

Theoretical Contributions

Quality of Life: Definition and Measurement

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Abstract

Quality of life (QoL) can be defined in many ways, making its measurement and incorporation into scientific study difficult. This is a theoretical paper regarding the definition and measuring of quality of life. The search strategy included a combination of key words 'quality of life', 'definition of QoL' as well as 'measuring QoL' in titles using Medline and Google Scholar databases. Quality of life is a complex, multifaceted construct that requires multiple approaches from different theoretical angles. Scientists from the various disciplines of social science are encouraged to exploit the strengths of other's contributions in a collaborative effort. A thorough understanding of subjective well-being requires knowledge of how objective conditions influence people's evaluations of their lives. Similarly, a complete understanding of objective indicators and how to select them requires that we understand people's values, and have knowledge about how objective indicators influence people's experience of well-being.

Keywords: quality of life, health, well-being, definition, measuring

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Background

In recent years, much attention has been focused on exploring the impact of physical and mental illness on overall quality of life. The switch to the measurement of psychosocial issues in addition to biomedical measures has been shown to play an important role in ensuring positive patient outcome from both a clinician's and patient's perspective, and is an important outcome measure when evaluating treatment (Skevington, 1999). In addition, ongoing evaluation of quality of life in normal healthy individuals, and specific general populations, such as the elderly, has also received attention. It has previously been argued that due to the subjective nature of an individual's 'quality of life', this is a difficult concept to measure and to define, but that in general terms it may be viewed as a multidimensional concept emphasizing the self-perceptions of an individual's current state of mind (Bonomi, Patrick, Bushnell, & Martin, 2000). Indeed a major challenge in defining quality of life might be in exploring which domains should be encompassed in the overall definition of this construct. However, investigations would indicate that for an effective explanation to be derived, it is essential to view quality of life as a concept consisting of a number of social, environmental, psychological and physical values.

Definition of Quality of Life

The concept of quality of life broadly encompasses how an individual measures the ‘goodness’ of multiple aspects of their life. These evaluations include one’s emotional reactions to life occurrences, disposition, sense of life fulfilment and satisfaction, and satisfaction with work and personal relationships (Diener, Suh, Lucas, & Smith, 1999). In the literature, the term ‘quality of life’ is also often referred to as ‘well-being’. However, there are a number of challenges to developing a meaningful understanding of the quality of life and/or well-being literature. The first is to ascertain what, exactly, the terms mean (Clarke, Marshall, Ryff, & Rosenthal, 2000; Farquhar, 1995). Almost 30 years ago, in one of the seminal geographical studies in this field, Smith (1973) proposed that well-being be used to refer to objective life conditions that apply to a population generally, while quality of life should more properly be limited to individuals’ subjective assessments of their lives because of what Smith felt to be the evaluative nature of the term. Today, this distinction has been lost. The terms are often undefined or used inconsistently or interchangeably within studies. In some instances, one term is even used to define the other (De Leo et al., 1998). The lack of distinction can in part be traced to the multiple conceptualisations of quality of life that have evolved over the years (Beesley & Russwurm, 1989), starting with the economic approaches popular in the late 1960s and 1970s when quality of life/well-being was assessed by quantitative measures and unemployment rates (Liu, 1976). In reaction to this rigidly quantitative approach to the subject, researchers began inquiring in to individuals’ subjective experiences of their lives in the belief that objective measures alone were incomplete measures of ‘quality of life’ (Andrews & Withey, 1976; Campbell, Converse, & Rogers, 1976).

A second reason for the loss of distinction between the terms is the acknowledgement that quality of life/well-being has both objective components – i.e., components external to an individual and measurable by ‘others’ – and subjective components – i.e., personal assessments of one’s own life or of particular aspects of life using measures of satisfaction, happiness, or other self-assessment scales (Campbell et al., 1976). Thus, although researchers such as Smith (1973) maintained a conceptual distinction between the two types of measures, it is clear that those who followed did not. Here, both terms will be used interchangeably. Diener et al. (1999) summarise some common components of subjective well-being. He mainly focuses on top-down factors that represent individual factors (such as values and goals) influencing well-being.

