

ARTICLE

Service users' perceptions of quality of life measurement in psychiatry

Jan Wallcraft

Jan Wallcraft is a Visiting Fellow for the Centre for Mental Health Recovery, University of Hertfordshire and the Centre for Excellence in Interdisciplinary Mental Health, University of Birmingham, both UK. Her research interests include service user involvement, recovery and crisis alternatives.

Correspondence Dr Jan Wallcraft, School of Social Policy, University of Birmingham, Edgbaston, Birmingham B15 2TT, UK. Email: janet.wallcraft@yahoo.co.uk

SUMMARY

This article describes the concept of quality of life (QoL) as applied to mental health. It also outlines relevant tools for measuring QoL, both generic and health-specific, and explains their approaches and purposes. These tools are intended to enable researchers to ask questions that are more patient-centred and psychosocial than traditional clinical measures for evaluating outcomes of treatment. However, a number of studies have criticised existing QoL tools in terms of their sensitivity to change and their relevance to mental health patients' concerns. Studies have shown that patients can give accurate self-reports even when ill. Given that government and professional policies favour effective service user involvement and routine outcome monitoring, more effort should be made to develop measures in partnership with service users, as this might better reflect individual priorities in assessment of quality of life.

DECLARATION OF INTEREST

None.

Quality of life (QoL) measurement is now found in most aspects of health research, including mental health. It is intended to ensure a more psychosocial, patient-friendly approach to measuring and evaluating healthcare treatments and outcomes than the usual clinical outcome measures. The latter include the Health of the Nation Outcome Scales (HoNOS), which measure 'clinical problems and social dysfunctions' (Wing 1998) as observed by professionals, not as experienced by patients.

The development of QoL measures

UK mental health policy continues to emphasise the routine measurement of outcomes as a means of enabling a more systematic approach to improving quality of care. However, I think that clinicians remain as reluctant to integrate outcome measurement into their practice as they were over a decade ago (Gilbody 2002), perhaps for one of the reasons that Gilbody *et al* suggested: the continuing lack of evidence of the value of the available measures.

This article addresses QoL measurement only, not the wider range of outcome measures in use, such as, for example, the Mental Health Recovery Star (Mental Health Providers Forum 2008). Quality of life is a descriptive term for people's emotional, social and physical well-being, and their ability to function in carrying out the ordinary tasks of living. The World Health Organization (WHO) has developed an international QoL measure (WHOQOL-BREF; Box 1) and define QoL as:

'An individual's 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.' (WHOQOL Group 1994)

Ruggeri *et al* (2001) say that whereas the WHO definition is subjective, other QoL constructs include objective indicators of health, housing and other material circumstances.

Basu (2004) traces concepts of QoL in medicine to the early 1960s, with major work on developing systems of QoL measurement from the 1980s onwards, including mental health-specific measures.

The QoL concept can enable systematic investigation of the social, emotional and physical effects of illnesses and treatments on people's daily lives, from objective and subjective perspectives. In theory, well-constructed, reliable, valid and responsive QoL measures can help doctors and healthcare providers, families and patients, to choose between different treatment approaches and monitor outcomes. The reality may not match the theory, particularly from the perspective of service users.

In their selective literature review of studies of QoL in severe mental illness, Holloway & Carson (2002) list four focuses of investigation:

- 1 objective life circumstances
- 2 the individual's subjective appraisal of their life
- 3 overall health status (health-related quality of life: HRQoL)
- 4 health economics.

The second and third approaches are of concern in this article. Objective measures of QoL are generally

integrated with subjective measures in tools developed since the 1980s and the health-economic approach (e.g. quality-adjusted life-years, or QALYs) is not covered here. It should be distinguished from measures of QoL.

This article traces some of the controversies and questions arising in the past 30 years of QoL measurement from a service user perspective.

Theoretical basis for QoL

It is difficult and controversial to define and measure quality of life, an essentially subjective and personal matter. The contested area of mental health and illness presents particular problems, such as whose values are these measurements based on, and what is being measured, by whom and for whom?

