The Quality of Life of People with Dementia and Their Family Carers

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Key Words

Quality of life · Dementia · Carer · Proxy · Depression ·
Activities of daily living impairment · Hobby

Abstract

Background: We aimed to identify factors associated with the quality of life (QoL) of 'persons with dementia' (PWDs) and their family carers. **Method:** Two-hundred and thirty dyads of PWDs and their family carers were included. The PWDs were assessed with the Neuropsychiatric Inventory (NPI-Q), two Activities of Daily Living (ADL) scales, the Cornell Scale and the QoL-Alzheimer's Disease scale (QoL-AD; self- and proxy-reported scores). The carers were assessed with the QoL-AD and the Geriatric Depression Scale. **Results:** Factors associated with self-reported QoL were depression ($\beta = -0.26$, $p < 0.001$) and impaired ADL ($\beta = -0.26$, $p < 0.001$) and with proxy-rated QoL were NPI ($\beta = -0.18$, $p = 0.02$), depression ($\beta = -0.32$, $p < 0.001$) and impaired ADL ($\beta = -0.43$, $p < 0.001$). Factors associated with QoL in carers living together with the PWDs were depression ($\beta = -0.56$, $p < 0.001$) and having a hobby ($\beta = 0.19$, $p = 0.01$), whereas depression was associated with QoL in those who lived separately from the PWD ($\beta = -0.60$, $p < 0.001$). **Conclusion:** Depression and impaired ADL were associated with the self- and proxy-rated QoL of the PWDs, whereas depression in the carers negatively affected their QoL.

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Introduction

Dementia is a very common condition in older people and the number of people affected by dementia is expected to double every 20 years from 24.3 million in 2005 to 81.1 million in 2040 [1]. Memory impairment is the main symptom of dementia, along with impairment of general intellectual functions [2]. Cognitive dysfunction and loss of skills in the performance of the activities of daily living (ADL) are progressive, irreversible and lead to helplessness and dependency [2]. Neuropsychiatric symptoms are common [3] and lead to a perception of a lower quality of life (QoL) [4, 5]. Dementia often causes severe problems for the persons themselves, the family carers [6, 7] and the public social and health services [8].

QoL is a broad concept reflecting the person's physical health, psychological state, personal beliefs and relationships [9]. The World Health Organization defined QoL as the individual's perception of life in the context of the culture and value system related to their own goals, expectations, standards and concerns [9]. Lawton [10] describes QoL as a concept that reflects objective and subjective factors linked to psychological well-being, behavioral competence and environment, with self-perceptions as a main component. Thus, these definitions, based on individual assessment [9, 10], could be difficult to apply to a person with dementia (PWD) as their re-

duced cognition may limit them in reporting their own perception of QoL. In addition, the various scales used to measure the QoL of the PWD do not necessarily emphasize the same domains [11, 12] and, therefore, may not be strongly correlated [13]. Hence, we are facing challenges in measuring and assessing the QoL in PWDs. The collection of data for assessing the QoL could, however, be carried out by different methods, either by self-reporting (e.g. QoL-Alzheimer's disease scale, QoL-AD), by observation (e.g. Dementia Care Mapping), or by proxy reporting (by a relative or a carer; e.g. the QoL in late-stage dementia and the QoL-AD). All these methods have limitations. Although self-rated QoL is considered as the standard for the evaluation of QoL [14], such assessment is not always easy to obtain. To answer questions about the QoL, the person must understand the questions in the scale and be able to communicate an answer, which is not always the case for PWDs. Describing the QoL in another person (by proxy) – either on the basis of observation or knowledge about the person – also has limitations. Several studies have shown that carers rate the QoL of the PWD lower than the PWD him/herself does [15, 16]. However, despite the limitations of the different methods, they can provide useful information about relevant aspects of a person's life beyond the more commonly used approaches such as signs of depression.

Thus, the main aim of this study was to measure the QoL in PWDs by self-reporting and by proxy report and to identify factors affecting the QoL in PWDs as assessed by themselves and a proxy. Secondly, we wanted to examine the QoL of the family carers to explore how the factors associated with their QoL compared to those of the PWD.

