



Measuring quality of life in mental health: Are we asking the right questions?



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ABSTRACT

Measuring quality-adjusted-life years using generic preference-based quality of life measures is common practice when evaluating health interventions. However, there are concerns that measures in common use, such as the EQ-5D and SF-6D, focus overly on physical health and therefore may not be appropriate for measuring quality of life for people with mental health problems. The aim of this research was to identify the domains of quality of life that are important to people with mental health problems in order to assess the content validity of these generic measures. Qualitative semi-structured interviews were conducted with 19 people, recruited from UK mental health services, with a broad range of mental health problems at varying levels of severity. This complemented a previous systematic review and thematic synthesis of qualitative studies on the same topic. Seven domains important to quality of life for people with mental health problems were identified: well-being and ill-being; relationships and a sense of belonging; activity; self-perception; autonomy, hope and hopelessness; and physical health. These were consistent with the systematic review, with the addition of physical health as a domain, and revealed a differing emphasis on the positive and negative aspects of quality of life according to the severity of the mental health problems. We conclude that the content of existing generic preference-based measures of health do not cover this domain space well. Additionally, because people may experience substantial improvements in their quality of life without registering on the positive end of a quality of life scale, it is important that the full spectrum of negative through to positive aspects of each domain are included in any quality of life measure.

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1. Introduction

There has been a shift in mental health service policy from an emphasis on treatment focused on reducing symptoms, based on a narrow notion of pathology and illness, to a more holistic approach which takes into consideration well-being, recovery, social functioning, and quality of life (Hogan, 2003; Department of Health, 2011). A policy that more people attending mental health services will recover and have a good quality of life necessitates that appropriate outcome measures are in place. However few such measures are standardised and routinely collected across mental health services (Department of Health, 2011).

A review of eleven instruments for measuring quality of life for people with severe mental illness identified that the most commonly assessed domains are employment or work, health,

leisure, living situation, and relationships (Van Nieuwenhuizen et al., 2011). However, concerns have been raised regarding the relative importance of the domains measured in such instruments (Dolan et al., 2008; Eack and Newhill, 2007).

At the same time there has also been a growing need for the economic evaluation of mental health services. This has resulted in an increased use of generic preference-based quality of life measures, such as EQ-5D (which measures mobility, self-care, usual activities, pain/discomfort and anxiety/depression) and the SF-6D (which measures physical functioning, role limitation, social functioning, pain, mental health and vitality). These measures are also used to estimate a score representing the health related quality of life. This is calculated on a scale where full health is one and states as bad as being dead is zero in order to calculate Quality Adjusted Life Years (QALYs; Dolan, 1997; Brazier et al., 2002). However, there is evidence that these generic measures may not be appropriate for people with the most severe mental health problems, particularly in psychosis (Papaionnou et al., 2011) and bi-polar disorder

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(Papaionnou et al., 2013; Hastrup et al., 2011) and there is limited evidence about their appropriateness for people with anxiety and personality disorder (Brazier et al., 2014). Some argue that these measures have been designed primarily for use within physical illness and thus place disproportionate importance on pain and disability rather than mental health (Saarni et al., 2010).

Quality of life measures have also been criticised for being generated from the perspective of mental health professionals rather than considering what individuals with mental health problems perceive to be important to their quality of life. It is recognised that the views of health service users should play a central role in the development and testing of patient reported outcome measures (US Department of Health and Human Services Food and Drug Administration, 2009).

As part of a wider study to explore the appropriateness of generic preference based measures for people with mental health problems (Brazier et al., 2014) we conducted a systematic review of qualitative research of the meaning of quality of life for people with mental health problems (Connell et al., 2012). We identified six domains of quality of life: well-being and ill-being; control, autonomy and choice; self-perception; belonging; activity; and hope and hopelessness. One limitation of the review was that available studies focused on quality of life of people with severe and enduring mental health problems, particularly schizophrenia. To complement the review we undertook primary research with people with severe and enduring mental health problems and mild-to moderate common mental health problems. This allowed us to explore the extent to which the review addressed important aspects of quality of life for those with severe mental health problems, given that most concerns have been expressed about the appropriateness of preference based measures in this group, and also address a gap in the current evidence base around the views of people with less severe problems.

2. Method

We undertook a qualitative study of face to face semi-structured interviews with current users of mental health services.