One of the problems with QoL measurement in mental health is the lack of an overt theoretical basis. This is particularly true of the health-related and disease-specific QoL measures:

'The lack of a widely agreed definition of health related quality of life means that many existing measures do not have any underlying theoretical conceptualisation of quality of life.' (Carr 2001)

Barry & Zissi (1997) similarly critique the lack of attention to methodological and theoretical issues in QoL studies:

'The assumptions underlying current measures of quality of life need to be critically examined as the results obtained are undoubtedly influenced by how researchers have approached the measurement of the concept ... assessing quality of life implies making a judgement of a relative kind, and this begs the question of what frame of reference should be used, an individualistic or normative viewpoint.'

QoL and HRQoL in mental health

According to Barry & Zissi (1997), the first large-scale mental health QoL studies were carried out in the USA, in the context of the transition to community care. Lehman *et al* (1982) linked objective domains with a subjective approach, developing the Quality of Life Interview (QoLI), a structured self-report tool. It contains a global measure of life satisfaction, plus measures of objective and subjective quality of life in the domains of living situation, daily activities, family and social relations, finances, work and school, legal and safety issues, and health. Information was obtained from respondents about their objective quality of life and then about their level of satisfaction in each life area, pairing objective and subjective results for each person.

Many QoL mental health measures, for example the Oregon Quality of Life Questionnaire (Bigelow 1991), the Lancashire Quality of Life Profile (Oliver 1997) and Manchester Short Assessment of Quality of Life (Priebe 1999) were influenced by Lehman's work. They are close in spirit to generic QoL measurements such as WHOQOL (WHOQOL Group 1994), although they are adapted for mental health and are often used alongside other measures.

Holloway & Carson (2002) describe this QoL approach as containing three domains: (1) personal characteristics, (2) objective life conditions and (3) subjective appraisal of life; and examining the impact of these on the global quality of life of the person or group. One aim of this approach is to find out how mental health services can improve people's well-being as they move from institutional to community living.

BOX 1 Individuals' assessment of their position in life using the WHOQOL-BREF

- | | |
|--|---|
| 1 How would you rate your quality of life? | 14 To what extent do you have the opportunity for leisure activities? |
| 2 How satisfied are you with your health? | 15 How well are you able to get around? |
| 3 To what extent do you feel that physical pain prevents you from doing what you need to do? | 16 How satisfied are you with your sleep? |
| 4 How much do you need any medical treatment to function in your daily life? | 17 How satisfied are you with your ability to perform your daily living activities? |
| 5 How much do you enjoy life? | 18 How satisfied are you with your capacity for work? |
| 6 To what extent do you feel your life to be meaningful? | 19 How satisfied are you with yourself? |
| 7 How well are you able to concentrate? | 20 How satisfied are you with your personal relationships? |
| 8 How safe do you feel in your daily life? | 21 How satisfied are you with your sex life? |
| 9 How healthy is your physical environment? | 22 How satisfied are you with the support you get from your friends? |
| 10 Do you have enough energy for everyday life? | 23 How satisfied are you with the conditions of your living place? |
| 11 Are you able to accept your bodily appearance? | 24 How satisfied are you with your access to health services? |
| 12 Have you enough money to meet your needs? | 25 How satisfied are you with your transport? |
| 13 How available to you is the information that you need in your day-to-day life? | 26 How often do you have negative feelings such as blue mood, despair, anxiety, depression? |

(WHOQOL Group 1994)

The HRQoL approach takes the generic concept of QoL and adapts it to specific questions of disease. Lehman (1996) describes the purpose of one such HRQoL-type scale for schizophrenia as to assess the negative symptoms of schizophrenia and therefore not belonging to mainstream QoL measures. Holloway & Carson (2002) describe the HRQoL approach as containing the domains of: (1) psychosocial performance, (2) side-effects of medication and (3) symptoms; and assessing the impact of these on the global quality of life of the person or group.

