

Quality of life: measures and meanings in social care research

Ann Bowling

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Methods Review 16



The School for Social Care Research

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About the authors

Professor Ann Bowling is a social scientist at the University of Southampton, with a research focus on measuring quality of life of older people, patients' experiences and expectations, and equity of access to services. She has worked in public health and primary health care settings including both the London & St Bartholomew's Hospital Medical Colleges, London School of Hygiene and Tropical Medicine, and University College London, as Professor of Health Services Research. More recently she was based in Health and Social Care, St George's, University of London, as Professor of Health Care of Older People.

NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE
Email: sscr@lse.ac.uk
Tel: +44 (0)20 7955 6238
Website: www.sscr.nihr.ac.uk

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ABSTRACT

This review provides an overview of the measurement of quality of life (QoL) in social care, or social care-related QoL. Because the field is wide, this overview focuses on older people.

Outcome can be complex to measure in social care, because several types of outcomes of both the user and any family carers may be relevant; these may also be affected by multiple factors. Measuring quality of life is one of several components for assessing the effectiveness of interventions. Maintaining people's broader quality of life is also a potentially important outcome to consider ensuring that the person can 'live well' and that their care and support up until their death meets their needs. In reflection of the wider goals and provision of social care, compared to health care, client-based outcome measures need to be more multidimensional than narrower health-related or disease-related QoL measures reflecting the impact of circumstances and interventions on users' wider lives. However, given overall lack of agreement on concepts or measures of social care and QoL outcomes, investigators have tended to use separate measures of social involvement and/or life satisfaction as indicators of QoL as well as measures of morale, health status, anxiety/depression, physical functioning, and needs. There has been a heavy emphasis on health status, physical and mental functioning. There are also several technical issues to consider when choosing and administering a measure of QoL. These are described but are not intended to be daunting to the researcher. Few measures satisfy all psychometric criteria perfectly. This overview is intended to be an informative summary of the main steps involved in selecting and testing a measurement scale.

RECOMMENDATIONS FOR THE USE OF QUALITY OF LIFE MEASURES IN SOCIAL CARE RESEARCH

- Rigorously conducted conceptual and methodological research is needed as a result of the lack of conceptual models developed specifically to measure social care related quality of life.
- Being concerned about the quality of a person's life is good practice in social care, as well as health care, and important to include in the measurement of outcomes. When a person has a long-standing or restricting condition or circumstances, their QoL can influence how they cope. Equally, the management of their situation and care can affect their overall QoL, beyond the condition itself.
- Client-based outcome measures need to be more multidimensional in social care to reflect the impact of circumstances and interventions on users' wider lives.

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- Account should be taken of changes in people's circumstances and values in analysis of quality of life.
- Methodological issues should be considered when choosing a measure, such as relevance and appropriateness to client or user group as well as relevant in different settings.
- Principles of good practice should be applied in selecting measurement scales such as thinking about research questions and what approach should be used (single measurement scale or battery of complementary measures), examining the relevant literature, considering careful piloting of potential measures (see conclusion).

KEYWORDS

quality of life, social care, research

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INTRODUCTION

This review provides an overview of the measurement of quality of life (QoL) in social care, or social care-related QoL (Netten 2011). Because the field is wide, potentially encompassing children, adults and older people, this overview will focus on older people. This is justified by the increasing numbers of older people, including people with possibly higher expectations than previous generations (Bowling *et al.* 2012) and policy interest in the provision of cost-effective services. These factors have led to international interest in the enhancement and measurement of QoL in older age.

Public policy is increasingly concerned with enabling older people to maintain their mobility, independence, their active contribution to society and to respond effectively to the physical, psychological and social challenges of older age – in effect, to add quality to years of life. This reflects a shift of emphasis away from a traditional view of structured dependency in which the focus of research is on ill health, functional decline and poverty in older age. It moves towards a positive view of old age as a natural component of the lifespan and development of personal fulfilment, although this can still be restricted by limited resources, ill-health or frailty. It also builds on the model of cognitive efficiency proposed by Baltes and Baltes (1990) and Baltes *et al.* (1996) with its emphasis on control over life, role functioning, cognitive competence, and adaptability to the challenges encountered at older ages consistent with the current focus on reablement in social care (Francis *et al.* 2011).

DEFINITIONS

Social care

There is no simple definition of social care, although it is generally used in the UK to describe a wide range of services provided by local authorities and the independent sector, to people with assessed needs for social care, either in their own homes or in a care home. It also covers short-break or day-centre care. The support includes assistance with personal hygiene, dressing, going to the toilet, feeding, provision of meals, social and leisure activities, home care and shopping. Often, people pay for these themselves, or their payments are means-tested. Clients or users include those with physical and/or sensory impairments, learning disabilities and mental health problems including dementia. Netten *et al.* (2012) and Malley *et al.* (2012) argued that social care ultimately aims to improve people's QoL – i.e. to compensate people for the effect of their impairments on their QoL in a way that is enabling and enables people to make choices about how their needs are met.

Outcome

Outcome is defined broadly in this context as the effect of social care on people's lives (PSSRU 2009). Outcomes in a social care context include QoL rather than simply levels of

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ability, health, employment or housing status.¹ Outcome can be complex to measure in social care, because several types of outcomes of both the user and any family carers may be relevant – these may also be affected by multiple factors. Moreover, interventions may require time to influence people’s lives, and the appropriate timing of the administration of measurements is crucial in order to detect any changes.

Given the high costs of social care overall, and the context of an ageing population, commissioners and providers of social care services increasingly need to demonstrate the effectiveness of their services from the perspectives of users. This is in addition to their standard quality targets. In health research, there has long been such pressure, and, as a consequence, a large industry devoted to the development and assessment of patient-based outcome measures (PROMS) has been established. In contrast, social care-specific outcome measures have been comparatively neglected. A survey of progress in the development of outcomes-focused services for older people in England found that these were relatively recent and fragmented (Glendinning *et al.* 2008).

