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Validation of the ICF Core Sets for schizophrenia from the perspective of psychiatrists: An international Delphi study

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ABSTRACT

Schizophrenia is a chronic mental illness associated with several functional impairments. The International Classification of Functioning, Disability and Health (ICF) Core Sets for schizophrenia are shortlists of ICF categories that are relevant for describing the functioning and disability of people suffering from schizophrenia. The aims of this study were to explore the content validity of these Core Sets from the perspective of psychiatrists and to identify — from this perspective and using the ICF framework – the most common problems of patients with schizophrenia. In a three-round survey using the Delphi technique, psychiatrists experienced in schizophrenia treatment were asked about the problems they commonly encounter in these patients. A total of 352 psychiatrists from 63 countries representing all six WHO regions responded to the first-round questionnaire, and 303 completed all three rounds (86% response rate). From the first-round responses, 7133 concepts were extracted and linked to 387 ICF categories and 35 personal factors. Of these, consensus (≥75% agreement) was reached for 91 ICF categories and 31 personal factors. Eighty-seven of the 97 ICF categories that form the Comprehensive ICF Core Set for schizophrenia were represented in this list. Only four of the categories for which consensus was reached do not feature in the Comprehensive Core Set. From the perspective of psychiatrists the content validity of the ICF Core Sets for schizophrenia was largely supported. This suggests that these Core Sets offer an effective framework for describing functioning and disability in individuals with schizophrenia.

1. Introduction

Schizophrenia is a chronic, disabling mental disorder involving symptoms such as delusions, hallucinations, disorganization of thought and neuropsychological impairment (American Psychiatric Association, 2013; World Health Organization, 2016). It is also associated with significant deficits in personal, social and occupational functioning (Kalin et al., 2015; Penadés et al., 2010; Tandberg et al., 2013). In fact, several studies have suggested that cognitive functioning and negative symptoms are the best predictors of functional outcomes, such as work skills, community activities and interpersonal functioning (Bowie and Harvey, 2006; Lepage et al., 2014; Ventura et al., 2015). Impairments in these areas vary widely from individual to individual, as well as in a given individual over the course of the disease (Karpouzian et al., 2016), and they are mediated by environmental and personal factors (Fett et al., 2011; Schennach et al., 2012). These impairments are strongly associated with limited performance of activities of daily living, restricted participation in social activities, and reduced quality of life (Hunter and Barry, 2012). Thus, the main long-term therapeutic goals in schizophrenia should go beyond symptoms and include improving patients' psychosocial functioning (Brissos et al., 2011; McGurk et al., 2007). Addressing all these aspects requires a multidisciplinary approach and a proper understanding of the patient's functioning and health status.

The International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001), and the integrated biopsychosocial model on which it is based, represent a comprehensive and universally accepted framework for describing functioning, disability and health in persons with all kinds of health conditions. According to the ICF, the problems associated with a disease may concern *Body functions* and *Body structures*, as well as *Activities and participation* in a person's life situation. All these problems are also modified by contextual factors such as *Environmental factors* and *Personal factors* (see Fig. 1). There is also a bidirectional and dynamic interaction between

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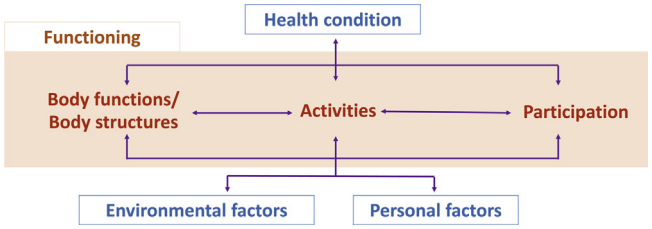

Fig. 1. Integrative biopsychosocial model of functioning and disability.

these components. In contrast to profession-specific guides, the common language of the ICF can be used by different professions and healthcare disciplines.

The ICF framework has given rise to different instruments for assessing functionality, notably the World Health Organization Disability Assessment Scale 2.0. (WHODAS 2.0; World Health Organization, 2010). The WHODAS 2.0 has been shown to be more informative than the Global Assessment of Functioning Scale (GAF) (Aas, 2010) when assessing functionality in people with mental disorder, and it is now used in conjunction with DSM-5. However, when applied to individuals suffering from schizophrenia, studies have shown that there are strong floor effects on several sub-scales of the WHODAS 2.0 (Guilera et al., 2012). These authors found that on sub-scales such as Self-care, more than 60% of patients obtained the best possible score (i.e., 0), and hence there is a restricted range. A more precise assessment of functionality in patients with schizophrenia therefore requires the use of measures specific to this health condition and which are able to discriminate between all levels of disability.