HRQoL tools

The use of HRQoL tools enables clinical researchers to ask about psychosocial issues such as income, environment and freedom. Guyatt *et al* (1993) say that HRQoL is important for measuring the impact of chronic disease, providing a way for patients' concerns to come into the clinical picture and helping to explain different responses to treatment between patients with the same clinical criteria. They also refer to the role of HRQoL in funding issues:

'Administrators are particularly interested in HRQL because the case mix of patients affects use and expenditure patterns, because increasing efforts exist to incorporate HRQLs as measures of the quality of care and of clinical effectiveness, and because payers are beginning to use HRQL information in reimbursement decisions.'

Differences in health-related quality of life between groups of patients at a point in time or longitudinal changes for individual patients over a set period can be studied using HRQoL questionnaires. Some tools focus on people with mental illnesses generally, others on specific illnesses, such as depression, bipolar disorder or schizophrenia.

Comparisons of patients' well-being with that of non-patients can be made using QoL measures but HRQoL measures are only relevant to patient populations.

Applying the QoL approach in mental health

Lancashire Quality of Life Profile

The Lancashire Quality of Life Profile (Oliver 1997) is typical of the generic QoL approach in mental health. This schedule (based on Lehman *et al*'s Quality of Life Interview) provides objective and subjective ratings of QoL across a range of domains (Box 2). Subjective QoL is measured by asking service users to rate their satisfaction with each separate life domain on a 7-point Likert scale:

- 1 Can't be worse
- 2 Displeased
- 3 Mostly dissatisfied

- 4 Mixed feelings
- 5 Mostly satisfied
- 6 Pleased
- 7 Can't be better.

An average subjective QoL score across the domains can be calculated. Service users are also asked to make a mark on Cantril's Ladder (Cantril 1965), that is, where they would put their life at the present time, with the top of ten steps considered as the optimum and the bottom the very worst outcome they could have expected. The Lancashire Quality of Life Profile also uses Bradburn's Affect Balance Scale (Bradburn 1969) and Rosenberg's self-esteem scale (Rosenberg 1965).

Manchester Short Assessment of Quality of Life

A shortened form of the Lancashire Quality of Life Profile is the Manchester Short Assessment of Quality of Life (MANSA; Priebe 1999), taking only 3–5 minutes instead of 30, while retaining similar properties of validity. The authors state that, like its predecessor:

'All questions allow comparisons with the general population, and are not specifically illness or symptom related. If in research or routine evaluation the interest is in more specific symptom-related measures, other scales should be used in addition to or instead of the MANSA.'

Priebe *et al* also point out that 'mean satisfaction scores from use of MANSA may serve as non-specific outcome criterion' and that 'satisfaction ratings with single life domains should be used for testing domain specific and a priori stated hypotheses, and for generating such hypotheses if mean scores reveal significant differences'.

Quality of life and schizophrenia

A literature review of quality of life in patients with schizophrenia (Pinikahana 2002) looked at studies from 1995 to 2000, most of which appear to have

BOX 2 Life domains rated in the Lancashire Quality of Life Profile

- Work/education
- Leisure/participation
- Religion
- Finances
- Living situation
- Legal status and safety
- Family relations
- Social relations
- Health

(Oliver 1997)

used QoL (not HRQoL) measures such as the Lancashire Quality of Life Profile and the Lehman *et al* Quality of Life Interview. They note conceptual and methodological problems such as lack of a consensus definition of the concept, variability of instruments and difficulties in interpretation of findings. However, they argue that their article presents 'an extensive review of the factors affecting QoL for patients diagnosed with schizophrenia'.

Another key limitation of the QoL approach, as noted by several authors (Barry 1997; Khatri 2001; Holloway 2002; Basu 2004), is that subjective QoL, especially for people with schizophrenia, poorly reflects changes in objective QoL. Barry & Zissi (1997) ask:

'[do] states of well-being ... in fact have clear-cut objective counterparts, i.e. is satisfaction with social relations necessarily determined by the frequency of social contact? It may be that in order to reflect individual values, subjective measures of quality of life need to expand beyond the standard list of aspects of life deemed to be important by societal values ... to also include more individualistic determinants of life quality.'