Table 1 describes multidimensionality through consideration of satisfaction with life across typical segments of daily living such as work, family, health, leisure and so forth. Satisfaction itself has several aspects, including desire for change and satisfaction with past, present and future aspiration fulfilment. Affect, both positive and negative, also influences personal sense of one’s quality of life (Diener et al., 1999). Satisfaction with one’s life implies a contentment with or acceptance of one’s life circumstances, or the fulfilment of one’s wants and needs for one’s life as a whole. In essence, life satisfaction is a subjective assessment of the quality of one’s life. Because it is inherently an evaluation, judgments of life satisfaction have a large cognitive component. In the context of the distinction from related constructs, it is essential to mention that subjective well-being has both an affective (i.e., emotional) and a cognitive (i.e., judgmental) component. The affective component consists of how frequently an individual reports experiencing positive and negative affect. Life satisfaction is considered to be the cognitive component of this broader construct (Sousa & Lyubomirsky, 2001).

Health Related Quality of Life

Health Related Quality of Life (HRQoL) is concerned specifically with health aspects while also accounting for general QoL components. HRQoL has been understood in several different ways and so has been measured

Table 1

Components of Subjective Well Being

Pleasant affect	Unpleasant affect	Life satisfaction	Domain satisfaction
<ul style="list-style-type: none"> • Joy • Elation • Contentment • Pride • Affection • Happiness • Ecstasy 	<ul style="list-style-type: none"> • Guilt and shame • Sadness • Anxiety and worry • Anger • Stress • Depression • Envy 	<ul style="list-style-type: none"> • Desire to change life • Satisfaction with current life • Satisfaction with past • Satisfaction with future • Signification others' views of one's life 	<ul style="list-style-type: none"> • Work • Family • Leisure • Health • Finances • Self • One's group

using a variety of instruments (O'Connor, 2004; Theofilou, 2011a). McDowell and Newell (1996) for example suggest that there is little difference between general health and quality of life, and that the two can be measured in similar ways. On the other hand, Mathers and Douglas (1998) draw the distinction between observable objective measures of health status, such as in a clinical profile and an individual's perception about the quality of their life. A range of definitions for HRQoL have been applied in the development of HRQoL instruments, for example, an individual's definition of their overall satisfaction with life, or, a sense of personal psychological, physical and social well-being in being self-determining, independent and satisfied with control of disease processes (O'Connor, 2004), e.g. comparative studies regarding HRQoL in patients undergoing haemodialysis or peritoneal dialysis treatment (Ginieri-Coccosis, Theofilou, Synodinou, Tomaras, & Soldatos, 2008; Karamanidou, Theofilou, Ginieri-Coccosis, Synodinou, & Papadimitriou, 2009; Theofilou, 2011b, 2011c, 2011d, 2011e, 2012a, 2012b, 2012c, 2012g), in breast cancer (Theofilou, 2011f, 2012d), multiple sclerosis (Theofilou, 2011g), chronic obstructive pulmonary disease (Theofilou, 2012e), hypertension (Theofilou & Panagiotaki, 2012), chronic heart failure (Theofilou, 2011h), rheumatoid arthritis (Theofilou, 2012f) and musculoskeletal disorders (Theofilou & Panagiotaki, 2011).

Most Frequently Used Questionnaires

At the current time, there are in excess of 1000 instruments (Ubel, Loewenstein, & Jepson, 2003), designed specifically for the measurement of quality life. Some of these are generic, for use in the general population and can be applied to a number of conditions, others are disease specific, pertaining to a particular pathology. It is important to note however, that quality of life might be experienced differently and encompass different values within and across different cultural groups and country populations, in addition there are often discrepancies between quality of life evaluations from people with a form of somatic or psychiatric illness, and the general public (Ubel et al., 2003). Further, frequency of use does not necessarily mean the best or most appropriate use, and there are many publications purporting to measure HRQoL that have not in fact employed instruments with robust psychometrics or valid collection methods.

