

Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths

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Abstract

Background: providing support to a family member with dementia often comes at a cost to the quality of life (QoL) of the carer (caregiver), giving rise to current and future unmet needs for health and social care and support themselves. These have important implications for cost-effective health and social care support services and pathways. This article summarises the findings of a scoping review of the literature on QoL measures for carers of people with dementia that was commissioned by the Medical Research Council to address what is 'state of the art' in measurement and identification, any gaps in the evidence base, and challenges for further research.

Method: a scope of the literature using Medline and Psychlit (all years) as these are particularly relevant to health psychology was undertaken in March 2013, using combinations of the following keywords: quality of life, measure, scale, caregiver (including carer), chronic illness (the term long-term condition is generally captured under this phrase), dementia, cognitive impairment, Alzheimer's disease.

Results: there is a dearth of carer-reported QoL measures, in contrast to the existence of proxy scales for carers which are used to measure the patient's/client's QoL (prevalent in relation to dementia). Several methodological challenges were identified.

Conclusion: caring for people with dementia often has both negative and positive consequences which need inclusion in measures but these may vary by individual and over time. The lack of consensus about what to measure and how in QoL of carers of people with dementia does not help practitioners or service funders. Measures need to be appropriate for younger and older carers, type of carer and caring tasks, and be sensitive to cultural and socio-demographic differences.

Keywords: dementia, carers, quality of life, health care, social care, measurement, questionnaire, psychometrics

Background

There is international interest in finding out the most effective ways of supporting family carers of people with long-term conditions and disabilities (Parker, Arksey & Harden, 2010) and concern that the numbers of carers will be insufficient to meet the needs of people requiring care and support leading to a possible 'care gap' (Pickard, 2015). The United Kingdom (UK) Coalition Government's action plan - '*Recognised, valued and supported: Next steps for the Carers Strategy*' (HM Government, 2015) - expressed a commitment to '*reciprocate the support carers show with measures that ease the responsibility of caring*' (p.3). It emphasised that supporting carers to remain mentally and physically well should be a key component of prevention and requires a public health approach (HM Government, 2015). In England, all carers were given new legal rights to assessments of their needs under the Care Act 2014 and campaigning groups for carers are active in the policy sphere (Carers UK, 2013; Carers Trust, 2015).

Of the 5.8 million adult carers in England and Wales (White, 2013) there are an estimated 550,000 carers of people with dementia in England. While the costs of dementia are calculated at £19 billion a year (DH, 2013), their carers are estimated to save £8 billion a year in public expenditure and societal costs (Alzheimer's Society, 2012). As with many other carers of

people with long-term conditions, including dementia, carers provide a wide range of practical and emotional support, social care, home nursing, and help with many aspects of daily living. Tasks can include help with personal care, managing finances and legal affairs, provision and assistance with consumption of food and drink, social activities, mobility, emotional support, administering and coordinating medication. Support may be substantial and regular or low level and fluctuating, however, people with dementia generally need higher levels of care as their symptoms progress (Brodaty & Donkin, 2009). There is also increasing recognition of the diversity of carers and Moriarty *et al.* (2011) note that, as the population of Black and Minority Ethnic (BME) people with dementia and their carers becomes more diverse in England, access to support tailored to their own individual circumstances will need to be assured.

Maintaining carers' quality of life (QoL), including mental and physical functioning and their economic wellbeing, is therefore important at several levels. First there is a need to ensure that the person with dementia can 'live well' (DH, 2009) and that their care and support up to death meets their needs and wishes. Second, there is a need to minimise the risks to carers of adopting this role, for their own benefit physically, mentally and economically, and also socially to enable them to stay in or return to employment (King & Pickard, 2013). Potentially the QoL of one affects that of the other, whether or not they live together. However, it is increasingly acknowledged that providing support to a family member with dementia often comes at a cost to the QoL of the carer, potentially giving rise to current and future unmet needs for health and social care and support themselves. These have important implications for cost-effective health and social care support services and pathways, and the QoL of the carer requires understanding, accurate measurement and identification and a tailored, sensitive and timely response from practitioners and the wider community.

