessive- compulsive disorder

Epidemiological studies are very important in Psychiatry, as they give a more comprehensive view of mental disorders, including their rates of prevalence and incidence, natural course, associated risk factors and health service requirements. Population-based studies, in contrast to clinical studies, evaluate all cases of the disorder within a specific population rather than only those who sought or were selected for treatment. It is well known that treatment-seeking behavior is influenced by a variety of factors, including demographic characteristics (age, sex, educational level, marital and occupational status and social class) and variables directly related to the disorders (duration, level of severity and incapacitation, types of symptoms, comorbidity, etc.)

For several reasons, reluctance to seek treatment is particularly important when we consider obsessive-compulsive disorder (OCD). Despite the fact that effective treatments are available, individuals suffering from this condition seek help from health professionals at a low rate,¹ even when it interferes significantly with their quality of life. Since most sufferers retain insight about the irrationality of their symptoms, OCD has long been considered a hidden problem. Many OCD sufferers consider their obsessive thoughts and compulsive rituals to be ridiculous or socially unacceptable. Therefore, they attempt, as much as possible, to conceal their symptoms, even from their families, and understandably, avoid seeking professional help. In the absence of professional advice, ignorance of treatment options is widespread.

As pointed out by Simonds and Elliot,² OCD patients may avoid talking about their symptoms for a variety of reasons. In addition to embarrassment or the fear of being negatively judged by others, they may also fear hospitalization or internment. They may believe that they would be considered insane or dangerous if they divulged thoughts of an aggressive or sexual nature. Furthermore, OCD patients may labor under the magical belief that telling someone else could cause the dreaded event to occur. Moreover, there is evidence that they reveal only the less disagreeable symptoms and hide the more eccentric or embarrassing ones. For example, ritual checking to prevent accidents may be considered more acceptable than washing to the point of self-harm or having homicidal thoughts towards loved ones. Concealment of OCD symptoms is therefore quite understandable but has significant consequences for treatment seeking and for prognosis.

Important population-based surveys conducted in the USA and Canada showed that only 34% to 37% of OCD sufferers had ever disclosed their symptoms to a doctor.¹ In clinical settings, the average delay in seeking treatment has been estimated at 11 years.² In addition to the inherent embarrassment, other factors may contribute to this delay. It is possible that some individuals with OCD wish to deal with the problem on their own, think that the

problem will resolve itself spontaneously, believe that no one can help, do not know how or where to seek treatment, or perceive financial difficulties as a barrier to treatment.² Fear of contamination or concern about drug side effects, as well as other obsessive thoughts, may also prevent some OCD sufferers from seeking treatment. Others may seek treatment indirectly, from dermatology clinics (for skin problems secondary to washing compulsions),² from general practitioners, or from infectious disease specialists (for repeated HIV tests, etc.), without disclosing the primary problem – their OCD. The general assumption that the most severe cases are under treatment is not necessarily true for OCD, since some individuals may be housebound by the condition itself or may lose their insight regarding their symptoms, reducing the probability of treatment acceptance. The chronicity of the condition also favors a frequently encountered situation in which, in order to avoid conflict, family members adjust to the symptoms and demands of the individual with OCD.

Another important characteristic of OCD, consistently reported in both clinical and epidemiological studies, is the high rate of comorbidity with other psychiatric conditions. Comorbidity can increase the likelihood of help seeking.¹ However, OCD sufferers may find it more acceptable to discuss other symptoms, such as depression, phobias, generalized anxiety and panic attacks, than to reveal their obsessions and compulsions. Therefore, although symptoms resulting from a related disorder may lead the patient to seek treatment, the primary ailment (OCD) may go undiagnosed. In fact, one study⁴ showed that there is marked underreporting of OCD symptoms in clinical settings. The authors found that, among 32 new patients with OCD, none reported obsessions and compulsions as their motivation for seeking treatment. Concealment of symptoms, in either the presence or absence of the confounding effects of such comorbidity, is but one of the barriers to effective recognition. Even when symptoms are reported, this does not guarantee that the disorder will be recognized, or that the patient will be properly treated or referred.² For example, one study,³ conducted in England, showed that 83% of OCD cases in primary care settings were either undiagnosed or misdiagnosed.

Worldwide, OCD is not a rare disorder, with an estimated point prevalence of approximately 1% and lifetime prevalence of 2%.⁵ It is also frequently chronic and disabling, causing much distress and having a considerable negative impact on the quality of life of the individual,¹ sometimes reaching a level of social impairment comparable to that seen in psychotic disorders. However, for the reasons previously mentioned, many OCD sufferers do not enter the health system or receive treatment from a mental health specialist. It is therefore unsurprising to find individuals within the community suffering from clinically significant but untreated OCD,² which can differ considerably from cases under treatment. Most epidemiological studies have shown that OCD rates are higher in women than in men, that it is not correlated with any level of education and that most sufferers have only obsessions and no compulsions.⁵ These findings are in conflict with those from clinical reports indicating that OCD afflicts both genders equally, that OCD sufferers have a high level of education, and that most of them present both obsessions and compulsions. Epidemiological

studies have also detected lower employment and marriage (or cohabitation) rates, as well as lower socioeconomic levels, among OCD sufferers – both in comparison to individuals without mental health problems and in comparison to those with other anxiety disorders. Comorbidity of OCD with substance use disorders also seems to be considerably higher within the community than among clinical cases.^{1,4} Nevertheless, most of our current knowledge regarding OCD is based on clinical samples, which are subject to important selection biases and are not representative of the entire OCD population. Therefore, well-conducted and representative epidemiological studies, involving large samples, play a crucial role in shedding more light on this serious, complex and underdiagnosed disorder.

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