Methods

Study Design

This study used the baseline data from a randomized controlled trial that aimed to examine the effect of a psychosocial intervention program for PWDs living in their own homes.

Participants

The data came from 230 PWDs living in their own homes – carer dyads recruited from 20 Norwegian municipalities. The inclusion criteria for the PWD were: a diagnosis of dementia according to the ICD-10 criteria, a score of at least 15 points on the Mini-Mental State Examination (MMSE) [17, 18] and having the capacity to give informed written consent to participate in the study. No specific exclusion criteria were defined. Carers had to have at least weekly face-to face contact with the PWD to be included.

Data Collection

The participants were enrolled in the study from October 2009 to May 2011. Trained nurses and occupational therapists in the participating municipalities collected the data after being educated and trained on a 2-day course on how to conduct the interviews, perform the cognitive testing and use the assessment scales. They were also supervised individually. To ensure the quality of the data collection, telephone meetings took place during the data collection period.

Assessment of the PWDs

The PWDs completed the QoL-AD [19]. This consists of 13 items, rated on a 4-point scale (from 1 = poor to 4 = excellent), with a total score ranging from 13 to 52. A higher score indicates a better QoL. Cognitive function was assessed by the MMSE, Norwegian revised version [17, 18]. The scale consists of 20 items, with a possible score between 0 and 30. A higher score indicates better cognitive function. The Neuropsychiatric Inventory (NPI-Q) [20], a 12-item scale, was used to assess neuropsychiatric symptoms. In this study we used the severity score, which can vary between 0 and 36. A higher score indicates more severe symptoms. Functioning in the ADL was assessed by the Physical Self-Maintenance scale (PSMS) and the Instrumental ADL scale (IADL), both developed by Lawton and Brody [21]. The PSMS scale measures basic activities such as bathing, eating and using the toilet. It has 6 items rated on a 5-point scale from 1 = 'maintain the activity' to 5 = 'do not maintain the activity at all/need full assistance'. The minimum score is 6 and the maximum is 30. A higher score indicates a poorer function. The IADL scale assesses the more complex instrumental ADL that are required for independent living such as shopping, cooking and managing finances. The scale has 8 items, and the scoring system is similar to that of the PSMS, but the maximum score on each item varies between 3 and 5, which gives a minimum score of 7 and a maximum of 31. A higher score indicates a greater need for assistance.

The Cornell scale for depression in dementia [22] was used in the assessment by interview with the family carer. The scale has 19 questions scored from 0 (absent) to 2 (severe) or 'symptom not possible to evaluate', with a minimum score of 0, a maximum of 38 and a cutoff point of 8/9 [23].

Assessment of the Family Carers

The carers completed the Norwegian version of the QoL-AD scale [19] to assess the QoL of the PWD, called 'proxy QoL' in this article. In addition, the carers were asked to rate their own QoL using the same scale. The QoL-AD has been used for carers of PWDs in two previous studies [24, 25].

Depression in the carers was evaluated with the Geriatric Depression Scale (GDS) [26] translated and adapted to the Norwegian language and culture by one of the authors (K.E.). This is a self-rated 30-item scale. Each item is scored as 0 (symptom not present) or 1 (symptom present). A higher score indicates a more severe depression [26].

Age, gender, education, occupational status, kinship with the patient, having a hobby and physical activity were recorded. Carers were asked to estimate the time they had used to

