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RESEARCH PAPER

Factors associated with self- and informant ratings of quality of life, well-being and life satisfaction in people with mild-to-moderate dementia: results from the Improving the experience of Dementia and Enhancing Active Life programme

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Abstract

Background: a large number of studies have explored factors related to self- and informant ratings of quality of life in people with dementia, but many studies have had relatively small sample sizes and mainly focused on health conditions and dementia symptoms. The aim of this study is to compare self- and informant-rated quality of life, life satisfaction and well-being, and investigate the relationships of the two different rating methods with various social, psychological and health factors, using a large cohort study of community-dwelling people with dementia and carers in Great Britain.
Methods: this study included 1,283 dyads of people with mild-to-moderate dementia and their primary carers in the Improving the experience of Dementia and Enhancing Active Life study. Multivariate modelling was used to investigate associations of self- and informant-rated quality of life, life satisfaction and well-being with factors in five domains: psychological characteristics and health; social location; capitals, assets and resources; physical fitness and health; and managing everyday life with dementia.

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Results: people with dementia rated their quality of life, life satisfaction and well-being more highly than did the informants. Despite these differences, the two approaches had similar relationships with social, psychological and physical health factors in the five domains.

Conclusion: although self- and informant ratings differ, they display similar results when focusing on factors associated with quality of life, life satisfaction and well-being. Either self- or informant ratings may offer a reasonable source of information about people with dementia in terms of understanding associated factors.

Keywords: *dementia, measurement methods, well-being, quality of life, life satisfaction, older people*

Key points

- This study compared self- and informant ratings of quality of life, life satisfaction and well-being and their associated factors.
- Self-rated quality of life, life satisfaction and well-being scores were higher than informant ratings in people with dementia.
- Factors related to self-rated quality of life, life satisfaction and well-being were also associated with informant ratings.

Introduction

Although many people with dementia can report meaningful ratings on measures of the ability to 'live well' with the condition, such as quality of life, life satisfaction and well-being [1,2], the informant-rated approach, which asks family or professional carers to rate the quality of life of people with dementia, has been widely used in research and clinical practice [3]. Nevertheless, discrepancies between self- and informant-rated scores have been reported, with informant ratings more negative than self-ratings [3–10]. Such differences may potentially compromise the ability to evaluate the experience of people with dementia and identify relevant cut-offs for clinical significance if ratings are obtained from only one perspective. However, this issue might not affect the validity of studies aiming to investigate factors related to living well with dementia. It remains to be established whether self- and informant ratings of living well measures have similar relationships with the relevant factors. If this is the case, either approach could provide valid information.

A recent review summarised the findings from 174 articles focusing on self-ratings of quality of life by people with dementia and 185 articles on informant ratings [3]. Ninety-four articles included both types of ratings and reported variation in the factors associated with self- and informant-rated quality of life measures [3]. These studies tend to have relatively small sample sizes or assess a limited number of sociodemographic factors (such as age, gender, education), health conditions (depression, anxiety, comorbidity) and dementia symptoms (neuropsychiatric symptoms, functional ability). These factors were highly correlated and did not cover all aspects of psychological and social health that support people with dementia to cope with challenges, participate in social life and develop capability to live well with the condition [11,12]. To address the limitations of statistical power and explore associations with a wider range of factors, the aim of this study was to compare self- and informant ratings of quality of life, life satisfaction and well-being (here, described collectively as measures of 'living well' with the condition) and investigate whether these two ratings had similar associations with various psychological, social and physical health factors. This was done using the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study, a large cohort study of people with mild-to-moderate dementia and their carers in England, Scotland and Wales. This study built on the previous IDEAL findings reporting on factors associated with subjective perceptions of living well [2]. The same analytical approach was applied to identify factors related to self- and informant-rated quality of life, life satisfaction and well-being.