Aim and method

This article summarises the findings of a scoping review of the literature on quality of life (QoL) measures for carers of people with dementia that was commissioned by the Medical Research Council to address three key questions: 1) What is the 'state of the art' regarding QoL measurements for carers, specifically of people with dementia and living at home?; 2) What topics require further investigation?; and 3) What are the possible and predictable challenges of such research that will need to be addressed?

A scope of the literature on this topic using Medline and Psychlit (all years) was undertaken in March 2013 using combinations of the following keywords: quality of life, measure, scale, caregiver, chronic illness, dementia, cognitive impairment, Alzheimer's disease.

Scoping reviews are of value in identifying research gaps, and are increasingly used for such purposes (Arksey & O'Malley, 2005). A summary of the findings, with gaps in research identified, is presented next (for full details of the review please contact the authors) with discussion focusing on England in particular. While various terms are used in the literature (caregivers, family carers, informal carers), we use the term 'carer' to reflect the choices of the main carers' organisations, and policy and legislation in England. Similarly, the term 'dementia' is used as an overarching term, although the term 'Alzheimer's disease' is referred to even though it is not necessarily being used in a diagnostic sense. In this review, we use 'dementia' to cover different types of diagnosed or recognised cognitive impairment.

Findings

Concepts of QoL, and in dementia: the state of art

With the increasing emphasis on evidence-based, or evidence informed, policy and practice (DH, 2014) inclusion of patient- or user-reported outcome measures of generic health-status, health-related and/or disease-specific QoL, are generally used in evaluations of care.

The information they yield has a key role in policy-making. Thus, the US Food and Drug Administration and the European Medicines Agency have released guidelines specifying minimum criteria for the scientific adequacy of scales used in clinical trials, although controversies remain (Bottomley *et al.*, 2009). The quality of research inferences is inevitably influenced by the appropriateness and robustness of the measurement scale used.

In England there has been great interest in developing carer outcomes to be used in parallel with outcome measures for users of social care services; 2012-13 was the first year in which the ASCOF measures, based on the Personal Social Services Survey of Adult Carers in England (Carers' Survey), were included in a national survey of whether social care users and carers feel that the social care they receive is leading to better outcomes (HSCIC, 2013). This carer-reported QoL score has an optimal positive score of 12; in 2012-2013, the average score was 8.1, interpreted as meaning that 42.7 per cent of carers reported themselves as extremely or very satisfied with social care services (arranged, provided or funded by local councils) (HSCIC, 2013, p.18). The ASCOF quality of life score was based on responses to six questions; one of which was satisfaction with care services (see Netten, 2011 for a helpful overview of ASCOF).

Quality of life (QoL) is an increasingly important measure in evaluations of health and social care more generally (Bowling, 2014a). Aside from the ASCOF Users and Carers Survey (see above), models and measures of QoL used to evaluate health and social care interventions are primarily health-related, with a heavy emphasis on physical and mental functioning. In contrast, carers themselves often identify a wider range of life areas as important to them, although, not surprisingly, these may be affected by health conditions (Bowling *et al.*, 2014). The concept of QoL is relative, and the perspectives of people with dementia – as well as their carers, and carers generally – were neglected in its early developments. Where a condition can affect life overall, broader QoL measurement is required, in addition to capturing elements specific to the caring circumstances. For policy outcomes to be relevant to carers, measures of QoL need to have social, as well as policy, relevance, and conceptual strength. QoL is a subjective concept, and thus measures need to be socially relevant and need the participation of the population concerned in their development. Few investigators developed their measures 'bottom-up' with the population of interest, and tended to focus instead on 'expert opinions'. Thus, most measures have unknown social relevance, and there is no certainty about whether they are measuring the right things.