Table 1. Characteristics of the 230 carers and 230 PWDs

	All	Not living together (n = 100)	Living together (n = 130)	p value
Carer characteristics				
Females, n	177 (77)	82 (82)	95 (73.1)	NS
Spouses, n	122 (53)	1 (1)	121 (93.1)	<0.001
Children, n	92 (40)	85 (85)	7 (5.4)	<0.001
Other, n	16 (7)	14 (14)	2 (1.6)	<0.001
Age, years	63.5 (12)	53.7 (7.6)	71 (8.9)	<0.001
Years of schooling	12.7 (3.8)	14.3 (3.6)	11.3 (3.3)	<0.001
Employed outside household, n	98 (43)	79 (79)	19 (14.6)	<0.001
Hours spent on caring daily	4.9 (5.1)	2.7 (3)	6.7 (5.5)	<0.001
Help from other family members, n	102 (57)	69 (69)	33 (25.4)	<0.001
GDS	6.3 (6)	4.6 (5.5)	7.7 (6)	<0.001
QoL-AD score	41.2 (5.3)	42.6 (5.3)	40.1 (5.0)	<0.001
Having hobbies, n	138 (60)	67 (67)	71 (55)	NS
Being physically active, n	179 (78)	85 (85)	94 (73)	0.023
PWD characteristics				
Females, n	123 (54)	81 (81)	42 (32)	<0.001
Age, years	78.4 (7.5)	81.5 (6.4)	75.9 (7.2)	<0.001
Married, n	130 (57)	10 (10)	120 (93.3)	<0.001
MMSE score	21.3 (3.6)	21.3 (3.6)	21.2 (3.6)	NS
IADL score	21.4 (5.7)	20.1 (5.8)	22.3 (5.4)	0.003
Personal ADL score	9.7 (4.1)	10 (4.1)	9.5 (4.1)	NS
Total ADL score	31.1 (8.6)	30.2 (9.1)	31.8 (8.2)	NS
NPI severity score	9.6 (6)	9.9 (6)	9.3 (6)	NS
Duration of symptoms, years	4.4 (2.8)	4.3 (2.9)	4.4 (2.8)	NS
Cornell score	8.0 (5.6)	7.7 (5.3)	8.0 (5.9)	NS
Formal help, n	176 (77)	9.6 (96)	80 (62)	<0.001
Years of schooling	10.1 (3.4)	9.2 (2.9)	10.7 (3.7)	0.001
QoL-AD self-reported	36.9 (5.6)	37.4 (5.3)	36.5 (5.8)	NS
QoL-AD proxy rated	32.8 (5.0)	32.1 (5.1)	33.4 (5.0)	0.047

Results are means $\pm$ SD or numbers with percentages in parentheses. p values from group comparison, t test 'living together' versus 'not living together'.

assist or look after the patient during a typical day in the preceding month.

Statistics

Statistical analyses were performed with the IBM SPSS 19.0 program. Continuous variables were compared with a two-sided t test when normally distributed, or by means of the Mann-Whitney U test when skewed. Linear regression analyses were applied to determine the variables associated with the scores on the QoL-AD scales, according to the PWD, proxy and the carers as the dependent variables. We started with a high number of variables in the unadjusted analyses. In these analyses we summarized the scores on the PSMS and the IADL scales into one variable named total ADL, because they were highly correlated (Spearman's $\rho = 0.66$). Three variables, assisting with activities connected to the PSMS and the IADL, and preventing dangerous situations, indicated the time used to assist the PWD. They were summarized into one variable

named 'hours spent on caring daily'. The skewed variables were analyzed both with and without logarithmic transformation and the results were the same, so we present the results without logarithmic transformation. The variables that were associated with one of the three QoL measurements in the unadjusted linear regression analyses with $p < 0.2$ were used as independent variables in the further-adjusted linear regression analyses. Before we carried out the adjusted analyses we made a correlation analysis of all the independent variables. As the characteristics of the patients and carers 'living together' differed in many aspects from those 'not living together', we divided the carers into two groups as shown in table 1, and performed separate linear regression analyses for the two groups.

Ethics

Both the PWDs and the family carers received oral and written information about the study and gave written consent to participate. The study was approved by the Norwegian

Regional Committee for Ethics in Medical Research in the Southern Health Region. There was no reason to expect that the study would cause any harm to the PWDs or their carers.