Methods

Study population

The IDEAL programme, a longitudinal cohort study of community-dwelling people with dementia ($N = 1547$) and respective carers ($N = 1283$) in Great Britain, was established to identify social, psychological and economic factors that support people to live well with dementia and inform evidence-based policies and clinical practices aimed at preventing disability, maintaining independence and well-being and reducing caregiving, economic and societal impacts of dementia [13,14]. The recruitment was based on a network of 29 National Health Service sites across England, Scotland and Wales between July 2014 and August 2016. All participants were required to have a clinical diagnosis of dementia and a Mini-Mental State Examination score $\geq$15 on entry to the study. Those who were not able to provide informed consent were excluded from recruitment. For each person with dementia, a carer who provided practical or emotional unpaid support was also recruited where possible. For those who agreed to take part, trained researchers visited participants at home and implemented standardised questionnaires at baseline and two follow-up interviews 12 and 24 months later. The study was approved by the Wales Research Ethics Committee 5 (reference: 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference:2014–11684). The study is registered with the UK Clinical Research Network, registration number 16593. This analysis focused on the

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1,283 dyads of people with dementia and carers, allowing comparison of self- and informant ratings of living well measures and other factors.

Measurements

For each person with dementia, self-rated living well measures included three main aspects: quality of life, assessed using the Quality of Life in Alzheimer's Disease scale (QoL-AD; score range = 13–52) [15]; life satisfaction, assessed using the satisfaction with life scale (SwLS; range = 5–35) [16]; and well-being, assessed using the World Health Organization-Five Well-being Index (WHO-5; range = 0–100) [16]. Informant-rated versions of these measures were completed by the carers.

Measurement of factors potentially associated with living well included five latent constructs established in a previous IDEAL study [2]: psychological characteristics and psychological health; social location; capitals, assets and resources; physical fitness and health; and managing everyday life with dementia. A list of measures in these five constructs is provided in Supplementary Table S1. A sub-set of these measures had parallel ratings made by both the person with dementia and the carer where appropriate.

Covariates included age, sex, dementia subtype and relationship between the person with dementia and carer. Dementia subtypes included Alzheimer's disease (AD), vascular dementia (VaD), mixed AD and VaD, frontotemporal dementia (FTD), Parkinson's disease dementia (PDD), dementia with Lewy bodies (DLB) and other/unspecified dementias. The relationship between the person with dementia and carer was categorised into two types: spouse/partner and other (family or friends).

Analytical strategy

To examine differences between self- and informant-rated living well measures, Bland–Altman plots were used to calculate distributions of mean differences (self-ratings minus informant ratings) and 95% limits of agreement, which indicate the range of 95% differences between the two approaches.

The relationships between factors in the five domains and the self- and informant-rated living well measures were investigated using multivariate models, which allow all three living well measures to be fitted as dependent variables. Four types of multivariable models were implemented: (i) self-rated living well measures and self-rated factors; (ii) informant-rated living well measures and self-rated factors; (iii) informant-rated living well measures and informant-rated factors; and (iv) informant-rated living well measures and self- and informant-rated factors. Earlier IDEAL analyses have built a comprehensive 'living well' model for people with dementia based on the associations identified in all self-rated measures (Model a) [2]. This study further investigated informant-rated living well measures and their associations with various self- (Model b) and informant-rated factors (Model c) and compared these findings with results from Model a. To examine whether self- and informant-rated factors had independent relationships with informant-rated living well measures, all self- and informant-rated factors were fitted in one model where appropriate (Model d). All variables within each construct were fitted in one model adjusting for age, sex, dementia subtypes and the relationship between the person with dementia and carer. Given that multiple testing could be an important issue here, three selection criteria were applied to determine factors related to living well measures. A variable was selected if it achieved statistical significance (P-value < 0.05) based on the Wald test, had a meaningful effect size (QoL-AD > 1.5 or SwLS > 1.5 or WHO-5 > 5.0) based on the literature [17–19] and showed a potential 'dose-response relationship' (i.e. monotonically increasing or decreasing effect sizes across levels) with at least one of the outcomes. These criteria considered statistical significance as well as the direction and strength of associations and were also used in the previous IDEAL work [2]. All analyses were based on the IDEAL data set version 2.0 and conducted using Stata 14.2 [20].

Results

The median age of people with dementia was 77 (range = 43–98 years) and 58.9% were men (Table 1). The most frequently represented dementia subtypes were AD (56%), VaD (11%) and mixed AD and VaD (21%). Most carers (81%) were spouses/partners. Around half of the participants had received the diagnosis within the previous year and less than 2% had received the diagnosis over 5 years ago.

People with dementia generally reported higher scores on living well measures compared with the informant ratings made by their carers (Table 2). Mean differences and 95% limits of agreement were 3.3 (−9.3, 15.8) for QoL-AD; 5.6 (−8.9, 20.2) for SwLS; and 11.8 (−32.8, 56.4) for WHO-5. There was no consistent pattern of differences across demographic and clinical subgroups.