While health research now aims to measure outcomes of interventions with standardised health status and/or disease-specific quality of life measures, which facilitate making comparisons between studies, most studies of social care outcomes have used a diverse range of outcome measures, including social, physical and mental functioning, life satisfaction, morale, well-being, and health status. As few studies have used the same batteries of measures, comparisons between studies are more difficult to make. One example of the use of a battery of measures in social care is a prospective study to examine the success of a reablement intervention designed to help people (re-)learn the skills necessary for daily living (Francis *et al.* 2011). Apart from measures relating to changes in service use, which are important to include from a service outcome perspective, the authors also aimed to include measurement of the impact of reablement on people’s well-being. They examined this aspect of the outcome of reablement using the following battery of measures: a commonly used and adapted single item question on perceived global health status on a 5-point response scale from ‘very good’ to ‘very bad’; an adaptation of Bowling *et al.*’s (2003) single item on perceived global quality of life on a 7-point scale from ‘so good could not be better’ to ‘so bad it could not be worse’; the Euro-QoL EQ-5D instrument (Euro-QoL 2014); and the Adult Social Care Outcomes Toolkit (ASCOT) (Netten *et al.* 2012).

A systematic review of nine randomised controlled trials of interventions targeting frail elderly people in the community reported that five of these used outcome measurements with unclear psychometric properties, and four used disease-specific measures (Eklund and Wilhelmson 2009). For a fuller discussion of social care outcomes see Netten (2011).

1 www.ccpotland.org/wp-content/uploads/2014/01/outcomes-briefing.pdf

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Quality of life

Quality of Life encompasses how an individual perceives the 'goodness' of multiple aspects of their life. The increasing emphasis on evidence-based practice, and inclusion of user-based outcomes in evaluative research, focuses mostly on QoL outcomes. Maintaining people's broader QoL is a potentially important factor in ensuring that the person can 'live well' and that their care and support up until their death meets their needs. While several measures of broader QoL, embedded within holistic models of functioning, life and needs satisfaction, have been developed for use with people with chronic mental illnesses (Thornicroft and Tansella 1996, WHO 2010), and broader lay-based models and measures have been developed for use with older populations in general (Bowling *et al.* 2003, Gabriel and Bowling 2004, Bowling and Stenner 2011), their development for specific use in social care research has been slow.

Health-related and disease-specific QoL

Concepts of QoL in relation to health and disease ('health-related QoL', 'disease-specific QoL') are commonly used patient-based outcome indicators in health and medical research on patient and client outcomes. They are intended to focus only on the areas of life directly influenced by general health, or the condition, and aim to quantify individual's subjective perceptions about their experiences as affected by their health and of the impact of their health on everyday life (Bullinger *et al.* 1993).

These concepts were traditionally based on a negative model of impaired functioning measured with both objective and subjective indicators of health and functioning and, more commonly, ill-health and disability. Functional status refers to the degree to which a person is able to perform socially allocated roles, free from physical or mental health related limitations, reflecting a positivist or functionalist perspective of society. The aim of measurement has been to track the speed of return to normal activities – in short, to tap the level of difficulty in the performance of activities.

Definitions of health-related QoL overlap with broader health status and include physical, mental, social and role functioning, and health perceptions (for example see Ware and Sherbourne 1992). Some investigators focus mainly on mental and physical functioning. Measures typically ask respondents about the effect of their health (health-related QoL) or condition (disease-specific QoL) on their mental and physical functioning, including mobility and ability to perform everyday household and self-care tasks, and social roles (for example the Short-Form 36 Health Survey questionnaire (SF-36) (Ware *et al.* 1993). Narrower research based on negative models underestimates the QoL of people. A different approach to definition has conceptualised health related QoL as the gap between present health and functional status and one's aspirations for these ('gap' theory) (Calman 1984, Garratt and Ruta 1999). However, this approach necessitates the use of individualised measures of QoL, which are labour-intensive for fieldwork and analysis (O'Boyle *et al.* 1992, Ruta *et al.* 1994).

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The wide range of diverse measures used, and their varying or overlapping emphases, led to the adoption of the term 'patient based outcome measures' or 'patient-reported outcome measures' (PROMS) in recognition of this diversity (Fitzpatrick *et al.* 1998). In clinical and health care research, it is now standard practice to include standardised patient-reported outcome (PRO) measures of generic health-status, health-related or disease-specific QoL. Information from PROs now has a key role in health policy making.

Broader QoL

Broader QoL is more than just health: it is more multidimensional than health-related or disease-specific QoL and is relevant when examining the whole person, and also in evaluating interventions – or conditions – that can affect one's whole life, as in many chronic mental and physical illnesses, particularly in older age (Bowling 2005a). Much conceptual confusion has been created by clinical investigators who erroneously identify QoL with health status and then incorrectly attempt to measure QoL with a health status instrument, such as the Short-Form-36 health survey questionnaire (SF-36) (Ware *et al.* 1993). While health may be relevant to one's QoL, a narrow focus is unlikely to capture the full impact of social care on a person's life.

QoL has been defined in macro (societal, objective) and micro (individual, subjective) terms (Bowling and Windsor 2001). There is increasing recognition of the individual nature of QoL summed up in the WHO QoL Group's (WHOQOL 1993, 1995) definition:

... 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, and standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment.