Holloway & Carson (2002) conclude that the QoL approach focuses on 'the "nomothetic" (attempts to develop general laws governing the determinants of QoL and how to improve it) at the expense of the "idiographic" (concern with the individual and pertaining to the unique facts and processes that impact on their QoL)', which they regret since QoL 'is at root an individual matter'.

Applying the HRQoL approach in mental health

SF-36

The large-scale Medical Outcomes Study (MOS) in the USA provided a model for HRQoL, developing widely used tools such as the SF-36 (Ware 1992). This is a general health measure, meant to be comprehensive but easy and practical to use, including concepts widely used in health surveys, such as physical, social and role functioning, mental health and general perceptions of health.

The SF-36 includes a 5-item mental health scale with items from each of the four major mental health dimensions (anxiety, depression, loss of behavioural or emotional control and psychological well-being).

SF-20

Spitzer *et al* (1995) carried out a major HRQoL study of primary care patients with mental disorders using the general health measure SF-20 from the Medical Outcomes Study. They studied 1000 patients, finding substantial impairment of HRQoL in patients with depression and significant

impairment in patients with anxiety and eating disorders, although arguably the causal mechanism could work either way. The authors say that their study shows the value of widespread screening for mental disorders. Mental disorders were shown to account for a large proportion of HRQoL impairment in primary care patients.

Schizophrenia Quality of Life Scale

Wilkinson *et al* (2000) developed a 30-item self-report QoL measure (Schizophrenia Quality of Life Scale; SQLS), comparable to SF-36 but specific to schizophrenia (Box 3). It is based on semi-structured interviews with patients with schizophrenia. The authors claim that the measure is a valid and feasible self-completion questionnaire addressing the perceptions and concerns of people with schizophrenia; they do not claim that it can address all patient concerns or replace conventional outcome measures.

Quality of life and bipolar disorder

A 2005 literature review of QoL in bipolar disorder (Michalak 2005) found an increase in HRQoL studies relating to the disorder since 1999 when there were few. The instruments were often based on the Medical Outcomes Study range of measures, including SF-36, and the authors recommend this scale and the WHOQOL-BREF. No disease-specific QoL measures for bipolar disorder were identified. The authors point out, however, that existing QoL measures 'may be insensitive to some of the unique problems posed by this complex psychiatric

BOX 3 Statements in the Schizophrenia Quality of Life Scale

- | | |
|--|--|
| 1 I lack the energy to do things | 16 I find it hard to concentrate |
| 2 I am bothered by my shaking/trembling | 17 I tend to stay at home |
| 3 I feel unsteady walking | 18 I find it difficult to mix with people |
| 4 I feel angry | 19 I feel down and depressed |
| 5 I am troubled by a dry mouth | 20 I feel that I can cope |
| 6 I can't be bothered to do things | 21 My vision is blurred |
| 7 I worry about my future | 22 I feel very mixed up and unsure of myself |
| 8 I feel lonely | 23 My sleep is disturbed |
| 9 I feel hopeless | 24 My feelings go up and down |
| 10 My muscles get stiff | 25 I get muscle twitches |
| 11 I feel very jumpy and edgy | 26 I am concerned that I won't get better |
| 12 I am able to carry out my day-to-day activities | 27 I worry about things |
| 13 I take part in enjoyable activities | 28 I feel that people tend to avoid me |
| 14 I take things people say the wrong way | 29 I get upset thinking about the past |
| 15 I like to plan ahead | 30 I get dizzy spells |

(Wilkinson 2000, with permission)

condition' and suggest that a disease-specific instrument be developed, based on individual qualitative interviews and focus group work with patients and families.

