PAPER

Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia

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Objectives: To explore the extent to which commonly used measures of specific outcomes in dementia are an appropriate proxy for quality of life in dementia.
Methods: This was a cross sectional study set in communities in London and Nottingham, comprising 101 people with dementia and their 99 main family caregivers. The main outcome measures were health related quality of life in dementia (measured by the DEMQOL-Proxy), cognition (Mini Mental State Examination), functional impairment (Barthel Index), behavioural and psychological symptoms in dementia (Neuropsychiatric Inventory; NPI), and carer mental health (General Health Questionnaire).
Results: On univariate analysis, decreased quality of life was statistically significantly correlated with higher levels of behavioural and psychological disturbance (NPI total score and its agitation, depression, anxiety, disinhibition, and irritability subscales); younger age of the person with dementia; and poorer mental health of the carer. Quality of life was not statistically significantly associated with cognition or carer age. In a multivariate model, psychological and behavioural disturbance and patient age remained statistically significantly associated with quality of life. Carer mental health was no longer statistically significantly associated, and cognition and functional limitation remained statistically insignificant.
Conclusions: These data suggest that quality of life in dementia is complex, and that simple proxy substitutions of discrete measures such as cognition or function are likely to miss important factors.

Dementia causes irreversible decline in global intellectual, social, and physical functioning. It is one of the most common and serious disorders in later life, with a prevalence of 5% and an incidence of 2% per year in those >65 years of age[1 2] equating to 500 000 people with dementia at any one time and 200 000 new cases every year in the UK. The economic cost of caring for people with dementia is immense. The direct costs of dementia are £7–15 billion in the UK.[3] More importantly, the negative impacts of dementia on people with dementia, in terms of deteriorating function, and on carers[4 5] are profound. The need to improve care for people with dementia is a national policy priority.[6]

Given the complexity of dementia, how can the effects of interventions in dementia best be measured? It has been suggested that broad outcomes such as health related quality of life need to be measured, in addition to discrete areas such as cognition and behaviour.[7] Measuring quality of life in dementia is challenging, but recent studies indicate that meaningful measurements can be made, using subjective and proxy instruments.[8–10] However, these have not yet been used in randomised controlled trials of anti-dementia medication and other treatments, which have instead concentrated on discrete areas of function, most commonly cognition, with the implicit assumption that these are acceptable surrogates for quality of life. These are sparse and potentially inaccurate data from which to estimate the value of intervention in dementia, as the National Institute for Clinical Excellence (NICE) has done in its draft guidelines on the use of anti-dementia medication.[11] In this study, we analysed associations between commonly used measures of specific outcomes in dementia and quality of life in order to consider the extent to which such measures are an appropriate proxy for quality of life in dementia.

METHODS

Participants

We recruited people with ICD-10[12] dementia from clinical contacts in south London and Nottingham (where the researchers were based) and their main family caregivers. Ethics approval was obtained from the Institute of Psychiatry and Nottingham Local Research Ethics Committees.

Measuring quality of life: the DEMQOL system

The DEMQOL system consists of two interviewer administered instruments. DEMQOL (28 items) is completed by the person with dementia; DEMQOL-Proxy (31 items) is a proxy report of the person with dementia's quality of life completed by the main carer (score range 31 to 124, with higher score indicating better quality of life). The detail of the system's development and psychometrics have been reported elsewhere.[10] DEMQOL has acceptable psychometric properties for people with mild to moderate dementia (defined as a Mini Mental State Examination (MMSE) score[13] of ⩾10) while DEMQOL-Proxy can be used for mild, moderate, or severe dementia. In this study, we report data for DEMQOL-Proxy only in order to consider the whole range of dementia severity.