Results

Patient Characteristics, Gender Differences and Measure of Depression

The characteristics of the PWDs are summarized in table 1. The male patients were younger than the female [mean age = 76, SD = 7 (7.3 vs. 80.4), $p < 0.001$], had poorer functioning as measured by the total ADL score [33, SD = 8.6 (8.2 vs. 29.5), $p = 0.002$] and had more years of education [mean years = 9.1, SD = 3.9 (2.6 vs. 11.2), $p < 0.001$]; fewer men than women received formal help (65 vs. 86%, $p < 0.001$). There were no significant gender differences for the duration of symptoms, the severity of neuropsychiatric symptoms as measured by the NPI, the self-report of QoL, cognitive function by means of the MMSE or the severity of depressive symptoms according to the Cornell scale.

Carer Characteristics

Carer characteristics are also summarized in table 1 for the carers living together with the PWDs and for those not living together with the PWDs, respectively. In relation to the PWDs, 37% of the carers were wives, 15% husbands, 32% daughters, 8% sons and 7% 'others' (grandchildren, friends or siblings). The female carers were younger than the male carers [62.2, SD = 13.6 (11.2 vs. 67.9), $p = 0.007$]. There were no significant differences between the genders in years of education, hours spent caring, being employed, having a hobby, being physically active, receiving formal help, or in depression symptoms as measured by the GDS. The carers living together with the PWDs (54%) had a higher mean score on the GDS [7.7 (SD = 6) vs. 4.6 (SD = 5.5), $p < 0.001$] and spent more hours caring daily [mean 6.7 (SD = 5.7) vs. 2.7 (SD = 3), $p < 0.001$]. Fewer patients of these carers received formal help (62 vs. 96%, $p < 0.001$) and fewer were physically active (73 vs. 86%, $p = 0.019$) compared to those who lived in a household other than that of the patient. There were no significant differences between these two groups in the duration of dementia symptoms, the MMSE score, the NPI or the total ADL scores of the PWD.

QoL Measures

The scores on the three different QoL measurements are shown in table 1, the unadjusted linear regression

analyses are shown in table 2 and the adjusted analyses in table 3.

The PWD self-reported QoL score was higher than the proxy-reported QoL score. However, this gap was smaller between dyads living together than between those who did not live together [3.2 (SD = 5.5) vs. 5.3 (SD = 6.3), $p < 0.001$]. There were no differences in the PWD self-reported QoL whether the dyads were living together or not. The self- and proxy-reported scores correlated with Spearman's rho ($r = 0.38$, $p < 0.001$). Spearman's rho between the proxy-rated QoL and the carers' self-reported QoL was $r = 0.26$, ($p < 0.001$). The carers who lived together with the PWDs reported poorer QoL than those who lived in another household.

Discussion

The difference between self- and proxy-reported QoL of the PWDs as reported in the present study is in line with previous studies [15, 16, 27]. There is an ongoing debate about the explanation for this. In the original version of the QoL-AD scale [19], the self- and proxy-reported scores were meant to be summarized in the following proportions: self-report $\times 2$ with proxy $\times 1$. A study by Hoe et al. [28] claimed that proxy-rated QoL is not a replication of self-reported QoL. This view was supported by Bosboon et al. [16] who concluded that self- and proxy-rated scores should be considered complementary, not interchangeable, being driven by different factors. One explanation for this difference is put forward by Banarjee et al. [29], suggesting that poor insight in the PWD leads to the discrepancy, and we concur with this view. Loss of insight and low awareness of decline in memory function seem to affect QoL in a positive way [30, 31]. According to Vogel et al. [32], the disagreement between self- and proxy-rated QoL may be caused by anosognosia even in an early stage of dementia. Unfortunately, we did not measure the degree of insight in our patients and cannot add any data to support Vogel's results. Another understanding of the discrepancy in proxy- versus self-rated QoL of the PWD may be an adaptive coping strategy in the PWD getting used to his/her decreased abilities, described as the 'disability paradox' by Conde-Sala et al. [33].

The severity of depressive symptoms and the degree of impairment in ADL were the two strongest factors associated with both the self- and proxy-reported QoL of the PWDs. These findings are in line with previous studies, even when different scales are used to measure the QoL.