Each of these areas is relevant to younger and older adults, to those who live in their own homes, and those who live in care homes. However, different people, and people in different age groups, with different characteristics and levels of health, and those with various living circumstances, may have different priorities. For example, relationships, finances and opportunity to work may be prioritised more highly by younger adults, and health and relationships more highly prized by people aged 65 and over (Bowling 1995a, 1995b, 1996). People who have social care needs, particularly those living in care homes, might prioritise the ability to control aspects of their lives and the way they spend their days as most important (Qureshi *et al.* 1994).

Broader models of QoL were heavily influenced by the early social science literature on well-being and satisfaction with life (such as Andrews and Withey 1976, Campbell *et al.* 1976). Some consider these concepts to be major components of QoL, especially in later life, along with psychological components that can be affected by life challenges (e.g. self-esteem) (George and Bearon 1980). A popular model in relation to older adults is Lawton's multidimensional perspective involving assessment of QoL by the person and by social-

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normative criteria of four domains: behavioural competence (ability to function in adaptive and socially appropriate ways), objective environment (everything that exists externally to the individual, including physical and interpersonal factors), psychological well-being (mental health, emotional state), and one's subjective satisfaction with overall QoL (Lawton 1991, 1994). Lawton (1997) expanded on his conceptualisation of QoL to include the multiple domains of:

- affect (happiness, agitation, depression, affect state, emotional expression, spirituality);
- self-esteem (self-esteem, life satisfaction, morale);
- appraisal of physical functioning (self care);
- social relationships (satisfaction with family and friends);
- social environment (social engagement, meaningful time use, physical safety, presence of amenities, privacy, stimulating quality, aesthetic quality, satisfaction with spare time and housing (institution) and healthcare; freedom from barriers); and
- health (behavioural symptoms, psychiatric symptoms).

Lim and Zebrack (2004) defined QoL as multidimensional, both generically and in relation to people with chronic conditions and family care-giving. They acknowledged that, while there is no consensus on specific elements, it encompasses physical health and functioning, socioeconomic status, psychological, emotional, and social well-being, although for carers there are additional elements. These were said to include: burden and family functioning, as well as life satisfaction, adaptation, health, and distress. Netten (2011) referred to an earlier literature review by Schalock (2004) which identified eight core QoL domains: interpersonal relations; social inclusion; personal development; physical wellbeing; self-determination; material wellbeing; emotional wellbeing; rights.

However, such lists omit the considerations of older people's own definitions of, and priorities for, their QoL despite publications identifying these. Fry's (2000) research was based on a combination of survey data and in-depth interviews with older people in Vancouver. She concluded that older adults valued personal control, autonomy and self-sufficiency, their right to pursue a chosen life style and a right to privacy. Farquhar's (1995) in-depth interviews with people aged 65 and over in East London and Essex reported that family, social activities and social contacts were the three commonly mentioned areas that gave quality to their lives. Browne *et al.* (1994), on the basis of semi-structured interviews using the Schedule for Self-Evaluation of QoL (SEIQoL) with people aged 65 and over in Ireland, reported that both family and health were nominated by people as most important to their QoL, with almost equal frequency, followed by social and leisure activities.

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Bowling and Windsor (2001) reported, on the basis of a national survey of adults in Britain, that the highest proportion of adult respondents nominated relationships with family, relatives, friends and others (e.g. neighbours) as the most important area. However, among those aged 65+, relationships were ranked second in importance after health (Bowling 1995b). Population surveys of all adults and people aged 65 and over have reported that people themselves have identified a wider range of life areas as important to them and to their QoL (Bowling 1995b, 1996, Bowling *et al.* 2003, Gabriel and Bowling 2004). The core components, and the central planks, of QoL, which were consistently emphasised by qualitative and quantitative methods, were self-constructs and cognitive mechanisms (psychological outlook, optimism-pessimism, independence and control over life), health and functional status, personal social networks, support and activities, neighbourhood social capital and financial circumstances (Bowling *et al.* 2003, Gabriel and Bowling 2004). There is also a dynamic interplay between people and their surrounding social structures, which influences QoL.

Broader measures of QoL for older people

Many investigators have used measures of well-being, life satisfaction or morale as proxy measures of the broader QoL of older people. One example is the MRC trial of assessment and management of older people aged 75 years and over living at home in the community. This involved evaluations of outcomes, over 36 months, of packages of assessments in primary care, including a multidisciplinary geriatric assessment team (Fletcher *et al.* 2002). Apart from mortality outcomes and use of services, these investigators aimed to measure QoL outcomes. In home interviews, they used the 17-item Philadelphia Geriatric Morale Scale (Powell-Lawton 1975) and the QoL domain of the Sickness Impact Profile, which is a health status measure (Bergner *et al.* 1981) (the QoL domain was limited to items on mobility, self-care, home-management and social interaction).

However, since the turn of the 21st century, broader QoL measures for older people have been developed and tested with good results. The Older People's QoL (OPQOL) questionnaire (Bowling and Stenner 2011) was derived from older people's views, in mixed method survey and qualitative interviews, about what gave their lives quality, what took quality away from their lives, and their relative importance, and compared with psycho-social theory (Bowling *et al.* 2003). These open-ended questions, which are of value when examining people's own views of their QoL, are shown in Box 1.

The full version of the OPQOL has 35 items covering: social relationships and participation; independence (control over life, freedom); psychological and emotional well-being; Perceived financial circumstances; area (home and neighbourhood); life overall; health; and religion and culture. A short version has been developed with good reliability and validity (Bowling *et al.* 2013). The OPQOL was shown to have better psychometric properties than two comparable measures of broader QoL for older people: the CASP-19 and WHOQOL-OLD (Bowling and Stenner 2011).

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Box 1: Open-ended questions to elicit views of QoL (Bowling *et al.* 2003)

'Thinking about your life as a whole, what is it that makes your life good – that is, the things that give your life quality? You may mention as many things as you like.'

