



Original article

To what extent do clinical practice guidelines respond to the needs and preferences of patients diagnosed with obsessive–compulsive disorder?☆

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ABSTRACT

Introduction: The number of clinical practice guidelines (CPG) to help in making clinical decisions is increasing. However, there is currently a lack of CPG for obsessive–compulsive disorder that take into account the requirements and expectations of the patients.

Objective: The aim of the present study was to determine whether recommendations of the NICE guideline, “obsessive–compulsive disorder: core interventions in the treatment of obsessive–compulsive disorder and body dysmorphic disorder” agrees with the needs and preferences of patients diagnosed with OCD in the mental health service.

Material and method: Two focal groups were formed with a total of 12 participants. They were asked about the impact of the disorder in their lives, their experiences with the mental health services, their satisfaction with treatments, and about their psychological resources. Preferences and needs were compared with the recommendations of the guidelines, and to facilitate their analysis, they were classified into four topics: information, accessibility, treatments, and therapeutic relationship.

Results: The results showed a high agreement between recommendations and patients preferences, particularly as regards high-intensity psychological interventions. Some discrepancies included the lack of prior low-intensity psychological interventions in mental health service, and the difficulty of rapid access the professionals.

Conclusions: There is significant concordance between recommendations and patients preferences and demands, which are only partially responded to by the health services.

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¿En qué medida las guías de práctica clínica responden a las necesidades y preferencias de los usuarios diagnosticados de trastorno obsesivo compulsivo?

R E S U M E N

Palabras clave:

Guía de práctica clínica
Trastorno obsesivo compulsivo
Participación del paciente
Investigación cualitativa

Introducción: Para facilitar la toma de decisiones clínicas, están proliferando las guías de práctica clínica (GPC). Sin embargo, actualmente se carece de GPC para el trastorno obsesivo compulsivo (TOC) en las que se incluyan los requerimientos y las expectativas de los usuarios.

Objetivos: El objetivo del presente trabajo es conocer si las recomendaciones de la guía «Obsessive-compulsive disorder: core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder» del National Institute for Clinical Excellence (NICE) se corresponden con las necesidades y preferencias de un grupo de usuarios diagnosticados de TOC.

Métodos: Para ello, se conformaron 2 grupos focales con un total de 12 pacientes, a los que se preguntó sobre el impacto del TOC en sus vidas, su experiencia con los servicios de salud mental, la satisfacción con los tratamientos recibidos y los recursos personales de afrontamiento. Las preferencias y necesidades de los usuarios se compararon con las recomendaciones de la guía y, para facilitar su accesibilidad, se agruparon en 4 grandes áreas temáticas: información, accesibilidad, abordaje terapéutico y relación terapéutica.

Resultados: Se observó una alta correspondencia entre las recomendaciones y las preferencias de los usuarios; por ejemplo, respecto a las intervenciones psicológicas de alta intensidad. La escasez de intervenciones psicológicas de baja intensidad antes de acudir al servicio de salud mental o la dificultad para acceder a los profesionales son algunas de las experiencias narradas que discreparon con las recomendaciones de la guía y de las necesidades expresadas por este grupo de usuarios.

Conclusiones: Hay coincidencia entre las recomendaciones y las preferencias y necesidades de los usuarios; sin embargo, los servicios sanitarios responden a ellas parcialmente.

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Introduction

Obsessive-compulsive disorder (OCD) is mainly characterised by two elements. One is obsessions, recurrent and persistent thoughts or images that trigger intensely distressing feelings; the other is compulsions, defined as the different types of behaviour an individual engages in to attempt to get rid of or neutralise the obsessions. These obsessions and compulsions also greatly interfere in more than one area of the person's life.¹

The prevalence of OCD ranges from 1% to 2% of the population, and does not vary greatly from country to country.^{2,3} Onset is usually before the age of 25, generally in preadolescence.⁴

There are a number of difficulties in the approach to OCD. One is the variable nature of the symptoms from one person to another, making diagnosis difficult for primary care physicians. The person may also have comorbid conditions that very often mask the main problem.³ Moreover, it is common for sufferers to be embarrassed by their symptoms and they tend to hide it from people around them.^{5,6} All this contributes to a delay in diagnosis, with the consequent increase in the severity of the person's condition. It is therefore not surprising that OCD is considered as one of the potentially most debilitating mental disorders.

For OCD and other health problems which, because of their severity or prevalence require a more specific approach, the scientific healthcare community prepares clinical practice guidelines (CPG). Among other aspects, the CPGs include series of recommendations based on the available empirical evidence. To ensure that healthcare professionals and users follow and accept the recommendations, in the last 20 years there has been growing interest in encouraging the participation of users who suffer from the clinical problem in the preparation of the guidelines.^{7,8} The participation of users in the design of health services for chronic problems can make a key contribution, as it provides information on which aspects are essential for understanding new mechanisms to reduce complexity or strengthen the involvement of patients in looking after their own health.^{9,10} In fact, nowadays the quality and rigour of a set of guidelines are also measured according to who participated in their preparation.¹¹ With that in mind, the working group for this study developed a set of CPGs, in this case aimed at generalised anxiety disorder, in which we introduced the novelty of linking the guideline recommendations with testimonials from patients, gathered in a qualitative study, about their experiences with the healthcare system.¹² Other national health service mental health guidelines have also been put together involving patients.¹³

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