HRQoL and schizophrenia

The authors of a small, grounded-theory HRQoL study of schizophrenia (Gee 2003) describe the role of this type of measurement as a subjective 'biopsychosocial patient perspective' parallel to current multidisciplinary intervention methods. However, they point out that most questionnaires in schizophrenia were not developed from a qualitative patient perspective but from the perspectives of mental health professionals, whereas generic health measures are framed in too general a manner to establish the reasons for life problems (e.g. not leaving the house) and do not assess the experience of such problems for the individual:

'Development of HRQoL measurement in schizophrenia should be from a bottom up perspective, starting with qualitative interviews with schizophrenic people. This is at odds with the majority of current methodologies, which mainly apply HRQoL measures developed from a top down perspective using judgements from people other than the patient population.'

The authors used open-ended interviews to explore the issues that mattered to people with schizophrenia and used the analysis to identify ten HRQoL domains (Box 4). They offer the study as a starting point for development of a HRQoL more relevant to people with schizophrenia and suggest further research towards this using their ten domains. Such a survey, they suggest, would have the advantage of using participants' own language, making the questions more acceptable and having additional resonance for this group of patients.

BOX 4 Important HRQoL domains for people with schizophrenia

- 1 Barriers placed on interpersonal relationships
- 2 Reduced control of behaviours and action
- 3 Loss of opportunity to fulfil occupational roles
- 4 Financial constraints on activities and plans
- 5 Subjective experience of psychotic symptoms
- 6 Side-effects and attitudes to medication
- 7 Psychological responses to schizophrenia
- 8 Labelling and attitudes from others
- 9 Concerns for the future
- 10 Positive outcomes from experiences

(Gee 2003)

Holloway & Carson (2002) conclude that HRQoL measures are better at assessing treatment effects than the more generic QoL measures, but point to the heterogeneity of these measures and the fact that individual patients are likely to prioritise different domains (e.g., symptoms, side-effects of medications, weight gain). As Gee *et al* (2003) showed, it is possible for HRQoL measures to be developed with greater participation of service users in deciding which domains are of relevance to them. However, this does not seem to be the usual practice and, even if done, may not fully account for individual preferences within a study.

Suitability and validity of QoL/HRQoL tools to measure outcomes

Barry & Zissi (1997) argue that most studies (at that date) were cross-sectional, not longitudinal, and could not therefore demonstrate the role of QoL in measuring outcomes of service changes. In response, Ruggeri *et al* (2001) carried out a 2-year longitudinal outcome study using the Lancashire Quality of Life Profile. They found difficulty in building predictive models around subjective outcomes because of the tendency towards 'psychological adaptation or "response shift" that can occur over time in the subjective appraisal of a person's current state ... the multifactorial determinance of subjective outcomes and the diverse reaction of different individuals to the same circumstances'.

Holloway & Carson (2002) similarly find that QoL's generic approach has poor sensitivity to change, which they say may result from 'accommodation to adversity' leading to lowered life expectations. They argue that subjective QoL will always be problematic because the salience of life domains will vary between individuals, and even within individuals over time, depending on people's expectations, aspirations, self-appraisal, coping strategies and life experiences.

HRQoL measures also have their problems. Gilbody *et al* (2002) argue that they are designed to evaluate healthcare at a population level, not for making decisions about individual patients. Also, as mentioned above, HRQoL measures are rarely patient-centred, which Carr & Higginson (2001) argue reduces their value as outcome measures:

'Using measures that are not patient centred can result in a number of problems. If they do not cover domains that are important to individual patients they may not be valid measures for those patients. Thus, standardised measures (in which the questions and range of answers are predetermined and the same for all patients) may measure something distinct from the quality of life of individual patients ... If such measures do not capture the quality of life of individual patients they are unlikely to be responsive

to change after treatment because they may not be measuring what is important to the patient and their scores may be difficult to interpret. Measures that are not patient centred differ in content and the weights or importance they apply to different domains. Thus, significantly different scores may be obtained after the same intervention in the same patients.'

Can people give accurate self-reports when ill?