'What is it that makes your life bad – that is the things that reduce the quality in your life? You may mention as many things as you like.'

'Thinking about all these good and bad things you have just mentioned, which one is the most important to you?'

Again, thinking about the good and bad things you have mentioned that make up your quality of life, which of the answers on this card best describes the quality of your life as a whole? 7-point QoL self-rating scale: 'QoL so good, could not be better' – 'QoL so bad, could not be worse'

'Thinking about all these good and bad things you have just mentioned which one is the most important to you?'

And what single thing would improve the quality of your life?

'And what single thing, in your opinion, would improve the overall quality of life for people of your age?'

The CASP-19 has 19 items within four domains of control, autonomy, pleasure, self-realisation (Hyde *et al.* 2003), but this was developed 'top-down' based on a theory of needs satisfaction and self-actualisation. The World Health Organization's (WHO) quality of life measure for older people, the WHOQOL-OLD, contains 24 items within seven subscales: sensory abilities, autonomy, past present and future activities, social participation, death and dying, and intimacy (Power *et al.* 2005). This was based on the WHO's multi-dimensional definition of QoL (see above). It was tested across countries with convenience samples. The 'WHOQOL-OLD' consists of the pre-existing main WHOQOL questionnaire developed for all adults (Power *et al.* 1999) with physical functioning added, as suggested by focus groups.

Apart from the OPQOL, most investigators have developed their outcome or QoL measures based primarily on a pre-existing definition of QoL, or on 'expert opinions' of relevant domains to include. One exception in economics is the ICECAP set of measures. These broader benefit measures of well-being (a component of QoL) were designed for use in economic evaluation. These measures were developed from population research to assess 'well-being' based on individuals' level of functioning (includes concepts of health, nourishment, self-respect, socially integration) and capabilities (freedom to carry out these functions) (Al-Janabi *et al.* 2013). They are intended for use with adults, older people, and

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of life care, and carer-related well-being, and further development and testing is ongoing.² Without elicitation of the views of representative samples of the target population, measures will have unknown wider social relevance and no certainty about whether they are measuring the right things.

QOL IN SOCIAL CARE

Given the overall lack of agreement on concepts or measures of social care and QoL outcomes, investigators in social care tend to use separate measures of social involvement and/or life satisfaction as indicators of QoL, for example in assisted living environments (Mitchell and Kemp 2000), as well as measures of morale, health status, anxiety/depression, physical functioning, and needs (Walker and Warren 1996). There has been a heavy emphasis on health status, physical and mental functioning. For example, the evaluation of social care interventions in the Partnerships for Older People Programme (POPPS), across 29 local authority sites, used a narrow 5-item utility measure, with a main focus on physical and mental functioning (EQ-5D – see next section), to assess QoL outcomes (Windle *et al.* 2008). The investigators did attempt to balance this by also using Bowling *et al.*'s (2003) single item asking individuals to rate their QoL as a whole with response categories ranging from 'my life is so bad, it could not be worse', through to 'my life is so good, it could not be better'; each participant interpreting the question according to their own circumstances, preferences and beliefs. Client based outcome evaluations of re-ablement and restorative services in social care have also included the EQ-5D, self-assessed health, and instrumental activities of daily living (Lewin *et al.* 2006, 2013, Francis *et al.* 2011). While indicators of physical functioning and mobility domains within these measures are of obvious direct relevance, additional or broader QoL domains were excluded.

Health status measures

It has been common practice for investigators in social care, as well as health care, to use broader health status scales as proxy measures of QoL, as they tap some QoL domains. These types of measures are often combined with measures of mental and/or physical functioning, health status and well-being, including the Short-Form 36 Health Survey Questionnaire (SF-36) (Ware *et al.* 1993) and utility measures, such as the Euro-QoL 5d, or EQ-5D (EuroQol 2014). There is, of course, a close link and sometimes overlap between what is called social or health care; thus broader health-status and health-related QoL measures are often relevant (Netten 2011), but they are narrow in scope.

The SF-36 (Ware *et al.* 1993) was developed using a computer bank of questionnaires and their psychometrics and designed to measure broader health status. It comprises 36 items within eight subscales – physical functioning, role functioning (physical and emotional),

2 www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/ICECAP-A/index.aspx

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bodily pain, general health, vitality, social functioning, and mental health; two summary measures can be derived for the physical and the mental component summaries. Short 12- and 8- item versions have been developed and a utility measure. The EQ-5D (EuroQol 2014) is a brief health questionnaire consisting of five items covering mobility; self-care; usual activity; pain; anxiety/depression; plus a vertical 20cm visual analogue scale for recording an individual's rating of their health. It provides a simple descriptive profile, and a single index value, of health status for use as a health outcome and utility measure.

Social functioning measures

Measures of broader social functioning have also been used in social care research (e.g. OARS Social Functioning sub-scale, Fillenbaum 1988). The concept of social functioning includes effective interaction with others, and with the social environment, including participation in social groups, networks, activities and engagement in satisfying personal relationships. Social functioning in this multi-dimensional sense is an essential component of QoL. Social activities and interactions are important, as they provide the means by which human needs, satisfaction and well-being can potentially be met. Measures of social functioning and needs satisfaction can all be criticised for their normative bias, and the only method of avoiding this is to ask respondents themselves about their QoL irrespective of societal expectations, as in the Social Behaviour Assessment Schedule and the Social Functioning Schedule (Tyrer 1990, Platt *et al.* 1978, Remington and Tyrer 1979). These broader, social concepts and domains are more limited in narrower health-related and disease-specific QoL scales, which generally have a heavier emphasis on mental and physical functioning, and symptoms.