Definitions of QoL often vary by discipline of the investigator and by the population group being focused upon. Some dementia-specific measures of QoL (e.g. the Quality of Life in Alzheimer's Disease (QOL-AD & QOLAD-Carer proxy version; Logsdon *et al.*, 1999) claim to be conceptually based, but most have no conceptual underpinning, or are domain-specific or health-related. Overall, there is no consensus about QoL in dementia, and different investigators have developed frameworks and measures based on different domains and methodologies. Moreover, most measures of QoL or health-related QoL that are used with people with dementia and their carers (for proxy assessments of the former) have questionable reliability and validity, some require observations which are time consuming and expensive, or, more recently, rely on questioning the person with dementia themselves, which is possible with people with mild-moderate dementia (Smith *et al.*, 2005; Trigg *et al.*, 2007; Bowling *et al.*, 2014a), but is increasingly difficult as communication deteriorates as dementia progresses.

Scale development has been even slower in relation to carers' assessments of their own QoL, as opposed to their proxy assessments of the QoL of the person they are caring for. 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, socio-economic status, psychological, emotional, and social wellbeing, 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. Given the lack of agreement on concepts or optimal

measurement instruments, researchers commonly use broader health status scales as proxy measures of quality of life, or health-related quality of life. These types of measures are sometimes combined with disease-specific measures of symptoms, mental and/or physical functioning, generic and disease-specific 'quality of life', and wellbeing. The wide range of diverse measures used, and their varying or overlapping emphases, stimulated adoption of the term 'patient based outcome measures' (PROMS) (HSCIC, no date).

Outcome measurement: the 'state of art' specific to carers

Outcome measurement among carers, including those of people with dementia, relies heavily on the use of different measures. The reported negative effects of caring on the carer include high rates of burden, stress, exhaustion, anxiety and depression, use of psychotropic medication, social isolation and impaired family life, low life satisfaction, impaired sex life, fatigue/sleep deprivation, physical ill-health, financial difficulties, and partners feeling in marital limbo, fears for the future (Guerriero-Austrom & Hendrie, 1992; Jones & Peters, 1992; Rees *et al.*, 2001; Lim & Zebrack, 2004). Lim and Zebrack's (2004) review documented how caring for chronically ill family members, or 'significant others' at home influences multiple aspects of carers' lives (including worsened physical health, impaired social and family life, increased stress, anxiety and depression). Coen *et al.* (1997) - in a review of carers' QoL and that of people with Alzheimer's Disease - concluded that the level of burden and its impact on the QoL of carers must be taken into account when examining commonly used proxy assessments of the QoL of people with Alzheimer's. The negative aspects of caring for people with dementia tend to receive most attention in this research, but caring has also been associated with positive feelings and outcomes (Coen *et al.*, 2002), which are relevant for the assessment of QoL. Positive experiences include closeness, reciprocity, spiritual growth, increased self-esteem and mastery. Socio-demographic factors can also influence carers' perceptions of their roles. Positive perceptions have been associated with lower education and socio-economic status, greater satisfaction with social participation, better physical health status, being 'non-Caucasian', and being older (Haley *et al.*, 1996; Kramer, 1997; Rees *et al.*, 2001; Rapp & Chao, 2000).

Lim and Zebrack's (2004) review concluded that studies used diverse positive and/or negative outcomes and models to indicate carers' QoL (psychosocial: adaptation, mental health, life satisfaction, stress, emotional distress, health, caregiver burden, and depression). Of the 19 articles they reviewed, only one used a single measure of QoL for carers *per se*: the Caregiver Quality of Life Index, containing items related to physical, emotional, social, and financial wellbeing. This had been developed specifically for carers of cancer patients (Weitzner *et al.*, 1999). The remaining papers used modified measures, single or composite measures of selected QoL concepts (e.g. burden, mood, health status). Rees *et al.*'s (2001) earlier overview also reported that burden of care detracts from carers' QoL, but again QoL was measured by different batteries of domains, or modified measures; leading them to conclude that very few instruments had been developed specifically to measure carer QoL.