Table 3 summarises factors related to self- and informant-rated living well measures based on Model a–d. 'NA' denotes unavailable results as some factors could only be measured by either self- and informant-ratings. More detailed modelling results are provided in Supplementary Tables S2.1–S2.4. A summary for each construct is provided below.

- Psychological characteristics and psychological health: apart from life events, factors in this construct could only be measured using self-ratings. Self-rated living well measures were associated with seven factors in this construct (Model a). Of these seven factors, neuroticism, loneliness, depression and negative attitudes to ageing also had negative associations with informant-rated living well measures (Model b).
- Social location: community status was only measured using self-ratings while social comparison measures were rated by both people with dementia and carers. Self-rated status in the community was related to both self- (Model a) and informant-rated living well measures (Model b).

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Table 1. Means and standard deviations of self- and informant-rated living well measures across age, sex, dementia subtypes and relationship between person with dementia and carer

	N (%)	QoL-AD		SwLS		WHO-5	
		Self	Informant	Self	Informant	Self	Informant
Age							
≥80	482 (37.6)	37.2 (5.5)	33.6 (5.5)	27.3 (5.5)	21.7 (6.9)	64.2 (18.7)	49.0 (20.1)
75–79	306 (23.9)	37.3 (5.8)	33.6 (5.8)	26.9 (5.7)	20.4 (7.0)	61.5 (19.9)	49.2 (19.7)
70–74	232 (18.1)	36.9 (5.9)	34.1 (6.1)	26.0 (5.8)	20.6 (6.7)	59.2 (20.9)	51.2 (21.0)
65–69	160 (12.5)	36.2 (6.8)	33.8 (6.1)	25.7 (6.4)	20.6 (7.0)	58.3 (21.4)	51.0 (21.2)
<65	103 (8.0)	35.5 (6.8)	32.8 (6.3)	24.1 (6.9)	18.9 (7.0)	58.5 (25.8)	47.4 (22.0)
Sex							
Men	755 (58.9)	36.8 (6.0)	33.5 (5.8)	26.5 (5.9)	20.7 (6.9)	62.0 (20.0)	49.3 (20.2)
Women	528 (41.1)	37.1 (5.9)	33.9 (5.9)	26.5 (5.9)	21.1 (6.9)	60.6 (21.2)	49.9 (20.9)
Dementia subtypes							
AD	715 (55.7)	37.7 (5.5)	34.1 (5.7)	27.3 (5.5)	21.4 (6.8)	64.2 (19.5)	51.9 (20.1)
VaD	142 (11.1)	35.9 (6.5)	32.5 (6.3)	25.6 (6.3)	19.6 (7.2)	58.6 (21.2)	45.9 (20.9)
Mixed AD/VaD	263 (20.5)	36.3 (5.9)	33.8 (6.0)	26.3 (5.9)	21.5 (6.9)	59.8 (21.0)	48.9 (20.4)
FTD	45 (3.5)	38.7 (5.4)	33.1 (5.9)	25.7 (5.9)	21.7 (6.6)	61.0 (20.5)	49.7 (19.4)
PDD	43 (3.4)	33.1 (5.7)	32.1 (4.8)	22.0 (6.8)	16.8 (5.8)	47.9 (20.4)	42.1 (19.1)
DLB	43 (3.4)	33.0 (6.3)	31.4 (5.7)	23.7 (5.2)	17.3 (7.4)	50.7 (17.8)	38.8 (18.3)
Other/unspecified	32 (2.5)	34.7 (8.1)	31.3 (6.8)	26.2 (7.6)	18.2 (6.3)	58.5 (24.8)	43.2 (24.4)
Relationship between person with dementia and carer							
Spouse/partner	1,039 (81.0)	37.1 (6.0)	33.9 (5.8)	26.7 (5.9)	21.0 (6.9)	61.9 (20.5)	50.9 (20.4)
Other	244 (19.0)	36.1 (5.8)	32.3 (5.9)	25.6 (5.7)	20.4 (6.8)	59.6 (20.4)	43.8 (19.7)

Fronto-temporal dementia (FTD) has been added in the main text.