Broader QoL measures in mental and cognitive health research

In contrast to the developing field of outcomes measurement in social care, there is also a long tradition of broader QoL measurement to assess outcomes in mental health research. These tend to be based on models of needs and life satisfaction (Oliver *et al.* 1996), or models of social functioning (Baker and Intagliata 1982). Abilities to access social relationships, activities and opportunities in life can be impaired by poor mental health and deterioration of social functioning can be common. Subjective domains include indicators of well-being and satisfaction with life, adaptation and circumstances; objective indicators focus on areas such as suitability of housing, independent living and employment (Lehman 1988, Bigelow *et al.* 1991). The subjective components are based on classic socio-psychological models, which emphasise autonomy and control, self-sufficiency, internal control, self-assessed performance, social competence, subjective well-being, happiness, morale and life satisfaction (Andrews and Withey 1976, Larson 1978, Andrews 1986, Abbey and Andrews 1986, Fry 2000). The Lancashire Quality of Life Profile, for example, is frequently used to measure the QoL of people with mental illness (Oliver *et al.* 1996, 1997). This is based on a model of quality of life as an individual's success in obtaining certain prerequisite circumstances and a sense of well-being, needs and life satisfaction including social functioning (Lehman 1988). It includes objective and

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subjective indicators of work, leisure, religion, finance, living situation, legal and safety, family relations, social relations, and health, and also a measure of global well-being. Priebe *et al.* (1999) developed a brief, modified version called the Manchester Short Assessment of Quality of Life.

Several QoL measures have been developed more specifically for use with people with cognitive impairment, such as dementia. However, a systematic review and narrative analysis of the literature on QoL measures in dementia concluded that no existing measures are based on a rigorous conceptual framework (Bowling *et al.* 2014). Some authors state that their measure was based on a concept of health-related quality of life, but with neither little expansion nor reference to social (patient/client) relevance. Others are based on limited domains of QoL (e.g. activity, affect). Some claim to be underpinned by Lawton's conceptual model of QoL, but tap just part of it leaving their measure under-developed. One measure, the Bath Assessment Scales of QoL in Dementia (BASQID), was developed 'bottom-up' with people with dementia and carers, but it excluded some main themes in the final (brief) scale, and the studies underpinning it were small in size (Trigg *et al.* 2007). Many measures are based on proxy assessments or observations of the patients'/clients' QoL rather than patients'/client's own ratings.

Thus, measures of QoL have been developed that are relevant to social care outcomes, but there has been no development of a social care-related QoL measure building on this body of knowledge or incorporating lay perspectives (ASCOT was deliberately limited to experts' priorities and a review of the literature – see later).

The need for multi-dimensional QoL assessment in social care

In reflection of the wider goals and provision of social care, compared to health care, client-based outcome measures need to be more multidimensional than narrower health-related or disease-related measures, reflecting the impact of circumstances and interventions on users' wider lives. The use of a battery of measurement scales can be a strength in the case of complex social interventions influencing several areas of life, although this can be time-consuming and burdensome for the respondent and researcher. The current lack of consensus on conceptualisation, best measurement, and the diversity of approaches used in social care, is problematic for evaluation of services and for evidence-synthesis of the cost-effectiveness of interventions. Homogenisation or the pulling together of diverse measures in combined data sets for comparative analysis is a time consuming task and not always possible when measures have different conceptual backgrounds, different aims (e.g. questions about ability vs. performance in measures of functioning), different question wording and response choices.

In view of the subjectivity of the concept, and in order to achieve social significance, especially in ethnically and socially diverse societies, lay perspectives, not just those of experts, need to be incorporated. However, Netten (2011) argued that if too broad a measure of QoL is used, it may fail to detect effective social care interventions because of the confounding effects of other factors; instead, she advocated, an approach to

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measurement of identifying what outcomes decision makers specify. This reasoning was applied to the development of the adult social care outcomes toolkit for assessing social care-related QoL (ASCOT – see next section); hence, its components reflect deliberate top-down development (Netten 2011). This contrasts with Medical Research Council (2009) guidelines for research priorities for patient-reported outcome measures, which included that there needs to be:

better patient engagement throughout the process of PROM design, validation and reporting. By improving patient engagement, response rates should increase and the patient-important outcomes would become clearer to researchers.
(p.11).

Economics: Adult social care outcomes toolkit for assessing social care-related QoL (ASCOT)

ASCOT is described here because it was developed specifically for use in social care (Netten 2011) and to fill an acknowledged gap in measurement tools, given the absence of dedicated social care outcome measures. It was developed within an economic framework following the extra-welfarist approach (Brouwer *et al.* 2007) and with the aim of developing a utility scale for use in measuring cost effectiveness of interventions. As stated above (Netten 2011), this approach was intended to ensure that measures are sensitive to the impact of care and suitable for measuring the value of outcomes. The developers argued that studies in social care tend to use health outcome measures, such as the EQ-5D, to assess cost-effectiveness, but these focus on people's functional abilities rather than on the impact of support on their QoL. ASCOT was therefore developed to measure the full range of social care outcomes and was envisaged to be more sensitive than the EQ-5D (Netten *et al.* 2012).

ASCOT was designed based on expert review with social care stakeholders to identify the relevant attributes to include (Netten 2011). This was to ensure ASCOT's sensitivity to outcomes of interest to policy makers and relevance to the evaluation of social care interventions. Its development included a literature review of service users' understanding of social care outcomes, and finally cognitive interviews were conducted in order to check social care service users' understanding of terms in ASCOT, and clarify items where needed (Netten *et al.* 2012). Netten *et al.* (2012) and Malley *et al.* (2012) proposed that in order to measure the value of social care services a measure should reflect the compensatory activity of social care, be sensitive to client choice and capture social care-related QoL, and reflect those aspects of QoL that are the focus of social care support.