The whole ICF classification includes more than 1400 categories, making its implementation a major challenge for clinical practice. To facilitate its application, ICF Core Sets for several health conditions have been developed. An ICF Core Set (ICF-CS) is a selection of categories from the ICF that are considered essential for describing the functioning of a person living with a specific health condition. The Comprehensive ICF-CS for schizophrenia includes 97 categories covering the typical spectrum of problems in functioning of patients with schizophrenia (Gómez-Benito et al., 2017). The Brief ICF-CS for schizophrenia is a selection of 25 of these 97 categories, those regarded as the most important for the assessment and treatment of people with schizophrenia. These ICF-CSs for schizophrenia (https://www.icf-research-branch.org/icf-core-sets-projects2/mental-health/icf-core-set-for-schizophrenia) were developed following the methodology endorsed by the World Health Organization (WHO; Selb et al., 2015). Application of the ICF-CS for schizophrenia takes 30–45 min for the Comprehensive version and 10–15 min for the Brief version; the time needed depends ultimately on factors such as the professional's familiarity with the ICF and his/her knowledge of the history and state of the patient. However, a prerequisite for ICF-CS implementation in clinical practice is their validation from different perspectives. The objective of this study was therefore to examine the content validity of the ICF-CSs for schizophrenia from the perspective of psychiatrists, a key group of healthcare professionals in the treatment of patients with this health condition. More specifically, the aims were: 1) to gather the views of psychiatrists regarding the kinds of problems, personal characteristics/resources and features of the environment they commonly encounter when treating persons with schizophrenia; and 2) to analyze the extent to which these aspects are represented in the ICF-CSs for schizophrenia.

2. Method

A three-round, worldwide electronic-mail survey, based on a consensus-building Delphi method, was conducted. The Delphi method is a multistage process in which each stage builds on the results of the previous one, and where a series of rounds are used to both gather and provide information about a particular subject (Hasson et al., 2000). Its purpose is to gain consensus from a panel of individuals with knowledge of the topic being investigated (hereinafter, experts).

2.1. Recruitment of participants

Experts were defined as psychiatrists with at least two years' experience in the direct treatment of individuals with schizophrenia. No knowledge about the ICF was required to participate in the Delphi process. Experts who had already participated in an earlier stage of the development of the ICF-CS for schizophrenia were excluded.

Several strategies were used to recruit experts from around the world. International associations of psychiatrists, universities with healthcare professional training programs and hospitals were contacted. Literature searches, LinkedIn contacts and personal recommendations were also used. In order to avoid language barriers and to increase the representativeness and participation of experts from around the world, participation was possible in five languages: Chinese, English, French, Russian and Spanish. All the survey materials were translated and supervised by at least two independent native speakers.

The initial contact included an invitation to take part and a detailed description of the project targets, the Delphi process and the timeline. Demographic and professional data were also requested. A total of 7616 potential participants were initially contacted. Of these, 1002 (13.2%) agreed to participate, and 637 of them were psychiatrists eligible for this Delphi study. A final sample of 443 psychiatrists was selected using a purposeful sampling approach. In order to ensure proportional representation across the six WHO regions (i.e., Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific): first, all participants from Africa and Eastern Mediterranean were selected, and second, for the remaining WHO regions, psychiatrists were randomly selected considering maximum variation in terms of country and sex, and prioritizing those with more clinical experience.

2.2. Delphi process

The Delphi process and survey questions are shown in Fig. 2. Data collection lasted from April to June 2016, with participants being given two weeks to respond in each round. Three reminders were sent, one week before and two days before the deadline, and on the deadline day itself.

Responses in the first round of the Delphi process were collected through an online survey system (www.qualtrics.com). The selected experts received an e-mail with a link to the survey homepage and instructions, their task being to list all the aspects they considered to be relevant when assessing and/or treating individuals with schizophrenia. To facilitate this, they were asked six open-ended questions which covered all the ICF-CS components. The environmental factors component was divided into supportive and hindering factors (see Fig. 2). Responses were not limited in terms of word length. However, respondents were instructed to be brief and concise, and to avoid using abbreviations and vague technical terms. The experts were able to answer parts of the survey at different times, and the expected completion time for each survey round was about 15 min.

All the responses collected in the first round were then linked to ICF categories, and those reported by at least 5% of the experts were selected for inclusion in the second Delphi round. The ICF categories labelled 'other specified' and 'unspecified' were not included.

In the second Delphi round the experts who had responded in the first round received a list of the selected ICF categories linked to the responses of all the participants, as well as a summary of statements assigned as *Personal factors*. All the categories contained in the ICF-CSs for schizophrenia were presented, along with their respective definitions. Participants were asked to judge, for each category, whether they thought the category was relevant from the perspective of psychiatrists to the assessment and/or treatment of individuals with schizophrenia, taking into account that the final list should be as short as possible to be