Generic Health Related QoL Instruments

Arguably the most important and frequently used generic HRQoL assessment is the 36-Item Short Form Health Survey (SF-36) (McDowell & Newell, 1996). This multi-purpose, short-form health survey is comprised of 36 questions which provide an eight-scale profile of functional health and well-being scores (physical function, role function, bodily pain, general health, vitality, social functioning, emotional well-being and mental health) as well as composite physical and mental health summary measures, and a preference-based HUI (Lenert & Kaplan,

2000; McDowell & Newell, 1996). The SF-36 has been used in literally thousands of general and specific population surveys, permitting comparison of the relative burden of diseases, and differentiating the health benefits or harms of diverse treatments. The self-reported burden is not great but an even shorter validated version, the SF-12, comprised of 12 items, is also available. The instrument has been translated using backwards and forwards methodology into approximately 50 languages (McDowell & Newell, 1996).

The World Health Organisation Quality of Life - Brief (WHOQOL-BREF) has been validated among people with type 2 diabetes (Rose, Fliege, Hildebrandt, Schirop, & Klapp, 2002). Development of the WHOQOL-BREF was a multi-national project, based on a cross-culturally sensitive concept, thus it is appropriate for use across different nationalities (Skevington, Lotfy, & O'Connell, 2004). The four domains measured are: physical, psychological, social and environment, through a set of 26 items that can be self-administered. Responses to the questions use a 5-point Likert scale, inquiring 'how much', 'how satisfied' or 'how completely' the respondent felt in relation to the domain being investigated. The WHOQOL-BREF has good to excellent psychometric properties of reliability and validity (Skevington et al., 2004).

The European Quality of Life (EUROQOL) or Euro-QoL 5-Dimensions (EQ-5D) is a self-administered generic scale used in evaluative studies and policy research to measure health status (EuroQol Group, 1990; McDowell & Newell, 1996). There are four components to the measure, two being relevant to Health Related Quality of Life. Disease specific measures are added to the EuroQoL for a comprehensive understanding of peoples' sense of well-being. The EuroQoL measures five health domains: mobility, self-care, role (or main) activity, family and leisure activities, and pain and mood. Responses to six items are obtained by the respondent ticking the appropriate answer to the best description of one's sense of current state of health. The respondent also rates their health on the EuroQoL thermometer which is calibrated 0-100 (worst imaginable health state-best imaginable health state) (Brooks, 1996). The EuroQoL has been used to determine the impact of diabetes on various health-related quality of life domains and has been compared to several summary utilities measures (Glasziou, Alexander, Beller, Clarke, & Group, 2007). The EQ-5D performed as well as the other instruments and was found to be generally simpler to use (Brooks, 1996).

Disease Specific Instruments

The Kidney Disease Quality of Life (KDQOL) survey was developed in 1994 by the Kidney Disease Quality of Life Working Group as a kidney disease-specific measure of HRQoL. The first version contained the Medical Outcomes Study 36 (MOS SF-36) as a generic chronic disease core, and added items relevant to patients with kidney disease, such as symptoms, burden of illness, social interaction, staff encouragement, and patient satisfaction. The KDQOL-36, available since 2002, is a 36-item HRQoL survey with five subscales (Hays, Kallich, Mapes, Coons, & Carter, 1994):

- *The SF-12 Measure of Physical (PCS) and Mental (MCS) Functioning (1-12)*, with items about general health, activity limits, ability to accomplish desired tasks, depression and anxiety, energy level, and social activities.
- *Burden of Kidney Disease subscale (13-16)*, with items about how much kidney disease interferes with daily life, takes up time, causes frustration, or makes the respondent feel like a burden.
- *Symptoms and Problems subscale (17-28b)*, with items about how bothered a respondent feels by sore muscles, chest pain, cramps, itchy or dry skin, shortness of breath, faintness/dizziness, lack of appetite, feeling washed out or drained, numbness in the hands or feet, nausea, or problems with dialysis access.

- *Effects of Kidney Disease on Daily Life subscale (29-36)*, with items about how bothered the respondent feels by fluid limits, diet restrictions, ability to work around the house or travel, feeling dependent on doctors and other medical staff, stress or worries, sex life, and personal appearance.