A frequent question about all forms of QoL measurement in mental health is whether patients' self-reports of their quality of life are credible, when they may have depression, schizophrenia or mania, and whether more objective reports by others should be used:

'Self-report measures are likely to contain biases due to cognition, periodic affective swings, and recent life events that may better reflect psychopathology and symptoms than actual life conditions or functions.' (Atkinson 1997)

Other sources argue that QoL is necessarily a primarily subjective measure and that the patient's viewpoint should therefore be accepted as valid:

'Depression will affect QoL but it does not "distort" it or make the assessment invalid.' (Orley 1998)

Oliver *et al* (1997) found on the basis of their data-set of more than 1500 patients that mental health problems (other than depression) do not significantly alter the results from QoL surveys. They agree with Lehman *et al's* (1982) earlier verdict that clinical depression lowers subjective well-being scores in all domains:

'nevertheless, patients remain able to discriminate between different life domains in terms of their satisfaction ratings.' (Oliver 1997)

Kuehner (2002) studied the validity of subjective QoL measures with depressed patients, comparing patients at different stages of depression with control groups using the Lancashire Quality of Life Profile. She found, as did Oliver *et al* (1997), that global measures of subjective QoL (general life satisfaction and Cantril's Ladder) were closely affected by concurrent levels of depression. Kuehner concluded that global assessments of quality of life mirror depression, remitting as symptoms remit. However, when patients and controls were compared on particular life domains, the results reflected changes in objective situations as patients reached different stages of depression:

'The present results suggest that patients were able to distinguish between illness-related and non-related domains, and reduced satisfaction reported by currently depressed patients was merely found in those QoL areas representing symptoms or functional impairments. This held true, for instance, with occupation, where a high proportion of non-remitted

patients was off work or retired as a result of illness. Similarly, non-remitted patients had participated in fewer leisure activities than remitted patients and controls and were less satisfied with their activities, which may be regarded as an obvious indicator of pronounced anhedonia in this acutely depressed subgroup.' (Kuehner 2002)

Satisfaction with other aspects of life such as living conditions, security and finances, were not found to be affected by depression. This supports Kuehner's argument that there is no evidence 'for a globally biased negative evaluation of individual QoL domains' by people with depression. She argues that the results of this study 'should be regarded as indicators of valid self-assessments of symptoms and impaired functioning by depressed patients rather than as indicators of their distorted self-evaluation' (Kuehner 2002).

Kuehner concludes that the same issues apply to other commonly used QoL instruments, including the WHOQOL, and recommends that subjective QoL information should be interpreted on individual or subdomain levels rather than on aggregated levels.

A small study by Khatri *et al* (2001) using the Lehman *et al* Quality of Life Interview also looked at the validity of responses by patients, this time with schizophrenia, as compared with patients with cancer. Both groups were asked to choose proxies (a carer or someone who knew them well) to complete the interview as well, so that responses of the two groups on subjective and objective domains could be compared. As is commonly reported, the patients with schizophrenia showed a low correlation between objective and subjective life indexes, tending to be more positive about their lives than would appear objectively justified (unlike those with cancer). The proxies of the schizophrenia patients mirrored this discrepancy. The authors say that this suggests that 'the reported difference between objective and subjective quality of life is a valid one', perhaps because patients with schizophrenia (and presumably their families too) adapt to their circumstances and lower their expectations. They comment that these findings suggest that self-reports of patients with schizophrenia can be taken at face value.

Pinikahana *et al* (2002) confirm this view, arguing that 'it is becoming clear that people with schizophrenia can validly and reliably report their internal experiences and perceptions'. They also confirm that the mismatch between patient and clinician ratings of QoL is no longer seen as proof that patient perceptions are erroneous. Rather, they are different and complementary constructs, and 'subjective assessment is now understood to be its own gold standard'.