ASCOT is a multi-attribute preference-weighted measure of SCRQoL. It includes eight distinct attributes: personal cleanliness and comfort; food and drink; control over daily life; personal safety; accommodation cleanliness and comfort; social participation and involvement; and occupation and dignity. ASCOT also includes a preference-weighted measure of social care-related QoL for use in economic evaluations. There is one item per

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attribute. Each attribute has four response options, reflecting four outcomes. The top two reflect states where outcomes are fully realised but differ in the extent to which respondents have choice over how the outcome is realised, or not. In order to generate a single score for use in cost-effectiveness analyses, it was designed to be preference-weighted to reflect the relative importance of the SCRQoL states (Netten *et al.* 2012). A survey of older people receiving publicly-funded home care services was conducted by face-to-face interview in several sites across England to assess the validity of ASCOT; 301 people in 10 areas of England were interviewed (10% by proxy) (Malley *et al.* 2012). Hypothesis testing was used to test construct validity for each ASCOT attribute. Some evidence for the construct validity of the attributes among this sample of older people was reported. It also demonstrated the feasibility of its use among older people, although the need for some proxy respondents indicated a need for a proxy version. While service and policy relevance is essential, the deliberate top-down development of this measure has the consequence that broader user-relevance is less certain, although its validity has been assessed in relation to different service user groups (Malley and Netten 2009, Milte *et al.* 2014).

WHAT ARE THE CRITERIA FOR A GOOD QOL MEASURE?

Where a condition, situation or intervention can affect life overall, comprehensive service evaluation requires broader QoL measurement using validated measures. While well-designed single-item questions have adequate levels of reliability and validity, none have as good psychometric properties as fuller measurement scales. The latter encompass multiple domains of relevance and several items, or questions, can balance out people's natural inconsistencies (Bowling 2005b).

Scientific rigor is required in the development of a measure (see Bowling 2014), including:

- Development of a clear conceptual basis underpinning the measure;
- Rigor in the research methods used to develop and assess the measure;
- Engagement with diverse range of people in the target group from the outset to ensure social significance, as well as policy and practice relevance;
- Use of adequate and generalisable sample sizes, coverage and types for testing, and provision of population norms;
- Use of gold-standard psychometric testing;
- Convincing trade-off between scale length and levels of psychometric acceptability.

It should be pointed out that, in contrast to broader outcome research in health and social sciences, traditional psychometric approaches are not necessarily well-suited to the development of economic preference-based measures, although debate on this issue is ongoing (Brazier *et al.* 1999).

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Psychometric testing of a measure

Whether a QoL outcome measure is potentially useful depends on its psychometric properties. Psychometrics is a well-established scientific field that is concerned with the evaluation of the properties of measures of subjective judgements. A good measure has robust evidence of its (i) validity (does the instrument really measure what it purports to measure?), and (ii) reliability (is the measure stable and internally consistent?). This section is based on Bowling (2014).

Dempster and Donnelly (2001) have also described the main measurement properties of QoL instruments appropriate for use in social care. In relation to QoL, the main challenge is that there is no universally accepted definition or conceptual model of QoL. The multiple definitions in existence largely reflect the interests of investigators, apparent experts' views, prevailing theoretical paradigms, and the multitudes of meanings attributed to QoL. A gold standard of QoL, against which to test the criterion validity of measures of QoL, does not exist.

QoL measures need to be assessed using psychometric gold standards, applied in a methodologically rigorous manner, and scale developers should describe the conceptual model they have used to underpin the measure. Psychometrics include both classic (or 'traditional') and modern psychometric methods, including the acceptability of the questions to respondents (including data quality such as number of missing items), scaling assumptions, reliability, validity, and responsiveness (Food and Drug Administration 1999). Eight criteria listed by Fitzpatrick *et al.* (1998) that investigators should apply to evaluate patient-based outcome measures are:

appropriateness (the match between the aims of the study and the instrument); reliability (the instrument should be internally consistent and reproducible);

- Validity (the instrument should measure what it purports to measure);
- Responsiveness (the instrument should be sensitive to changes of importance to patients);
- Precision (the number and accuracy of distinctions made by an instrument);
- Interpretability (how meaningful the instruments' scores are);
- Acceptability (how acceptable do respondents find its completion?);
- Feasibility (the amount of effort, burden and disruption to practitioners and services arising from the use of an instrument).

The steps that need to be followed for the development of a QoL measure are summarised below and detailed in Box 2.

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Box 2: Summary of classic psychometric methods (Bowling 2014, summarised from Cano *et al.* (2012) Tables 1 and 8 and Bowling (2009); see sources for references to criteria)

Psychometric property	Criteria
Item generation and reduction	<p>Potential questionnaire items should be generated from face-to-face interviews with samples of the target group, and then the pool of items is examined conceptually, and by experts, and reduced using standard psychometric approaches.</p> <p>The generation of the item pool should be conducted alongside literature reviews and consultations with expert groups. The latter should not be used as a substitute for this exercise.</p> <p>Redundant items and those with weak measurement properties, floor and ceiling effects, and high levels of missing data can then be removed, and the resulting items grouped into scales using factor analysis, and then refined to form the intended measurement scale for testing for acceptability, reliability and validity, in a larger survey, before final refinement and testing.</p>
Acceptability	<p>Assessed by data quality and targeting. Data quality: the completeness of item- and scale-level data, assessed by data completeness; criterion for missing data <10%. Targeting: the extent to which the range of the variable measured by a scale matches the range of that variable in the study sample; assessed by maximum endorsement frequencies <80%, aggregate endorsement frequencies >10%, skewness statistic -1 to +1, proximity of scale mean score to scale mid-point (closer matches = better), acceptable distribution of scores (close to 100%).</p>
Scaling assumptions	<p>Assessed by the extent to which it is legitimate to sum a set of items, without weighting or standardisation, to produce a single total score. Criterion is satisfied when items have adequate corrected-item total correlations ≥ 0.30, and grouping of items in subscales is correct.</p> <p>Assessed by principal components analysis (factor loadings >0.30, cross-loadings <0.20), item convergent and discriminant validity (item-own scale correlations >0.30, magnitude >2 standard errors than other scales)</p>
Reliability	<p>Reliability: the extent to which scale scores are not associated with random error.</p>