The Diabetes Quality of Life Clinical Trials Questionnaire Revised (DQLCTQ-R) was developed based on feedback from focus groups, expert clinicians, and literature searches. The questionnaire was validated using data from longitudinal clinical trials, which had the added benefit of showing responsiveness to change (Shen et al., 1999). The DQLCTQ-R incorporates previously validated scales which enhances the comprehensiveness of the instrument. The self-administered measure was revised to include 57 items comprising eight domains, Generic: physical function, energy/fatigue, health distress, mental health; and Diabetes specific (DQOL): treatment satisfaction, treatment flexibility, frequency of symptoms, satisfaction. Scaling responses include a range of 3-10 options including: 'all the time' to 'none of the time', 'very satisfied' to 'very dissatisfied', 'never' to 'all the time', and 'does not apply' to 'all the time'. This instrument has been found to be a valid and reliable way of measuring HRQoL of people with diabetes when new or alternative treatments have been implemented (Rubin & Peyrot, 1999; Shen et al., 1999).

The Minnesota Living with Heart Failure Questionnaire (MLHFQ) was designed in 1987 to measure the effects of heart failure and treatments for heart failure on an individual's quality of life. The content of the questionnaire was selected to be representative of the ways heart failure can affect the key physical, emotional, social and mental dimensions of quality of life without being too long to administer during clinical trials or practice. To measure the effects of heart failure symptoms, functional limitations and psychological distress on an individual's quality of life, the MLHFQ asks each person to indicate using a 6-point (zero to five) Likert scale how much each of 21 facets prevents them from living as they desire. For each question the answer may vary from 0 (no), 1 (very little) to 5 (very much). So the total score may vary from 0 - 105, the former being the best and the latter being the worst (Rector, Kubo & Cohn, 1987; Rector & Cohn, 1992).

The questionnaire assesses the impact of frequent physical symptoms - shortness of breath, fatigue, peripheral edema, and difficulty sleeping - and psychological symptoms of anxiety and depression (Bennett et al., 2002). In addition, the effects of heart failure on physical and social functioning are incorporated into the measure. Since treatments might have side effects in addition to ameliorating symptoms and functional limitations produced by heart failure, questions about side effects of medications, hospital stays and costs of care are also included to help measure the overall impact of a treatment on quality of life (Rector et al., 1993). Although the MLHFQ incorporates relevant aspects of the key dimensions of quality of life, the questionnaire was not designed to measure any particular dimension separately.

The EORTC QLQ-C30 (version 1.0) was used for all patients. This questionnaire has been developed by the European Organization for Research and Treatment of Cancer (EORTC) Study Group on Quality of Life to assess topics relevant to cancer patients. It is designed to be self-administered by the patients and consists of 30 items, 24 of which are organized into nine scales: Physical functioning, Role functioning, Emotional functioning, Cognitive functioning, Social functioning, Global health status/quality of life, Fatigue, Nausea and vomiting, and Pain. The response categories of the EORTC QLQC30 are "No (1)"/"Yes (2)" (items 1-7), "Not at All (1)"/"A Little (2)"/"Quite a Bit (3)"/"Very Much (4)" (items 8-28), or 1-7 scales with 1 anchored to "Very poor" and 7 to "Excellent" (items 29 and 30). Item scores were linearly transformed to a range from 0 to 100 (Aaronson et al., 1993). In the questionnaire for the breast cancer patients, the EORTC QLQC30 was followed by 39 additional items. The questionnaire used

for the gynecological cancer patients contained 73 additional items, some of which were inserted among the items of the EORTC QLQ-C30.

The Arthritis Impact Measurement Scales (AIMS) is a widely used disease-specific measure of physical, social, and emotional well-being in arthritis (Meenan, Gertman, & Mason, 1980). There is an original version, shortened version, an expanded version (AIMS2), a short-form of the AIMS2 (AIMS2-SF), a child version, and a version for the elderly (Geri-AIMS). AIMS has been translated into many languages including Portuguese, Canadian French, Italian, Spanish, French, Dutch, Swedish, Turkish, and Norwegian. The revised version, AIMS2 has good psychometric properties and the advantage of including measures of satisfaction with health and patients' priorities for improvement (Meenan, Mason, Anderson, Guccione, & Kazis, 1992). The full-length versions are quite time consuming to complete, and the short-form (AIMS2-SF) that has similar psychometric properties to the full-length versions, may be more appropriate for postal surveys, studies where patients are required to complete several questionnaires, and in clinical practice. There are 9 scales: mobility, physical activity (walking, bending, lifting), dexterity, household activity (managing money and medications, housekeeping), social activities, activities of daily living, pain, depression, and anxiety (Guillemin et al., 1997). AIMS2 includes arm function, social support, and work. AIMS has been used in other conditions including psoriatic arthritis, ankylosing spondylitis, fibromyalgia, carpal tunnel syndrome, colles fracture, hemophilia and in patients undergoing joint replacement surgery.