Most research, while purporting to measure QoL of carers, focuses mainly on specific domains, or uses batteries of several different measures [burden depression, anxiety depression, social support (Charlesworth *et al.*, 2008), stress and burden (Vitaliano *et al.*, 1991), brief QoL utility measures (EQ-5D, by Spijker *et al.*, 2009), or adaptations of patient-reported dementia-QoL measures, based on the untested assumption that they are relevant and tap pertinent domains for carers (e.g. Dementia QoL questionnaire (DQoL), by Graff *et al.*, 2007); adapted Alzheimer's Disease related QoL (ADRQL), Thomas *et al.*, 2006]. For example, Bruvik *et al.* (2012), in their study of 230 dyads of people with dementia and their family carers, adapted the QoL-Alzheimer's Disease scale (QoL-AD) (Logsdon *et al.*, 1999) to assess the QoL of the carer, and also used it for carers' assessments of the QoL of the person with dementia. They justified this with reference to the fact that the QoL-AD had been used to measure carers' QoL in two previous studies, while acknowledging that this scale had not been validated for assessments of carers' own QoL (Shin *et al.*, 2005; Rosness *et al.*, 2011).

The lack of validated carer-specific QoL measures has also led to the use of generic health status measures as proxies, as they tap some overlapping QoL domains, for example, the Short-Form 36 Health Survey Questionnaire (SF-36) (Ware, 1993). Argimon *et al.* (2004) aimed to assess the health-related QoL of carers of people with dementia, compared with an age- and gender-matched sample from the general population using the SF-36. This instrument includes sub-scales of physical, mental and social functioning, and was designed to measure broader health status. Argimon *et al.* (2004) used it with the implicit assumption that it is the same concept as health-related QoL, and appropriate for carers. They noted, however, that the SF-36 had not been validated in respect of the carers of people with dementia. Arango-Lasprilla *et al.* (2010) also used the SF-36 to measure the HR-QoL of carers of people with dementia in Colombia, although uncritically.

However, a condition specific measure of the QoL of carers of people with dementia was developed from studies of the difficulties of carers of people with dementia being cared for at home, and has been validated in France (Thomas *et al.*, 2002; 2006). This was based on the generic WHOQUAL Group (1993) concept of QoL as ‘the individual perception of a human being’s position about life, cultural background, considering his (sic) value in relation to his objectives, goals, and standards’, and on their research on carers’ complaints, interrelationships and what causes them – rather than quality of life *per se*. This measure includes 20 items spanning several areas of a carer’s life. Four main domains of observation were addressed: behavioural capacities to face difficulties generated by the person with dementia (A), relation with the environment (B), psychological perception of the situation (C), perception of a possible distress (D). These are summed to create an overall score of a carer’s QoL and represented as a percentage. A score of zero (0) indicates poor QoL, a score of 100 indicates good QoL. Validity was supported by correlations with socio-demographic characteristics of the people with dementia and their carers, a proxy measure of QoL of people with dementia that was administered to physicians and carers (Rabins *et al.*’s (1999) ADRQL (Alzheimer’s Disease Related Quality Life)), and neuropsychology assessments of behavioural and psychological symptoms of dementia; associations were weaker with duration of dementia (Thomas *et al.*, 2006). The measure still requires thorough testing, and addresses only a limited number of potential QoL domains.

One of the few ‘bottom-up’ studies of QoL of carers was a qualitative study of carers of people with dementia living in Sardinia, which asked carers themselves to identify the components of their QoL (Vellone *et al.*, 2012). Questions asked of carers included the following:

1. *Considering the fact that you take care of a person affected by Alzheimer’s disease, what do you think QoL is?*
2. *Which factors do you think improve your QoL?*
3. *Which factors do you think worsen your QoL?*

The themes identified from their phenomenological analysis of what constitutes QoL are presented in **Box 1** and illustrate the range of potential views. These may be useful areas around which to base evaluations and engagement.