Other measures

The person with dementia completed the MMSE. Caregivers completed the following in relation to the person with dementia: DEMQOL-Proxy, the Neuropsychiatric Inventory[14] (NPI; behavioural and psychological problems), and the

Abbreviations: BI, Barthel Index; GHQ, General Health Questionnaire; MMSE, Mini Mental State Examination; NICE, National Institute for Clinical Excellence; NPI, Neuropsychiatric Inventory

Barthel Index[15] (BI; functional ability). Carers also completed the 12 item General Health Questionnaire (GHQ-12; mental health) for themselves.[16]

Analyses

Univariate two tailed Pearson correlations (r) between quality of life (DEMQOL-Proxy) and continuous measures of interest were calculated. Multivariate analyses using linear regression were completed to examine associations between quality of life and the rating scales (along with any demographic variables found to be associated univariately). Variables were entered simultaneously.

RESULTS

We recruited 101 people with dementia, 99 of whom had a main family caregiver who consented to participate. The mean (SD) age of the people with dementia was 78.7 (8.3) years (range 54–93); 59 (58%) were women. The mean age of the carers was 67.5 (11.6) years (range 42–87); 62 (63%) were women. The carers included 63 spouses (63%) and 27 sons/daughters (or sons/daughters in law). The mean (SD) for the instruments used were: 16.0 (8.5) for MMSE, 17.0 (16.3) for NPI, 15.5 (4.5) for BI, and 3.4 (3.2) for GHQ-12.

On univariate analyses, there were statistically significant moderate to weak correlations between quality of life and the NPI total score ($r = -0.41$, $p<0.001$) and 5 of its 12 subscales: agitation ($r = -0.34$, $p = 0.001$), depression ($r = -0.47$, $p<0.001$), anxiety ($r = -0.30$, $p = 0.005$), disinhibition ($r = -0.23$, $p = 0.038$), and irritability ($r = 0.35$, $p = 0.001$), with increasing quality of life associated with lower levels of behavioural and psychological disturbance. The NPI subscales that were not statistically significantly associated with quality of life were: delusions ($r = 0.03$, $p = 0.753$), hallucinations ($r = -0.16$, $p = 0.157$), elation ($r = -0.20$, 0.072), apathy ($r = -0.127$, $p = 0.242$), aberrant motor behaviour (-0.13, $p = 0.253$), sleep disturbance ($r = -0.06$, $p = 0.596$), and appetite disturbance ($r = -0.04$, $p = 0.731$). Quality of life was also statistically significantly associated with the age of the person with dementia ($r = 0.33$, $p = 0.007$), with increasing age predicting better quality of life. Poorer carer mental health (GHQ-12) was marginally associated with decreased rating of quality of life for the person with dementia ($r = -0.21$, $p = 0.046$). Quality of life was not statistically significantly associated with cognition (MMSE score, $r = 0.03$, $p = 0.764$), functional limitation (BI, $r = -0.01$, $p = 0.943$) or carer age ($r = -0.03$, $p = 0.808$).

To check that the lack of association seen with dementia severity was not an artefact of an inability of people with severe dementia to complete the MMSE, a variable identifying those with severe dementia and those with mild/moderate dementia was constructed from MMSE scores (MMSE score<10) where available and Clinical Dementia Rating[17] severity scores (CDR score = 3) otherwise. The mean (SD) DEMQOL proxy score was 92.1 (12.9) for the mild/moderate group (n = 71) and 93.4 (16.3) for the severe group (n = 21), with no statistically significant difference between the two groups using a *t* test (95% confidence interval of the difference –5.44 to 7.96; $t = 0.37$, $p = 0.710$).

A final multivariate model (table 1) was constructed with the four scales of a priori interest and patient age (based on the univariate data). In the model, behavioural and psychological disturbance and patient age remained statistically significantly associated with quality of life. Carer mental health was no longer statistically significantly associated and cognition and functional limitation remained statistically insignificant. Using standardised beta coefficients, the contribution from the NPI was 52% of the model overall and patient age was 31%, compared with 16% from cognition, 7% from carer mental health, and 2% from functional limitation. The model accounted for 35% of the variation in quality of life overall.