Choosing an Instrument

The choice of instrument depends very much on the reason for measurement and the primary concepts of interest. A study looking at a new analgesic for the relief of arthritis may require a disease-specific instrument such as the Arthritis Impact Measurement Scales (AIMS) or a more generic instrument such as the SF-36 to evaluate the impact of pain on other aspects of QoL and compare across other conditions where the analgesic was also indicated or licensed. When examining the impact of a specialist nurse counselling service, a good anxiety or depression scale might be more appropriate. The key issues when choosing a test are to review the instrument for coverage of items of interest and to ensure that it is valid and reliable (Lenert & Kaplan, 2000; O'Connor, 2004).

The Validity of an instrument is the degree an instrument (such as a questionnaire) measures what was intended to be measured (O'Connor, 2004). Validity refers to the application of an instrument and the confidence that can be placed on the conclusions reached. Determining the soundness of the application is a matter of degree as the test is applied to different populations. The validity of an instrument is determined in a number of ways and includes the following:

- Content validity is whether the instrument includes all relevant aspects of the attribute being explored, which in this case is the multidimensionality of QoL. To establish what the relevant aspects are when creating an instrument, collecting information from patients, their relatives, health professionals, and relevant literature is necessary (O'Connor, 2004). This enables pertinent and comprehensive content to be collected for consideration in the instrument design. Content validity is also said to exist when an instrument has good internal consistency, that is, items within the instrument that are designed to measure the same aspect of QoL actually do so (Bowling, 1997).
- Face validity is a form of content validity describing whether the meaning of the questions used is clear, appears appropriate and balanced and measures the variables claimed. Face validity is usually determined by asking individuals who complete the instrument during its development about their understanding of the question (Bowling, 1997; O'Connor, 2004).

- Construct validity is the fidelity with which aspects of QoL are being measured and whether a comprehensive characterisation of aspects of QoL has been applied (Bowling, 1997; O'Connor, 2004). As this is often difficult to directly observe, testing constructs is an ongoing process.
- Predictive validity of an instrument is whether the measure can predict future differences in outcomes such as responsiveness to disease management interventions (Bowling, 1997).

The Reliability of an instrument is the precision and accuracy with which it measures a defined issue. Reliability is said to exist when it consistently produces similar results in a specified situation (Bowling, 1997; Snoek, 2000).

Barriers to the Application of HRQoL Assessment

Despite the apparent need and potential benefits of HRQoL assessments in chronic patients, there are limitations to the use of such assessments in clinical practice. The adaptation of HRQoL assessment by clinicians could be likened to the diffusion of any novel laboratory test in clinical practice. Similarly, it may be difficult for providers to understand the meaning of an individual's score on a HRQoL assessment measure and/or how to interpret a change in the score. Efforts to address this problem hinge on familiarizing providers with the instruments that are available for HRQoL assessment in the chronic disease population and their scoring (Najman & Levine, 1981). A second limitation to the implementation of HRQoL assessment in clinical practice relates to the inherent limitations of individual questionnaires. One alternative to using HRQoL surveys with a large number of questions would be to employ assessments of specific facets of HRQoL, such as symptom burden, depression, or physical functioning (Najman & Levine, 1981). Another exciting approach to HRQoL assessment has been the development of computer adaptive testing (CAT), which permits the response of the patient to inform the selection of the next question. In this way, the length of HRQoL questionnaires may be dramatically shortened, since the person who can walk a mile does not need to be asked if he/she can walk a block. The use of CAT with HRQoL surveys would allow physicians to gather a great deal of reliable data, while limiting the burden of survey administration on the patient and the staff (Najman & Levine, 1981).