Finally, the matter of a ‘condition-specific’ QoL measurement for carers is indicated by studies of carers that have reported different stresses by type of condition. Some studies have reported that caring for a person with dementia is more burdensome and stressful than caring for a person with a physical disability (Schulz *et al.*, 1990; Mohide *et al.*, 1998; Ory *et al.*, 1999). This suggests that condition-specific measures may be needed for carers. While using generic measures has the advantage of being able to compare different groups (see HSCIC, 2013), they may fail to capture areas that are carer- and disease/condition-specific. Thus the exploration of condition-specific QoL measurement among carers, with generic cores, merits attention, as does detailed analysis of existing data where such information can be compared and models of understanding developed.

Box 1. Summary of themes identified by Vellone *et al.*, 2012.

Overall components

Unity and cooperation in the family

Freedom, independence, having time for themselves

Serenity/tranquility

Wellbeing and health

Factors worsening QoL

Fear for the future: for the care needed and for the illness worsening

Continuous care of the patients, not having time for themselves

Factors improving QoL

No worsening of the illness

Help and support from family

Help from formal services

Satisfaction and reward from giving care

Financial support for paying other assistants

More free time

More public sensitization (awareness) about Alzheimer's Disease

What topics require further investigation?

Notions of carer stress are the most prevalent in the literature on the impact of caring on carers. Several factors contribute to stress, as summarised by Brodaty and Donkin (2009), these include: background factors (level of support received and impact of other life events), primary stressors of the illness (such as the level of help required, behavioural and psychological problems), secondary role strains (such as family conflict and social life), and intra-psychic strains (personality, competence, and role captivity of the caregiver such as feelings of being “trapped” in their caring role), as well as carer overload (e.g. fatigue and burnout). However, research findings are inconsistent on the impact on carers of the duration of caring. Explanatory models included suggestions that caring for someone with dementia leads to burden and strain that can be exacerbated (e.g. by behavioural disturbance, physical or psychological ill-health) or ameliorated (e.g. by support, mature coping mechanisms) (Poulshock & Deimling, 1984).

Three theories have been proposed to explain carer stress. The ‘adaptation hypothesis’ suggests that over time carers adapt to the demands of their role (Rabins *et al.*, 1990); the ‘wear and tear’ hypothesis proposes that the longer a carer remains in his or her role, the more likely negative outcomes are to occur (Townsend *et al.*, 1989; Zarit *et al.*, 1986); the ‘sequestration hypothesis’, proposes that people with dementia are more likely to move to long-term care where their carers are experiencing greater stress, thus removing them from population research samples (Brodaty *et al.*, 2005).

Other models focus on the consequences of reduced social support. Charlesworth *et al.* (2008) summarised the literature on the impact of caring on carers’ wellbeing. They found reductions in their social interactions and friendships, and increases in family role conflicts, owing to a lack of opportunities to socialise and/or the stigma associated with the condition. They reported that carers who are socially isolated are more vulnerable to the negative impacts of caring, including risks of loneliness and its reported associations with increased mortality and morbidity, including psychiatric morbidity. There is an established literature on the associations between low levels of social networking and increased morbidity and mortality. Theoretical models underpinning this literature focus on both the direct (e.g. information giving, instrumental and emotional support) and indirect effects (e.g. stress buffering model) of social support on health and mortality (see Holt-Lunstad *et al.*, 2010).

Lim and Zebrack (2004) argued that family stress theory has potential for the greater understanding of carers’ experiences and behavioural outcomes, by examining how multiple aspects of carers’ QoL may be partly influenced by other existing environmental stressors, stress appraisal, coping methods and social support: the family is seen as facing and dealing with challenges as a normal part of family life. Studies of variables influencing carers’ QoL were also summarized in their review (patient/user characteristics, carer characteristics, stressors, stress appraisal, stress coping methods, and social support).

What are the possible and predictable research challenges?