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Box 2: Summary of classic psychometric methods (Bowling 2014, summarised from Cano *et al.* (2012) Tables 1 and 8 and Bowling (2009); see sources for references to criteria)

Psychometric property	Criteria
Internal consistency reliability	Precision of the scale based on the homogeneity (inter-correlations) of items at one point in time. Assessed by testing whether the items are inter-correlated, using tests of internal consistency (e.g. Cronbach's coefficient alpha ≥ 0.70 ; some use ≥ 0.80), mean item-item correlations (homogeneity coefficient) ≥ 0.30 , and item-total correlations ≥ 0.30 .
Test-retest reproducibility and inter-interviewer reliability	Agreement between respondent's scores at two short time intervals, expected to be stable; it estimates the stability of scales. Scale-level intra-class correlation coefficients ≥ 0.80 , item-level intra-class correlation coefficients ≥ 0.50 , should be achieved. Inter-interviewer reliability: reproducibility of the scale when administered to same respondents by different interviewers.
Validity	Validity: the extent to which a scale measures the construct that it purports to measure.
Face validity	An estimate of whether a test appears to measure a certain criterion.
Content-related validity	The ability of the measure to reflect what is predicted by the conceptual framework for the measure – this can include tests for discriminant, convergent and known-groups validity (see separate listings below).
Validity (within scale)	Evidence that a scale measures a single construct, and that scale items can be combined to form a summary score. Assessed using internal consistency reliability (Cronbach's alpha ≥ 0.70 , again ≥ 0.80 is used by some) and factor analysis (factor loadings > 0.30 , cross-loadings < 0.20).
Validity (correlations between scales)	Correlations between scales: moderate correlations (0.30–0.70) expected.
Discriminant validity	Evidence that a scale is not correlated with other measures of different constructs, hypothesised as not expected to be correlated with the scale.
Known-groups validity testing/ hypothesis tests	Ability of a scale to detect hypothesised differences between known sub-groups.

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Validity

The content and comprehensiveness of a measure are assessed with face and content validity and its burden on respondents requires examination (e.g. how long does it take to administer?).

Construct validity can be ascertained by the extent to which a measure corresponds with theoretically relevant concepts.

The predictive validity of the measure can be assessed using correlations between QoL and, for example, depression, and, for assessment of responsiveness – or sensitivity – to change, these associations are examined longitudinally.

Finally, convergent and discriminant validity are assessed by correlations with the variables QoL is expected to be associated with (e.g. depression) and between variables it is not expected to be associated with (e.g. income among people who are retired) (Bowling 2005a). Its ability to distinguish between groups can be indicated with its correlations with, for example, severity of depression.

Reliability

This is assessed by examining the internal consistency of the measure with item-item, item-total and split-half correlations, including Cronbach's alpha coefficients; and by examining the stability of scale scores over repeated administrations, during different time periods when no changes are expected, whether different interviewers of the same respondents obtain similar results, and whether different modes of administration (e.g. paper questionnaires, telephone or computer-assisted questionnaire, face-to-face interview schedule) produce similar results, and whether it can be used, and is relevant, in different settings (e.g. residential care, clinic, home settings). Scale scores need interpreting and cut-off points need justifying. For example, what does a severe score mean for users and services? How many scale points correlate with improvements or deterioration in other relevant areas?

Structure

The structure of a measure also needs to undergo statistical examination. Does the measure comprise multiple domains (e.g. sub-scales comprising either social relationships, activities, psychological well-being, independence, environmental) that can be scored separately and overall, or just one domain?

Statistical techniques using *classic psychometric methods* include principal components analysis, or exploratory and confirmatory factor analysis (for preference see Tabachnik and Fidell 1996). These methods require item scores to be normally distributed and measured at interval level, although it is commonly used with ordinal level data which carries the risk of biased or inconsistent results. In such cases, it should be used only as an approximate guide to factor structure.

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Modern psychometric item response theory (IRT) is a superior technique, but there are advantages and disadvantages of both approaches. Non-parametric item response theory – Mokken scaling modelling – can be used to evaluate the unidimensionality of the measure, as indicated by scalability (Mokken 1971, Sijtsma and Molenaar 2002, Bowling *et al.* 2013). Mokken's *monotone homogeneity model* comprises an item selection phase, in which ordinal items measuring the same construct are clustered using an iterative procedure, followed by tests of the monotonic relationship between each item and the resulting scale. The summed scores of a set of items conforming to this model stochastically orders respondents on a single dimension.

Other considerations

Additional issues include whether carer versions have been developed to measure carers' QoL also, and whether proxy measures can be used, if individuals are too ill or unable to complete a measure, and whether these are reliable. Proxy measures are commonly used in research evaluating palliative and dementia care, although they have been reported to have poor reliability (Addington-Hall and Kalra 2001). If a measure is to be used in other languages than the one it was designed in, then cultural equivalence needs to be established using standard, rigorous processes. The quality of research inferences is influenced by the psychometric robustness of the measurement scale used.

