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Evaluating the quality of life of people with dementia in residential care facilities

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ABSTRACT

Aims: Our purpose was to compare recipient and caregiver perception of the quality of life (QoL) of people with dementia in residential care facilities and to identify the factors associated with their perception of QoL.

Methods: Residents' QoL was evaluated by both the patient and the caregiver, using the Quality of Life in Alzheimer's Disease (QoL-AD) and several other indices.

Results: The correlation between the self-rated QoL score and the staff-rated QoL score was low.

Conclusions: The staff tended to underestimate QoL. The main determinants of QoL were the functional status and depression. Improving physical function and mood may be beneficial in providing a better QoL.

Key words: quality of life, dementia, activities of daily living, depression, residential care.

INTRODUCTION

There are approximately 28 million elderly people over the age of 65 in Japan. The number of elderly people who take part in the elderly care insurance system is approximately 3,780,000. Twenty-eight percent of those who receive elderly care insurance utilize facility services [1]. Many dementing disorders have a chronic progressive course, and they impair the overall cognitive function and social functions. The number of people with dementia living in care facilities and the ratio of people with severe dementia are expected to increase. Thus, while it is important to maintain and promote the quality of life (QoL) of people with dementia living in residential care facilities, there is a lack of understanding of these individuals' well-being.

Health-related QoL is a multidimensional and complex concept involving physical, psychological, social functioning. The existing scales for evaluating self-rated QoL, such as the MOS Short-Form 36-Item Health Survey and the Euro QoL, are generic scales that can be used for people with various diseases as well as for healthy individuals [2-4]. The QoL in people with dementia is an important outcome of care [5,6]. The generic scales are considered unsuitable for people with dementia because of their cognitive and communication impairment. In studies on dementia, patients' subjective ratings may be the benchmark for measuring QoL, while proxy (family caregiver or professional caregiver) informant ratings are necessary for people with severe dementia who are no longer able to appraise their own QoL [5,7]. There is growing evidence that even people with moderate to severe dementia can reliably rate their own QoL using disease-specific scales [8,9]. The Quality of Life in Alzheimer's Disease (QoL-AD) is a disease-specific QoL scale for dementia, which makes it easier for those with dementia to answer questions through one-on-one interviews; includes questions on memory functions; and is itemized in interpersonal, environment, functional, physical, and psychological status [10]. A significant advantage of QoL-AD is that the same versions can be used for both self-rating by and proxy rating for residents. The QoL-AD has been translated into several languages [11-14]; the Japanese version was translated by Matsui et al. [12].

Only a few studies deal with self-rated QoL by people with dementia in residential care facilities [8,9,15]. The QoL-AD can be applied to relatively severe

dementia [16]; however, the correlation between resident' QoL as rated by the patient and the staff often varies [8,9,15,16]. This study compares residents' QoL as rated by both dementia patients receiving care in facilities and their professional caregivers, and examines how a series of factors (including functional status, psychological symptoms, cognitive function, and severity of dementia) impacts QoL.

METHODS

Evaluation scale

The QoL-AD was designed to obtain a rating of the patient's QoL from both the patient and the caregiver. Patients are interviewed and asked to evaluate their QoL; caregivers are administered a questionnaire wherein they evaluate their residents' QoL [7]. The QoL-AD is composed of 13 items: physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to perform household chores, ability to engage in leisure, money, and life as a whole. For each item, the participant assigns a score of poor (1 point), fair (2 points), good (3 points), or excellent (4 points). The score can vary between 13 and 52 points, with the greater total score corresponding to a higher QoL. The interview ends if two or more question items cannot be answered, at which point the patient is deemed incapable of taking part in the evaluation.

In this study, a Japanese version of the QoL-AD was used for patients and the staff members who were responsible for their care and were aware of the patients' recent lives. The Mini-Mental State Examination (MMSE) [18] and QoL-AD were administered by researchers in face-to-face interviews with the patients. The staff answered the corresponding questionnaire of QoL-AD. The researchers asked the staff questions to evaluate the Neuropsychiatric Inventory (NPI) for behaviour and psychological symptoms [19,20] and the Barthel Index for activity pertaining to daily life (ADL) [21]. The Clinical Dementia Rating (CDR) to evaluate the severity of dementia [22] was carried out on the basis of the information obtained in the interview and from the staff. The interview took place in a quiet location and was conducted in such a way as to avoid causing excess distress in the patients.

Subjects

The study population consisted of people who (1) met a clinical diagnosis

of dementia according to DSM-IV (American Psychiatric Association), (2) had an MMSE total score lower than or equal to 24, (3) were 65 years old or more at the time of participation, and (4) were receiving residential care and remained at the current facility continuously for a minimum of one month. Residents with severe confusion or with acute medically unstable conditions were excluded. Caregivers included in the study were those working at the same facility as the patient, who directly took part in patient care, and who were familiar with the patient's medical status, including physical and psychological symptoms over the past month. The unit chief recommended candidates who met the inclusion criteria and would participate in an interview of approximately one hour.