Table 2. Mean differences (self-ratings minus informant-ratings) and standard deviations for three living well measures by demographic factors

	QoL-AD ($N = 1075$)	SwLS ($N = 1204$)	WHO-5 ($N = 1220$)
Overall	3.3 (6.3)	5.6 (7.3)	11.8 (22.3)
Age			
≥80	3.7 (6.2)	5.6 (7.2)	15.2 (22.4)
75–79	3.6 (6.2)	6.4 (7.5)	11.8 (21.8)
70–74	2.5 (6.2)	5.4 (6.9)	7.9 (21.7)
65–69	2.5 (7.0)	5.0 (7.4)	7.9 (22.6)
<65	3.1 (5.9)	5.0 (7.7)	11.4 (22.2)
Sex			
Men	3.2 (6.4)	5.9 (7.3)	12.5 (22.4)
Women	3.3 (6.1)	5.3 (7.3)	10.7 (22.3)
Dementia subtypes			
AD	3.5 (6.1)	5.9 (7.2)	12.3 (22.4)
VD	3.1 (6.3)	5.9 (7.3)	12.8 (21.7)
Mixed AD/VD	2.9 (6.5)	4.9 (7.1)	11.0 (22.1)
FTD	6.1 (7.4)	3.2 (7.4)	10.4 (24.4)
PDD	1.2 (6.0)	5.3 (8.8)	5.5 (21.9)
DLB	0.7 (7.1)	6.6 (7.7)	10.7 (23.1)
Other/unspecified	2.6 (5.2)	7.5 (7.2)	14.5 (21.5)
Relationship between person with dementia and carer			
Spouse/partner	3.1 (6.2)	5.7 (7.3)	10.9 (22.3)
Other	4.0 (6.8)	5.2 (7.2)	15.6 (22.0)

The social comparison measures rated by people with dementia and carers were associated with both self- and informant-rated living well measures (Models a–c) and had independent relationships with informant-rated living well scores (Model d).

- Capitals, assets and resources: in this construct, social networks and cultural capital were the only two factors rated by both people with dementia and carers. Self-rated living well measures were associated with four self-rated factors, including local trust, civic participation, social networks and cultural capital (Model a). Of these four self-rated factors, only cultural capital was associated with informant-rated living well measures (Model b). An additional self-rated factor, personal relations, had a positive association with informant-rated living well measures in Model b. Both self- and informant ratings of cultural capital showed

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Table 3. Summary of associations between self- and informant-rated living well measures (LW) and other factors

	Model a: self-rated LW + self-rated factors	**Model b:** informant-rated LW + self-rated factors	**Model c:** informant-rated LW + informant-rated factors	**Model d:** informant-rated LW + self- and informant-rated factors
Psychological characteristics and psychological health				
Personality neuroticism [s]	−	−	NA	−
Loneliness [s]	−	−	NA	−
Depression [s]	−	−	NA	−
Attitudes toward own ageing [s]	+	+	NA	+
Optimism [s]	+		NA	
Self-esteem [s]	+		NA	
Subjective age [s]	+		NA	
Social location				
Social comparison [s/i]	+	+	+	+[s][i]
Community status [s]	+	+	NA	+
Physical fitness and health				
Poor eyesight [s]	−	−	NA	−
Poor hearing [s]	−	−	NA	−
Poor self-rated health [s]	−	−	NA	−
Changes in olfaction [s]	−		NA	
Poor appetite [s/i]	−	−	−	−[i]
Poor sleep [s/i]	−		−	−[i]
Low physical activity[s/i]			−	−[i]
Falls [s/i]			−	−[i]
Capitals, assets and resources				
Low local trust [s]	−		NA	
Low civic participation [s]	−		NA	
Personal relations [s]		+	NA	+
Low social network [s/i]	−			
Cultural capital [s/i]	+	+	+	+[i]
Managing everyday life with dementia				
Functional ability [s/i]	−	−	−	−[i]
Dependence [s/i]	−	−	−	−[i]
Neuropsychiatric symptoms [i]	NA	NA	−	−

Note: +, positive associations with living well measures; −, negative associations with living well measures; NA, not available; [s], self-rated; [i], informant-rated; [s/i], both self- and informant-rated measures were included.

associations with informant-rated living well measures in individual models (Models b and c). When including all self- and informant ratings, only self-rated personal relations and informant-rated cultural capital were related to informant-rated living well measures (Model d).