Table 2. Unadjusted associations between PWD self-reported QoL, proxy-reported QoL and carers' QoL and carer and patient characteristics (QoL-AD): Linear regression analyses

	PWD self-reported		Proxy reported		Carers self-reported	
	β	p value	β	p value	β	p value
Carer characteristics						
Age, mean	0.01	0.93	0.02	0.071	-0.15	0.020
Gender (female = 0, male = 1)	0.03	0.65	-0.08	0.258	-0.06	0.464
Spouse	-0.02	0.73	0.09	0.172	-0.25	<0.001
Children	-0.00	0.99	0.05	0.497	0.21	0.002
Living together (no = 0, yes = 1)	-0.08	0.23	0.13	0.046	-0.23	<0.001
Years of schooling (n = 221)	-0.01	0.88	0.02	0.727	0.15	0.027
Employed outside household (n = 227; no = 0, yes = 1)	-0.04	0.68	0.02	0.803	0.32	<0.001
GDS score	-0.03	0.63	-0.25	0.000	-0.62	<0.001
Having hobbies	0.10	0.119	0.15	0.021	0.23	0.001
Being physically active	0.07	0.265	0.03	0.658	0.23	0.001
Hours spent on caring daily	-0.13	0.047	-0.09	0.200	-0.07	<0.001
PWD characteristics						
Gender (female = 0, male = 1)	-0.03	0.792	0.07	0.302	0.25	<0.001
Age	-0.07	0.318	-0.01	0.832	0.10	0.132
Married (no = 0, yes = 1)	0.01	0.918	0.07	0.328	-0.21	0.001
MMSE score	0.04	0.547	-0.16	0.019	0.10	0.120
ADL sum score	-0.29	<0.001	-0.40	<0.001	-0.20	0.002
NPI severity score	-0.12	0.072	-0.45	<0.001	-0.16	0.027
Duration of symptoms, years	0.10	0.153	-0.10	0.156	-0.11	0.099
Years of schooling	0.17	0.011	0.19	0.005	-0.05	0.465
Cornell score	-0.29	0.000	-0.49	<0.001	-0.18	0.006
Formal help (no = 0, yes = 1)	-0.14	0.029	-0.15	0.021	-0.02	0.786

Table 3. Adjusted linear regression analyses with QoL-AD as the dependent variable

	PWD QoL-AD						Carer QoL-AD					
	self-reported		proxy reported, carers not living together with PWD		proxy reported, carers living together with PWD		all		not living together with PWD		living together with PWD	
	β	p value	β	p value	β	p value	β	p value	β	p value	β	p value
Cornell score	-0.25	<0.001	-0.34	0.001	-0.33	<0.001						
ADL score	-0.26	<0.001	-0.23	0.009	-0.43	<0.001						
NPI severity score			-0.20	0.043	-0.16	0.050						
Hours spent on caring daily					0.17	0.018						
GDS					-0.20	0.004	-0.60	<0.001	-0.61	<0.001	-0.56	<0.001
Carers having a hobby					0.14	0.029	0.16	0.002			0.19	0.010
Explained variance, R ² (%)	15		33		53		40		39		37	

In the study by Andersen et al. [34], impairment in ADL was found to be the strongest factor associated with low QoL in the PWDs (measured by EQ5D), whereas Hoe et al. [28] found that impaired ADL and depression (as measured by Cornell) were the most important factors that influenced the QoL-AD score. In addition, Barca et al. [35] found depression and ADL to be the strongest factors for QoL measured by the QoL in late-stage dementia in the PWDs. In other studies, behavioral disturbances in the patients have been reported as the most important factors for a poorer proxy-rated QoL [25, 28]. We could confirm this result as we found that poorer proxy-reported QoL was associated with a higher NPI score. Like Hurt et al. [36], we found the NPI to be a factor affecting proxy-rated but not self-rated QoL of the PWDs.