Table 1 Linear regression of variables of interest with DEMQOL-Proxy scores

Variable	B (95%CI)	Beta	t	p
Patient age	0.48 (0.09 to 0.87)	0.32	2.50	0.016
NPI total	−0.45 (−0.68 to −0.23)	0.52	−3.99	<0.001
MMSE score	−0.25 (−0.71 to 0.21)	−0.16	−1.09	0.281
Carer GHQ	0.25 (−0.78 to 1.28)	0.07	0.49	0.623
BI	−0.04 (−0.89 to 0.81)	−0.02	−0.10	

Adjusted $r^2 = 0.35$. NPI, Neuropsychiatric Inventory; MMSE, Mini Mental State Examination; GHQ, General Health Questionnaire; BI, Barthel Index.

DISCUSSION

The main finding of this study is that quality of life in dementia does not have a simple relationship with cognition. These data suggest that behavioural and psychological disturbance and patient age are more strongly associated with quality of life than cognition or functional limitation. This is an important finding, as it suggests that cognitive improvement may be a poor proxy for quality of life improvement in dementia. This brings into question the validity of cognition and function based assessments of the value of interventions for people with dementia, such as those included in the recent UK draft guidelines for the prescription of anti-dementia drugs.[11]

Limitations and strengths

There are limitations to this study: Firstly, it is cross-sectional, so direction of causation cannot be ascertained. Poor quality of life might cause depression and thus behavioural disturbance, or vice versa. Secondly, this study is relatively small in scale, making interpretation of negative findings problematic due to possible low statistical power. Thirdly, the participants were drawn from contacts with secondary care services and so generalisability may be limited. Fourthly, the study was primarily designed as a psychometric field test and so other confounders or variables impacting on quality of life, such as social network and function, were not available. Finally, all the measures in this study (other than GHQ-12 and MMSE) involve proxy report. Proxy bias, the inherent error involved in making a proxy assessment, along with the possibility that the state of the proxy will influence their rating of the attribute in the person with dementia, is therefore possible.

Positive aspects include the ability of the DEMQOL-Proxy to measure quality of life across the range of severity in dementia and the availability of widely accepted and well validated instruments measuring the four areas of functioning most commonly considered in interventions in dementia (cognition, behaviour, functional ability, and carer strain).

Associations with quality of life

The observed association of quality of life with behavioural and psychological symptoms in dementia is intuitively understandable, and the negative effects of such symptoms on people with dementia and their carers are well understood.[18] Increasing problems with agitation, depression, anxiety, disinhibition, and irritability, and the consequences of these difficulties are likely to impair quality of life.

The association with patient age is of interest. Older patients and their carers may find it easier to adapt to dementia because they have had more experience of

dementia in their peers, because they are free of the expectations of the early retirement period, or perhaps because their peers are more accepting of dementia. Accommodation to dementia over the length of the illness is less likely, given that dementia severity is controlled for in these tests. This has similarities with findings that carer burden in dementia is higher in younger carers.[5] Patient age in this study may be a proxy for a complex web of social determinates of quality of life in dementia.

This discussion of associations is speculative in the light of the limitations of the study. Further work is needed to confirm the findings reported here. However, taken together, the data do give an idea of the likely relative strengths of association. Behavioural and psychological symptoms are three times more strongly associated with quality of life than is cognition.

CONCLUSION

These data suggest that quality of life in dementia is complex and that simple proxy substitution of cognition or function is likely to miss important factors. The NPI may be a better proxy for quality of life than cognition but it is still not a measure of quality of life in dementia and even taken with all the other measures in this study leaves 65% of quality of life in dementia to explain. These data support the need for trials of treatments in dementia to include measures of quality of life as well as measures of discrete functions such as cognition, function, and behaviour. Data on the quality of life impacts of dementia are simply not available at present and this makes any assessment of cost effectiveness of dementia treatments, such as that proposed by NICE,[11] highly speculative at the least. In other illnesses, there may be a simple association between quality of life and an easily measurable clinical variable such as pain or activity limitation, but this is not the case in dementia. A failure to assess dementia using broad outcome measures such as health related quality of life, and a reliance on measures of discrete functions such as cognition, could lead to the positive effects of interventions being overlooked or to potential negative effects of intervention being missed.

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The opinions represented here are those of the authors

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