Accountability of QoL and HRQoL measures to service users

There is little evidence in the literature of attempts to involve mental health service users as equal partners in creating QoL or HRQoL measures, although a number of the scales have been based on domains derived from interviews with patients of mental health services. Carr & Higginson (2001) say that few researchers creating measures have directly asked patients which factors they think constitute quality of life:

‘When they did involve patients, they asked about the impact of illness on people’s lives or behaviour ... and the sickness impact profile ... but not about the important things in people’s lives ... Several studies have shown that there is a disparity between patients’, doctors’, and relatives’ ratings of the patient’s quality of life, or have suggested that doctors are unsuccessful in identifying aspects of disease and treatment that are important to patients.’

Holloway & Carson (2002) recommend re-reading the paper by Lehman *et al* (1982), which presented verbatim comments of people about the issues that affected their quality of life, and suggest this needs updating for the 21st century.

Pinikahana *et al* (2002) argue that the divergence between the patient’s and the health professional’s perception of QoL ‘requires further exploration and indicates the need to develop an instrument with active input and involvement from consumers of mental health services’.

Individualising QoL and HRQoL measures

One way to individualise measures has been to allow individual weighting of the importance of domains. Prince & Gerber (2001) argue that this is insufficient:

‘Although allowing respondents to weight the importance of particular life domains has served to enhance subjective quality of life assessment, items selected for such instruments typically comprise domains derived through professional judgment, broad surveys of patient needs, or through literature review. This approach to developing subjective quality of life instruments implies there is a finite number of life domains which should be more or less important to all individuals or to which all people should aspire.’

Carr & Higginson (2001) suggest that QoL measures could be developed that allow individuals to make their own choices about which life domains are important to them.

SEIQOL-DW

One such measure, the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQOL-DW), was developed by Hickey *et al* (1996) and tested by Prince & Gerber (2001) with people with serious mental illness.

The SEIQOL-DW takes a patient-directed approach to assessing subjective quality of life. Rather than presenting a standardised list of domains, the interviewer first uses a semi-structured interview to elicit the five areas of life that the individual considers most important to them. Levels of satisfaction from ‘worst possible’ to ‘best possible’ for each of the chosen domains are then recorded using a visual analogue scale, and respondents manipulate a disk with five coloured sections representing the chosen domains to show the relative importance of each. These choices contribute to an overall QoL score as a percentage and test-retest and internal reliability have been established. This method is individualised, relatively quick to administer and does not require reading ability. The life domains that were nominated by respondents in the Prince & Gerber study differed from those in a standard QoL measure also administered to the same group. The authors suggest that this method facilitates therapeutic alliance and could improve patients’ motivation to work towards attainable goals, along with an objective assessment of issues such as housing, income and daily activities.

Other researchers have further tested this method. Pitkänen *et al* (2009) interviewed 35 patients with psychosis on acute wards and found that health, family, leisure, work/study and social relationships were the most frequently named areas, but other areas such as spirituality and religion, positive feelings and pets also emerged. Health issues raised by these patients were mainly not related to mental illness. The authors argue that the SEIQOL-DW method strengthens the notion that individual assessment of QoL is important in psychiatric nursing and can help to make nurses more aware of patients’ needs related to their life quality and what matters to them most. A systematic review of the use of the SEIQOL-DW (Wettergren 2009), although not addressing its use in psychiatry, found it a feasible and valid instrument that focuses on individualised QoL and can be used even with those who are severely ill.

PSYCHLOPS

Another measure, developed in partnership with the Depression Alliance (a service user organisation), is a simple self-report HRQoL measure to enable primary care patients to assess their state of mental health before and after talking treatments (Ashworth 2004). The measure (Psychological Outcome Profiles or PSYCHLOPS) is based on the Measure Yourself Medical Outcome Profile (MYMOP; Paterson 1996), a freely available primary care health outcome measure that enables patients to specify the symptoms they find most

MCQ answers

1 d 2 e 3 d 4 b 5 d

troublesome, the activities they are prevented from engaging in by their illness and their own views on their well-being. The authors report that service user involvement in PSYCHLOPS changed the language of the first draft to make it acceptable to people with depression and ensured that it was written in plain English.