Not surprisingly, compared with the carers who lived in another household, the carers who lived together with the PWDs (mostly spouses) rated the QoL of the PWDs somewhat higher and driven by other factors. In the adjusted linear regression analyses, the symptoms of depression in the carers, the number of hours spent on caring and the carers having a hobby influenced the proxy-reported QoL in carers living together with the PWDs. In Norway, PWDs living together with their family carers receive less home care than those who are living alone [37]. To our surprise, increased hours spent on caring was associated with a higher proxy-reported QoL, although hours spent on caring are probably a result of loss of ADL function in the PWD, which we found to be associated with a poorer QoL. How could this be explained? We believe that giving support to a loved one is a positive assignment and if a carer receives positive feedback from the PWD it is understandable that the carer rates the patient's QoL to be higher. It should be noted that 'hours assisting' were summarized from 'assisting in ADL' and 'time used preventing a dangerous situation'. The variable is, therefore, more likely to reflect 'time spent together'. Another factor is that 'having a hobby' had a positive effect on the proxy rating of the QoL of the PWD. It is still unclear whether carer characteristics or having a hobby itself caused this effect. In one way these two factors, assisting and having a hobby, can be seen as opposite factors, spending time together with the PWD and carers spending time on their own. Probably they are not, as the combination of spending time with a loved one (spouses), receiving positive feedback and having some time to spend on an interesting hobby is favorable for mental health. Poorer mental health in the carers living together with the PWD, as measured by the GDS in this study, was associated with poorer proxy-rated QoL. Why this differed from the result for

carers not living together with the PWD may be explained by the time spent together. People living together affect each other more than people not living together.

In the present study the PWD self-reported QoL scores were higher than those reported by Hoe et al. [38]. One reason for this could be that the PWDs in our study had a higher mean MMSE score (21.3 vs. 8.7), which is confirmed by the fact that a later study by Hoe et al. [28] reported both QoL and MMSE scores more level with our score. However, there is no consistent support for this explanation in the literature. Logsdon et al. [39] reported no differences in the QoL-AD between PWDs in mild, moderate and severe stages of dementia. Even though both Lyketsos et al. [40] and Vogel et al. [32] reported a decrease in the mean QoL over time, their findings of differences at the individual level did not clarify the effect of cognitive impairment on QoL. This is in line with our own findings where the severity of cognitive impairment (adjusted linear regression analyses) did not influence the score on QoL. Maybe the variation in the loss of insight into the patient's own cognitive impairment plays a role. Hurt et al. [30] found that impaired insight had a positive effect on the self-rated QoL in patients with dementia of a moderate degree, but not in those with dementia of a mild degree.

QoL of the Carers

The QoL of the carers was better than the self- and proxy-rated QoL of the PWDs. However, the carers living together with the PWDs had a lower QoL-AD score than those living in another household. By comparison, both groups of carers rated their QoL better than a carer group of memory clinic patients in an earlier Norwegian study using the QoL-AD in carers [24]. In that study the age of the carers was lower and age was found to affect QoL positively [24], which may explain this difference between the two Norwegian studies. However, we should bear in mind that only two previous studies have used the QoL-AD to rate the QoL in carers of PWDs, and only one of them reported the mean score, which makes comparison difficult.

Limitations and Strengths

The study has limitations. More than 30 coworkers collected the data in this study, which could have led to poor quality of the data compared with data collected by a smaller number of coworkers. We were aware of this possible limitation before the study and, therefore, all the coworkers were trained and we had telephone contact with them throughout the data collection period. A written manual on how to collect data was used. Another

limitation is the use of the QoL-AD among the carers. This scale has not been validated for carers, although it has been used in two previous studies [24, 25].

The strengths of the study are the relatively large number of patients and carers, the use of standardized assessment scales and the wide inclusion criteria of home-dwelling patients who had the capacity to give informed consent, which should indicate that they would have the capacity to give reliable information on their own perception of their QoL.

Conclusions

We found that depression and impairment in ADL were strongly associated with the self- and proxy-rated QoL of the PWD. The factor 'living together' seems to affect the QoL of the carers and the carers' proxy-rated PWD QoL negatively, but did not affect the PWD self-rated QoL.

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