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Review article

Quality of life instruments used in mental health research: Properties and utilization

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ABSTRACT

Quality of life (QoL) assessment is increasingly used in mental health. Multiple instruments exist, but the conditions for choosing one instrument over another for purposes of a specific study are not clear. We performed a systematic review to identify the QoL instruments used in mental health. The instruments were systematically described regarding their intrinsic properties (e.g., generic v. disease-specific) and their characteristics of utilization in studies (e.g., study objectives). Using cluster analyses, we investigated the existence of similar instruments with respect to each of these sets of characteristics and studied potential links between instruments' intrinsic properties and their characteristics of utilization. We included 149 studies in which 56 distinct instruments were used. Similarities were found among instruments in terms of their intrinsic properties as well as their characteristics of utilization, leading to the construction of four clusters of instruments in each case. However, no relevant links were identified between instruments' intrinsic properties and their characteristics of utilization, suggesting that the choice of QoL instruments did not depend on their properties. A consensus about common QoL instruments must be reached to facilitate the choice of instruments, the comparison of results and thus to have an impact on clinical and policy decision-making.

Contents

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1. Introduction

The concept of quality of life (QoL) is widely used as a complement and balance to survival time and symptom relief to account for the patient's point of view, particularly for chronic diseases requiring long-term care (Leplege and Hunt, 1997). While there is no consensus on a definition of QoL, the World Health Organization (WHO) has defined QoL as "individuals' perception 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" (WHO, 1997).

QoL assessment is currently used to support clinical and policy decision-making (Battista and Hodge, 1996) at both the macro- and micro-levels. At the macro-level, QoL instruments may be used in cost-of-illness studies (Segel, 2006) in order to quantify the overall burden of diseases as well as to inform resource allocation (Rice, 2000). At the micro-level, QoL may be used as an outcome in clinical trials, in health services research and in naturalistic population surveys (Basu, 2004) as well as for planning clinical care at the individual level (Katschnig, 2006) or for undertaking cost-utility analyses to determine population preferences (Guyatt et al., 1993).

Mental disorders are recognized as having a significant negative impact on QoL by generating disabilities and suffering over long periods of time (WHO, 2001). A wide range of instruments are used to measure QoL in the field of mental health. Several literature reviews of QoL measurement in patients with schizophrenia or bipolar disorders have highlighted the large number of distinct instruments used in this field (Awad et al., 1997; Pinikahana et al., 2002; Bobes et al., 2005; Michalak et al., 2005; Awad and Voruganti, 2012; IsHak et al., 2012). This may be partially due to the absence of a commonly accepted definition of QoL (Awad et al., 1997).

QoL instruments are made up of one or several questions that are grouped together in a number of domains that refer to the areas of behavior or experience assessed by the instruments (Guyatt et al., 1993). Contrary to some symptom or clinical outcomes based on an observer approach, QoL usually refers to what the respondent thinks about himself/herself (Basu, 2004). QoL instruments differ from each other in terms of aims and content. A first distinction may be made between generic and disease-specific instruments. Although the former can be applied across all populations, irrespective of the disease, the latter focus on particular issues associated with a particular disease or to a given nosographic domain (Fayers and Machin, 2007). A second distinction is whether the components included in an instrument are subjective, objective or both. The subjective components are usually associated with "well-being" or "life satisfaction" concerning different life areas, whereas the objective components focus on living conditions and social functioning (e.g., lodging, employment, finance) and are assessed by direct questions about these aspects of life (Barry and Zissi, 1997). Sometimes, objective assessment is also associated with additional evaluations performed by professionals, family members or friends (Katschnig, 2006). A third distinction may be made between instruments constructed as a single global question and those consisting of a number of items grouped into several domains depending on the area of behavior or experience that is being assessed (e.g., social functioning, physical health) (Guyatt et al., 1993). A final distinction is between the scoring methods: a summary score may be provided, including utility measures that reflect the population preferences, or the instrument may encompass multiple scores of one or several domains (Fayers and Machin, 2007).

In the field of mental health research, there does not appear to be a clear rationale for choosing a QoL instrument based on study objectives or common metrics that would facilitate comparison of results and data across studies, which may explain the lack of impact of QoL measurement on clinical care and policy decision-making (Awad and Voruganti, 2012). To our knowledge no study has surveyed the full range of QoL instruments used across all mental disorders and the way they have been used in mental health research. In the absence of common patterns in the use of QoL instruments, this information would provide key elements to researchers undertaking QoL studies so that they may more easily target the most adapted instrument.

Although many instruments appear to have similar characteristics, no studies have identified whether similar instrument clusters exist or whether potentially similar instruments are used in studies on similar populations sharing common objectives. Thus, the objectives of this paper were (1) to describe the QoL instruments used in mental health research in terms of their aims and content, which we refer to as intrinsic properties, and also in terms of their characteristics of utilization in studies; (2) to investigate the existence of similar instrument clusters with respect to each of these two sets of characteristics; (3) to study potential links between instruments' intrinsic properties and characteristics of utilization in studies.

2. Methods

We reviewed the QoL studies undertaken in the field of mental health and described the instruments in terms of their intrinsic properties and characteristics of utilization.

2.1. Data sources and search strategy

The literature search was conducted in the electronic databases Medline, PsyDoc, Embase and EURONHEED and covered the period from January 1995 to June 2013. We restricted our search to English- and French-language publications and used the following key words in Medline and Embase: 'quality of life' and 'mental health', 'mental disorders', 'behavioural disorders', 'psychiatry', 'schizophrenia', 'addiction', 'psychoactive substance', 'neurotic disorders', 'mood disorders', 'depression', 'anxiety', 'bipolar disorders', searched in titles, and 'measure', 'evaluation', 'cost', 'outcome', searched in titles and abstracts.

The Psydoc database is specific to the field of mental health, and thus we searched that database only on the term 'quality of life'. Similarly, we limited our search to the term 'mental disorders' in the EURONHEED database.

2.2. Inclusion and exclusion process

Titles and abstracts of articles were analyzed for eligibility. Articles were excluded if at least one of the inclusion criteria was not met (see below). Full texts of the articles retained at this stage were thoroughly examined and considered for inclusion if all of the following inclusion criteria were met: (1) QoL assessed through at least one identified instrument; (2) mental disorder diagnosis included in the chapter 'Mental and behavioural disorders' from the ICD-10, other than organic mental disorders (F00–F09), mental retardation (F70–F79) and disorders of psychological development (F80–F89), which were excluded because of the care specificities of these conditions; (3) participants older than 18 years; (4) studies undertaken in Europe, North America or Australia, geographical areas considered as having similar levels of development and culture. In addition, duplicate publications, literature reviews and articles validating or developing a measurement instrument were excluded.

2.3. Data extraction

From the selected articles, we extracted information related to both the instruments' intrinsic properties and their characteristics of utilization.