Psychometrics is a well-established scientific field that is concerned with the measurement of subjective judgements using numerical scales and the evaluation of the measurement properties of such scales (e.g. reliability, validity, responsiveness). The literature, when synthesised, suggests that these are possible steps to be followed for the development of a QoL measure (see **Box 2**). Psychometric properties would then be examined using both classic (or ‘traditional’) and modern psychometric methods: these include acceptability (including data quality), scaling assumptions, reliability (e.g. internal consistency and test-retest reproducibility); validity (e.g. convergent and discriminant validity); and responsiveness. These underpin the US Food and Drug Administration (FDA) recommendations for patient-reported outcome instrument evaluation (see FDA, 2006).

Box 2. Summary of classic psychometric methods (Bowling, 2014a, 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 a small sample of the target group, 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 from a sample of the target group should be conducted alongside literature reviews and consultations with users and 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 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 final 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 (closer to 100% indicates better targeting).</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. 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>
Internal consistency reliability	<p>Precision of the scale based on the homogeneity (inter-correlations) of items at one point in time. Assessed by testing whether 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</p>
Test-retest reproducibility and inter-interviewer reliability	<p>The agreement between respondents' scores at two short time intervals, where they are 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: the reproducibility of the scale when administered to the same respondent by different interviewers.</p>
Validity	<p>Validity: the extent to which a scale measures the construct that it purports to measure.</p>

Psychometric property	Criteria
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 later).
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 $\alpha \geq 0.70$, 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 testing	Ability of a scale to detect hypothesised differences between known sub-groups.

Discussion

This review focused on three key questions. We found that QoL outcome measures for carers are emerging and some are condition specific to dementia. They are even beginning to be used in practice or commissioning. However, several methodological challenges remain. For example, most studies assessing the impact of long-term conditions on carers are cross-sectional. There is a dearth of carer-reported QoL measures, in contrast to the existence of proxy scales for carers which are used to measure the patient's/client's QoL (these are prevalent in relation to dementia). This is important as the research community is becoming more aware that the carer's perceptions of the QoL of their relative or friend with dementia may be influenced by their own interests and stressors. Such a point is often made by practitioners in our experience. Similarly, generic versus condition-specific QoL measures for carers require assessment but there is also the complexity that most people with dementia have multiple long-term disabilities and/or impairments and that these are interrelated (Melis *et al.*, 2013). A particular challenge in outcomes research and in outcome measurement in local services is that people's values may change over time as they adjust to their circumstances. This has enormous implications for the assessment of QoL, the interpretation of change, and in shedding light on the paradoxical findings so often obtained.

As noted, caring for a person with dementia often has both negative and positive consequences which require inclusion in measures but these may vary by individual and over time. Measures need to be appropriate for younger and older people, type of carer, and be sensitive to cultural and class differences. For example, partners may respond differently to other family carers

such as adult children, and sons differently from daughters – so measures overall need to ensure relevance. Thus a broader approach to measuring the QoL of carers is needed and one that goes beyond health- and care-related items because caring can affect life as a whole, both currently and in the future. Scale development needs to start ‘bottom-up’ by eliciting the perspectives of the target group (e.g. carers); only through their rigorous and sensitive involvement can outcome measures be developed which have social relevance.

A great deal has been learnt from decades of work on QoL and from studies of carers. First, that scientific rigour is required in the development and testing of relevant carer QoL outcome measurement, in order to make their use worthwhile. Tools such as ASCOF have received substantial resource, much investment in terms of practitioner time and effort, and are continuing to be further evidence based, especially around intervention effects (Sutcliffe *et al.*, 2012) since the carers surveyed are in receipt (or the person they care for) of publically funded social care services (the intervention). Rand *et al.* (2015) recently reported following their interviews with 387 carers collecting data on variables hypothesised to be related to SCRQoL (e.g. characteristics of the carer, cared-for person and care situation) and measures of carer experience, strain, health-related quality of life and overall QoL, that:

The results provide evidence to support the construct validity, factor structure, internal reliability and feasibility of the ASCOT-Carer INT4 as an instrument for measuring social care-related quality of life of unpaid carers who care for adults with a variety of long-term conditions, disability or problems related to old age.