Inconsistent approaches to QoL

The Department of Health Outcomes Group report reviewed a range of outcome measures in mental health, including QoL measures, warning that 'there is a lack of a clear consensus of what quality of life constitutes, and how it should be measured' and that it is unclear how evaluations of quality of life by various different parties (including the patient) should be reconciled (Schmidt 2000: p. 5). A more recent review for the Department of Health (Fitzpatrick 2006: pp. 30–31) found that despite evidence that patients with chronic health problems benefit from increased involvement,

'it is disappointing that so few studies consider partnership in chronic disease as a long term matter with constant need to maintain and develop partnership and collaboration and assess long term impact on outcomes for patients ... Overall, the scope and potential for increased patient involvement and greater sharing of decisions is substantial and the evidence is encouraging that such changes are beneficial.'

An exploration of the use of patient-reported outcome measures (Greenhalgh 2005), focused on HRQoL instruments, found that although clinicians report giving a high priority to these measures, in practice biomedical, symptom-related factors overrule HRQoL factors in their decision-making about patient care. The authors argue that the influence of HRQoL would improve if more patient-centred instruments were used and there was greater engagement with the clinicians involved in the patient's care, fostering local ownership of the implementation of HRQoL measures. They advocate more research on how clinicians actually use outcome measures. Gilbody *et al* (2002) found no robust evidence that routine HRQoL measurement can improve quality of care or outcomes in psychiatry, and called for more systematic research to demonstrate the value of outcomes measurement.

QoL and policy

Since government policy is moving towards more effective service user involvement (Health and Social Care Act 2001, Section 11; National Health Service Act 2006, Section 242; Department of Health 2010: p. 13), quality of life measures need to move on from the generic welfarist well-being approach and the medicalised disease-specific approach to involve

service users more directly in conceptualising life quality and creating QoL measures. The problems with measuring subjective QoL may be overcome with more sensitive measures and greater reference to emerging ecological concepts such as social capital (Whitley 2005) and the capabilities approach (Hopper 2007). The latter looks at how people have been disabled not only by their mental disorder but also by limitations on their ability to dream, think and act as full members of society that result from psychiatric treatments and social discrimination:

'Affirming human flourishing as the orienting aim of public mental health is foremost. Our metric of progress should be those locally valued commitments people are actually able to make in their everyday lives.' (Hopper 2007)

The 'recovery' values espoused in mental health policy documents make an implicit promise to restore full citizenship to people with long-term mental health problems. Quality of life measures could incorporate these aspirations rather than take currently restricted capabilities for granted as the best that people can expect. Likewise, the Royal College of Psychiatrists has made a commitment to involve service users in research, training and service delivery (Fitch 2008).

A statement from a service user summarises the complexity of measuring quality of life outcomes, which (as many writers state) are and should remain individual and personal:

'We have had no say in how outcomes are measured. No-one ever asks me about my journey, what I have gained from treatment and the factors that remain. My helping my dying father (when no-one else in my family had that same ability) seems more of a good outcome from my therapy with my CPN than me working in [a supermarket] would be, though that probably wouldn't be recognised!' (Anon, personal communication 2009, published with permission.)

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MCQs

Select the single best option for each question stem

1 Which of the following types of measurement is discussed in detail in this article?

- a quality-adjusted life-years
- b quality circles
- c patient satisfaction
- d health-related quality of life
- e happiness measurement.

2 Which of the following is a key domain of the Quality of Life Interview?

- a school attendance
- b criminal activity

c living situation

d hearing voices

e patient satisfaction.

3 The Lancashire Quality of Life Profile uses:

- a the Beck Inventory of Depression
- b SF-36
- c the Simpson–Angus Scale
- d Cantril's Ladder
- e the Ladder of Citizen Participation.

4 The Medical Outcomes Study was carried out in:

- a Japan
- b the USA

c Sweden

d the UK

e Australia.

5 The Department of Health Outcomes Group report covered outcome measures in:

- a dementia
- b cancer
- c intellectual disability
- d mental health
- e forensic services.