Table 2 summarises the detailed HRQoL instruments' development, validity and reliability measures.

Conclusion

The present paper highlights some very important issues concerning the term 'quality of life'. Specifically, with regards to this term and the term 'subjective well-being', we believe that a distinction between them (such as that proposed by Smith) is conceptually useful, and should be reinstated. We also believe that the objective and subjective (i.e., external and internal) dimensions of life need to be better accommodated in conceptualisations of these terms, both to facilitate and integrate research on what is clearly a multidisciplinary (if not trans disciplinary) concept. The fact that the terms 'quality of life' as well as 'subjective well-being' are not differentiated in most cases may be related to the wide range of definitions for QoL and HRQoL. Taking these definitions into account, HRQoL is defined as optimum levels of mental, physical, role (e.g. work, parent, carer, etc.) and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being. It should also include some assessment of the patient's level of satisfaction with treatment, outcome and health status and with future prospects. It is distinct from QoL as a whole, which would also include adequacy of housing, income and perceptions of immediate environment.

Table 2
HRQoL Instruments

Instrument	Development	Validity	Reliability
Generic			
SF-36 (McDowell & Newell, 1996)	Ongoing development since 1970s, current form originated from 245-item questionnaire. 3,445 respondents in initial study	Good to excellent	Good to excellent. Sensitive to change
WHOQOL BREF (Skevington et al., 2004)	Multi-national project, 23 countries; 11,830 adults respondents; Cross-culturally sensitive; Sick & well respondents sampled	Discriminant validity and construct validity determined through confirmatory factor analysis performs well (needs further assessment of concurrent validity in comparison to relevant other measures)	Internal consistency determined good to excellent
EUROQOL/ EQ-5D (EuroQol Group, 1990; McDowell & Newell, 1996)	European project, 3 countries; 592 adult respondents; Cross culturally sensitive; Sick and well respondents sampled	Intraclass correlation coefficient good to excellent demonstrated	Studies of 87 and 104 respondents report good reliability
Specific			
DQLCTQ-R (Shen et al., 1999)	Multi-national project, 4 countries; 942 patients	Intraclass correlation coefficients range from good to excellent	Good to excellent reliability demonstrated, responsive to change
Kidney Disease Quality of Life (KDQOL) (Hays et al., 1994)	Multi-national project, 165 individuals with kidney disease	Intraclass correlation coefficients range from good to excellent	Good to excellent reliability demonstrated
Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Rector, Kubo, & Cohn, 1987)	Patients with LV dysfunction participating in several studies (83; 84% males)	The instrument correlated highly with patients' global assessments of restrictions on their lives ($r = 0.80$).	Good results for the reliability of the instrument
EORTC QLQ-C30 (Aaronson et al., 1993, European Organization for Research and Treatment of Cancer (EORTC) Study Group on Quality of Life)	305 patients with nonresectable lung cancer from centers in 13 countries	Intraclass correlation coefficients range from good to excellent	Good to excellent reliability demonstrated
Arthritis Impact Measurement Scales (AIMS) (Meenan et al., 1980)	The self-administered AIMS questionnaire has been pilot tested in a mixed arthritis population	Good to excellent	Good to excellent reliability demonstrated, responsive to change

Regarding the measurement of QoL, while many generic QoL instruments have been used with individuals with chronic illness, it would seem that more accurate determination of an individual's HRQoL can occur when disease specific instruments are used (Bradley, 2001; Patrick & Deyo, 1989). Choice of instrument is dependent on the scale of the research to be conducted or its utilisation in a practice setting, considerations of application such as time taken and time available for completion of the instrument and whether patient self administration is possible or desired. Questionnaire application can be complemented by conducting individual interviews with patients to follow up on issues of concern identified in the questionnaire responses. Healthcare professionals are well placed to support patients in developing self-management skills to address these issues or to organise referral to other appropriate specialists to further HRQoL. Further reports of the use of QoL instruments in general practice settings are needed to test the efficacy of using QoL instruments for clinical outcomes improvement over time. Whilst there is emerging evidence of the benefits of the use of QoL instruments in general practice settings, further research is also needed.

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