As the DH (2012, p.10) notes, the Carers’ Survey (on which ASCOF draws) is close to being the ‘carers’ equivalent of the overarching social care-related quality of life measure’. The present ASCOF Carers’ Survey is biennial, but may become an annual collection if the effort and expense of undertaking the survey can be substantially reduced, subject to local government agreements and national agreements about resourcing and data requirements. The results will likely be valuable to carers, practitioners and funders and when it is possible to cross-tabulate the findings related to carers of people with and without dementia then services and support may become more personalised and effective.

Second, wider assessments of carers’ QoL may benefit from development or refinement of a clearer conceptual basis underpinning the measure(s). Rigor in the research methods used to develop and assess the measure will be needed but so too is the need for these measures to be relevant to outcomes. Such work needs more engagement with diverse current and former carers from the outset, to ensure social significance, as well as experts and practitioners to ensure policy and practice relevance. Use of adequate and generalisable sample sizes, coverage and types for psychometric testing are also needed. We have proposed above that the use of gold-standard psychometric testing is required, using classic (traditional) and modern methods. These need to include assessment of predictive validity over time, responsiveness to changes in outcomes, interpretability, and use in decision-making.

There are wider implications in relation to the measurement of QoL. For example, dementia caring might be combined with other forms of care-giving (sometimes termed ‘sandwich’ caring when it involves care for children and for ageing parents), and some carers will have cared for more than one relative – with accumulating experiences. Investigators should consider using a core generic QoL measure (for generalisability across carers by condition of the person cared for), as well as relevant condition-specific modules (e.g. for carers of people with dementia or carers supporting people with severe learning disabilities). This also needs to take into account the trade-offs between scale length and levels of psychometric acceptability and the growing emphasis in practice on personalised support and funding for people with dementia and for their carers, amongst others (Glendinning *et al.*, 2013; Newbronner *et al.*, 2013). Changes in social care and health services between the different countries of the UK will make it all the more important to be able to have confidence that impacts on the carers of people with dementia (amongst others) are being accurately measured so that any comparisons are valid.

It should be cautioned that this overview does not claim to be comprehensive, and is limited to results from a scoping review rather than a systematically conducted review of the literature. Thus our conclusions are tentative. However, scoping reviews are of particular value with neglected topics, and in identifying research gaps (Arksey & O'Malley, 2005). Following our review the MRC subsequently commissioned a major study, DECIDE (Dementia Carers Instrument Development) (see <http://gtr.rcuk.ac.uk/projects?ref=MR/M025179/1>) (contact Penny Wright at the University of Leeds, e.p.wright@leeds.ac.uk). This study acknowledges that having an accurate and meaningful way of measuring carer quality of life is needed in three distinct areas and will focus on:

1. Individual carer assessment: to identify carers most at need,
2. Service development and evaluation,
3. Informing policy-making and decision-making around government spending.

In addition to this, the work of the DH's Policy Research Programme's Quality and Outcomes of Person-centred Care Policy Research Unit (QURU-<http://www.qoru.ac.uk/>) continues to add to the evidence base (most pertinently to this present paper, see Rand *et al.*, 2015).

Conclusion

There is great political and policy interest in promoting research in dementia (DH, 2013). This present overview has concluded that methodological development in the measurement of QoL outcomes is still needed. Few conceptual models have been developed specifically to measure carer QoL, including carers of people with dementia, and measurement has thus suffered accordingly. Rigorously conducted conceptual and methodological research, using gold standard psychometric techniques, and based on a participatory, 'bottom-up' model with carers, as well as policy makers and frontline practitioners, is needed to address this gap. Policy initiatives, as well as care and support more generally for carers of people with dementia can then be evaluated, modified and bolstered from this evidence.

Acknowledgements and disclaimer

We are grateful to the Medical Research Council (MRC) for commissioning this review. The views expressed are those of the authors and should not be interpreted as those of the MRC or the Department of Health.

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