2.1. Recruitment

Participants were recruited from three National Health Service (NHS) mental health providers in a city in the north of England, UK. One primary care service provided psychological therapies for those with mild to moderate depression and anxiety (Improving Access to Psychological Therapies – IAPT). The other two specialist psychiatric services were for those with more severe problems (Community Mental Health Teams – CMHT), one working with individuals with severe and complex non-psychotic disorders (e.g. severe depression, post-traumatic stress disorder, personality disorder) and the other psychotic disorders (e.g. schizophrenia, bipolar disorder). Recruitment was undertaken by service providers who applied wide inclusion criteria in order to capture as broad a range of mental health problems as possible. Exclusions included people experiencing acute episodes of their mental health condition, those not well enough to take part, where there was a known recent forensic history, and those who could not speak English or give consent. Further details on recruitment procedures can be found in Brazier et al. (2014). Approval for the research procedures was given by the local Research Ethics Committee, ref 10/H1308/11 and local NHS Research Governance, ref ZM03.

The services recruited 21 people to take part in the research and 17 were subsequently interviewed (two could not be contacted, one cancelled due to illness and one did not attend the arranged interview). Nine were recruited from the service for those with

Table 1
Research participants.

	Gender	Age range	Relationship status	Recruited from	Problem/diagnosis disclosed by participant
1	F	40–49	Married	CMHT	Depression/eating disorder
2	M	20–29	Married	IAPT	Anxiety
3	M	40–49	Separated	IAPT	Depression/anger
4	M	40–49	Single	CMHT	Depression/anxiety
5	F	50–59	Married	CMHT	Depression/anxiety
6	M	60–69	Single	Other	Schizophrenia/depression
7	M	40–49	Married	CMHT	Depression
8	F	40–49	Widowed	CMHT	PTSD/depression/anxiety/agoraphobia
9	F	50–59	Divorced	IAPT	Depression
10	M	40–49	Divorced	IAPT	Anxiety/agoraphobia
11	F	30–39	Separated	IAPT	Depression/anxiety
12	F	30–39	Single	IAPT	Depression
13	F	30–39	Single	CMHT	Depression/personality disorder/social anxiety
14	M	30–39	Single	CMHT	Schizo-affective disorder
15	M	50–59	Single	IAPT	Depression
16	M	30–39	Single	CMHT	Schizophrenia/depression
17	M	50–59	Single	Other	Schizophrenia
18	M	60–69	Married	IAPT	Depression
19	M	40–49	Separated	IAPT	Depression

CMHT – Community Mental Health Team – severe mental health problems.
IAPT – Increasing Access to Psychological Therapies – mild to moderate mental health problems.
Other – Recruited via participant.

mild to moderate problems and eight from the two services for those with more severe problems. A further two participants diagnosed with schizophrenia were recruited by one of the participants subsequent to their own interview.

2.2. Interviews

All 19 participants were interviewed Sept–Nov 2010 by the first author, a mental health researcher with a background in behavioural sciences, mental health service evaluation and outcome measure development. The researcher had previous experience of interviewing people with mental health problems and had also undertaken training on qualitative methods at a leading centre of social research in the UK. The interviews were semi-structured with the use of a topic guide to ensure that a common set of questions were asked. The topic guide was based on the synthesis of the systematic review of qualitative research (Connell et al., 2012). The first part of the interview aimed to elicit what was important to quality of life from the perspective of the individual, without any prompts. They were asked general open ended questions about what affected their quality of life both from a positive and negative perspective, what they enjoyed and why, what they would most like to change, what helped, and what was stopping them doing what they wanted to do. Once their own perceptions had been thoroughly explored the interviewer introduced concepts from the systematic review (Connell et al., 2012) or were included in the EQ-5D or SF-36. These were raised only if they had not already been discussed in the interview and included questions about the relative importance or effect on their quality of life of relationships, support, stigma, work, leisure activities, mental health symptoms and relative affects, medication and side effects, physical health/pain, energy/motivation, self-esteem/confidence, mental health services/workers, finances.

All the interviews were tape recorded apart from one, at the request of the interviewee, where notes were taken; one further interview was recorded but accidentally deleted so notes for this interview were made three days after the interview took place. The interviews lasted between 25 min and 1 h 50 min, averaging

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