- Physical fitness and health: several factors in this construct were measured by both self- and informant ratings. Self-rated eyesight, hearing and health status had negative relationships with both self- (Model a) and informant-rated living well measures (Model b). Informant-rated measures of physical activity and falls were associated with informant-rated living well measures but not self-ratings (Model c). Compared with self-rated measures, informant-rated sleep quality and appetite had stronger associations with informant-rated living well (Model d).
- Managing everyday life with dementia: Both self- and informant-rated functional ability and dependence were related to self- and informant-rated living well measures (Models a–c). Neuropsychiatric symptoms were only rated by carers and were associated with informant-rated living well measures (Model c). All informant-rated factors in this construct were associated with informant-rated living well measures (Model d).

Discussion

Based on a large cohort study of community-dwelling people with dementia and their carers, this study compared associations of self- and informant-rated quality of life, life satisfaction and well-being with factors across five domains. Informant-rated living well scores were lower than self-rated scores; despite these differences, the relationships between factors and living well measures were relatively consistent between the two approaches.

This study found that the mean score for self-rated quality of life was higher than the mean score for informant ratings. Several studies have emphasised discrepancies between self- and informant ratings [3–10]. Both ratings have value when investigating living well measures in people with dementia, but as with many other score-based metrics, both should be recognised as imperfect measures containing measurement errors. The findings also raise the possibility that people with dementia experience a higher quality of life than is thought to be the case by their respective carers. Alternatively, people with dementia might rate their experiences higher than is actually the case, or the carers might be doing the converse. It is important to understand whether self- or

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informant-ratings have been used when attempting to define those with 'poor' living well scores in clinical practice and research. Nevertheless, a main finding is that when considering factors which might affect the ability to live well with dementia, discrepancy between self- and informant-rated scores need not be a concern as the relative differences remained similar across both approaches.

The results of this study correspond to a French study of 574 community-dwelling people with AD and their carers where self- and informant-rated quality of life had consistent associations with functional ability, depression and caregiver burden [4]. In contrast, studies focusing on people with dementia in residential care facilities or as hospital outpatients have reported differential relationships between self-rated quality of life, informant ratings by carers and some health factors such as cognitive function, weight and pain [21,22]. The different findings might be related to the different recruitment contexts of study populations and involvement of formal carers. Severity of dementia and health status might influence the consistency of associations in self- and informant ratings.

A small number of factors had different associations with self- and informant ratings of living well measures. Some of the self-rated factors in the 'psychological characteristics and psychological health' and the 'capitals, assets and resources' domains were only associated with self-rated living well measures. In the 'physical fitness and health' and the 'managing everyday life with dementia' domains, informant-rated factors, such as physical activity and falls, were related to informant-rated living well measures but not self-ratings. Compared with psychological and social factors, physical health conditions and dementia symptoms were more likely to be observed by informants and therefore had stronger associations with informant-rated living well measures.

The strength of this study lies in including a wide range of social, psychological and physical health factors and eliciting responses from a large number of community-dwelling people with dementia and their carers. However, there are some limitations. The IDEAL study only included people with mild-to-moderate dementia at the baseline interview, so the results might not generalise to those with severe dementia. Longitudinal data from IDEAL will allow us to examine whether the consistency of associations in self- and informant-rated living well measures changes with the progression of dementia [13,14]. Informant ratings were not available for some measures of psychological factors and social status as it is difficult to obtain informant ratings for subjective psychological experiences. Self-ratings could be sensitive to individual conditions. For example, dementia symptoms such as impairments in memory, attention and language might increase measurement errors in self-rated measures. Future research may explore response variation across individuals with different symptoms. Extensive regression modelling in this study could lead to high false positive rates. To address this issue, the selection criteria were determined on the basis of both statistical significance and effect sizes.

Conclusions

The findings of this study suggest that self- and informant ratings are not equivalent when investigating levels of quality of life, life satisfaction and well-being. These differences can be crucial when defining those with 'poor' living well scores in clinical practice and research. However, both approaches can provide useful information for research examining factors associated with these living well measures. Our findings suggest that for researchers planning to examine factors related to living well with dementia, either self- or informant ratings offer a reasonable indication of quality of life, life satisfaction and well-being in people with mild-to-moderate dementia.

Supplementary data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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