Methodological issues

As QoL is subjective and reflects people's values, researchers need to take account of changes in these in their analyses of QoL: perceived QoL can change over time with life experiences. Consciously or unconsciously, people may accommodate, or adjust, to deteriorating circumstances, because they want to feel as good as possible about themselves, thereby leading to their perceptions of having a higher QoL when followed up (Diener *et al.* 1991). The roots of this process of adaptation are based on control theory, with response shift as a mediator that aims for homeostasis, and thus internal standards and values change - and with them, so do perceptions of QoL (Sprangers and Schwartz 1999). Thus all researchers using measures of QoL need to exercise caution when interpreting change data.

As the development of a QoL outcome measure in social care is in its infancy, there are several other methodological issues to consider when choosing a measure, including its relevance and appropriateness to the client or user group, and social policy and practice, as well as relevance in different settings (see summary in Box 3).

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Box 3: Summary of some key methodological issues

There is a dearth of broader social care related QoL measures.

A broad approach to measuring QoL in social care is needed, as social needs and care can affect life as a whole.

Measures need to be appropriate for younger and older people, different clients and types of services, and be sensitive to cultural differences.

Measures need to be relevant to the target group, and applicable in a range of settings (e.g. community to residential care); they also need to be responsive to changes in individuals resulting from interventions.

Consideration of a generic core measure of QoL is needed, with additional domains for specific groups and settings.

Partners may respond differently to other family carers – measures need to be appropriate for each type of respondent.

Scale development needs to start 'bottom-up' by eliciting the perspectives of the target groups: only through their rigorous and sensitive involvement can outcome measures be developed which have social relevance.

Response shift has enormous implications for the assessment of QoL, particularly in the interpretation of change and in shedding light on the paradoxical findings so often obtained.

CONCLUSION

Measuring quality of life is one of several components for assessing the effectiveness of interventions. When a person has a long-standing or restricting condition, their QoL can influence how they cope with their condition, everyday activities, and life in general. Equally, the management of their situation and care can affect their overall QoL, beyond the condition itself. Therefore, being concerned about the quality of a person's life is good practice in social, as well as health, care and important to include in the measurement of outcomes.

With the exception of ASCOT, which was developed within an economics framework, few conceptual models have been developed specifically to measure social care related QoL and measurement has thus suffered accordingly. There is no *specific* concept or measure of *broader* social care-related QoL that has been developed 'bottom-up' with users or clients using a participatory approach. Rigorously conducted conceptual and methodological

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research, using gold standard psychometric techniques, and based on a participatory, 'bottom-up' model, as well as inputs from policy makers and practitioners, is needed to address this gap.

No measurement scale is perfect. However, principles of good practice in scale selection, for those carrying out social care research where QoL is a target outcome, include doing the following things:

- Think about your research questions, the aims of interventions, and whether you need to use a single measurement scale or a battery of complementary measures within your questionnaire/interview schedule? What domains do you need to include?
- Examine the relevant literature in relation to the measurement of these domains and consider the psychometric properties of potential measures. In particular, check the ability of the instrument to measure what it purports to (validity), its stability (reliability), and responsiveness to change over time. This depends upon the rigour of its development and testing. Also check whether target user and client groups were involved in its development. Reviews of the measures of interest may have been published, which have the advantage of comparing measures and summarising their strengths and weaknesses.
- Check what populations the measure was developed with and in what settings: measures developed in community settings may not be appropriate for use in residential care settings.
- Consider whether the measure is easy to use in your study setting. Think about how long it will take to complete and how time-consuming it might be for the respondent and researcher.
- If translated versions of the selected measure are required, search for published translations where semantic, idiomatic, experiential and conceptual equivalence has been established by standardised translation, back-translation, panel review, and pre-testing techniques.
- Check whether the scale has been copyrighted and whether permission is needed to use it. Some can be used without charge; others require consent plus a fee per copy used.
- Consider whether you need to undertake expensive interviews or can use more economical self-administered questionnaires. While many instruments can be administered in either mode, some may be too lengthy for self-administration (and lead to people giving up and not responding). Self-administration also depends on people being able to see and read, and comprehend, the questions; telephone administration may not be appropriate for people with hearing difficulties; internet questionnaires also assume everyone has access to the internet. There is a digital divide among several social groups, in particular among older people: just 37% of

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households above the state pension age have internet access, compared with 79% of households below the state pension age (Randall 2010, Berry 2011). The best response rates, and best quality data, are obtained with interviewer administered questionnaires (Bowling 2005c).

- Ask whether the measure is sensitive enough to detect changes in individuals over time as a result of interventions – and at what time periods it should be administered in order to detect any changes.
- If unsure, then careful piloting of potential measures with the target group is needed.
- Finally, if existing QoL measures might not capture all relevant aspects of the situation, then the investigator can include open-ended questions for the respondent to add other issues important to them (e.g. see Bowling *et al.*'s open-ended generic QoL questions in Box 1). Their thematic categorisation and analysis, of course, while insightful, can be time-consuming.

This review aimed to provide a brief overview on the measurement of QoL in social care research. While there are several technical issues to consider when choosing and administering a measure of QoL, these are not intended to be daunting to the researcher. Few measures satisfy all psychometric criteria perfectly; the design and testing of all measures are time-consuming and expensive. The body of knowledge about the adequacy and applicability of each measure in different settings, and with various populations, is cumulative and established over time; all researchers can contribute to this by publishing critical papers about the performance of the measures they have used, whether on basic assessments of reliability and validity, or more complex examination of scaling criteria. This overview is intended to be an informative summary of the main steps involved in selecting a measurement scale and to test them further.

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NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE

020 7955 6238
www.sscr.nihr.ac.uk
sscr@lse.ac.uk



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