Setting

The study was conducted between February 2009 and November 2010 in four nursing healthcare facilities for the elderly located in Nagano prefecture, Japan, and one special nursing care home for the elderly. The interview survey was performed with 141 people with dementia and 74 professional caregivers who care for the participating patients (men: 18, women: 56; age: 32.3 years \pm 9.2). Gender, age, and length of stay at the facility of the 141 patients were sourced from medical records.

The study was approved by the Ethics Committee at Shinshu University's School of Medicine, and written informed consent was obtained from either the patient or their legally acceptable representative before the start of the study.

Data analysis

All statistical analyses were performed using SPSS software for Windows Version 18.0. The Mann–Whitney U-test was used to compare basic information, MMSE, CDR, NPI, and the Barthel Index between the two groups. Spearman's rank-order correlation matrix was used to determine the correlations between each variable in self-rated and staff-rated QoL. Pearson's correlation matrix was used to determine the correlations between the total score and each scale in self-rated and staff-rated QoL. A multivariate stepwise linear regression analysis was undertaken to determine predictors of the self-rated QoL-AD and staff-rated QoL-AD. In all analyses, $P < 0.05$ was taken to indicate statistical significance.

RESULTS

QoL-AD

QoL-AD was initially administered in 141 patients. Of these, only 116 (82%) who obtained an MMSE score of 15.1 ± 4.2 (range 5–24) were able to participate in the study. The remaining 25 (18%) obtained an MMSE score of 5.4 ± 2.9 (range 1–10) and were excluded. There were significant differences between the participating and non-participating groups in terms of the MMSE, CDR, NPI, Barthel Index, and staff-rated QoL (Table 1). We compared the characteristics of the two groups for those who scored below 10 points in the MMSE (Completers, $n = 13$, Non-completers, $n = 25$). Significant differences were observed in the MMSE (8.1 ± 1.8 , range 5–10, and 5.4 ± 2.9 , range 1–10, respectively; $P < 0.005$) and the Barthel Index (45.4 ± 26.0 and 18.0 ± 17.2 , respectively; $P < 0.005$).

Comparison between self-rated and staff-rated QoL-AD scores

The total self-rated QoL score was 28.9 ± 6.0 points, and the total staff-rated QoL score was 27.0 ± 4.7 points. The difference between the two was significant ($P < 0.005$). A comparison of the scores for the 13 items in the self-rated and staff-rated QoL showed low scores for ‘memory’ (1.8 and 1.8 points respectively) and for ‘ability to perform household chores’ (1.8 and 1.5 points respectively). On the other hand, relatively higher scores were observed for ‘family’ (2.5 and 2.5 points respectively), ‘marriage’ (2.8 and 2.5 points respectively), and ‘living situation’ (2.5 and 2.1 points respectively). Pearson’s correlation matrix produced a slight positive correlation between self-rated and staff-rated scores for ‘living situation’ ($r = 0.28$) and ‘family’ ($r = 0.24$) and in the total score ($r = 0.24$). There were no significant correlations in the other 11 items (Table 2).

Factors associated with self-rated and staff-rated QoL

The number of responses was 116 and 141 for self-rated and staff-rated QoL respectively. There were no significant correlations between gender, age, length of stay at the care facility, MMSE, CDR, or NPI total score in the self-rated QoL, but significant correlations were observed in the Barthel Index ($r = 0.30$), NPI-depression score ($r = -0.25$) NPI-disinhibition score ($r = 0.19$), and NPI aberrant motor behaviour score ($r = 0.20$). In the staff-rated QoL, significant correlations were observed in the MMSE ($r = 0.18$), CDR ($r = -0.23$), Barthel Index ($r = 0.27$), total NPI score ($r = -0.31$), and NPI-apathy score ($r = -0.30$) (Table 3). The frequency of psychological symptoms in the descending order was as follows:

depression (n = 57; 49%), apathy (n = 46; 40%), and agitation (n = 32; 28%). The average scores in the descending order were as follows: apathy (1.52 points), depression (1.19 points), and delusions (0.93 points).

Regression analysis

A multivariate stepwise linear regression analysis was undertaken to determine which scales were the best predictors of QoL. Self-rated and staff-rated QoL-AD scores were each used as the dependent variables. The multiple independent variables included age, length of stay, MMSE, Barthel Index, CDR, and each of the 10 NPI subscales. Residents' perception of their quality of life was significantly predicted by the Barthel Index (Beta = 0.207, $P < 0.018$) and NPI depression (Beta = -0.218, $P < 0.024$). The coefficient of the determination of the multivariate model was 0.094. The staff-rated perception of the patients' quality of life was significantly predicted by CDR (Beta = -0.223, $P < 0.010$), NPI-agitation (Beta = -0.193, $P < 0.019$), NPI-apathy (Beta = -0.203, $P < 0.017$), and NPI-disinhibition (Beta = 0.254, $P < 0.002$). The coefficient of the determination of the multivariate model was 0.155.

DISCUSSION

The QoL-AD is a disease-specific QoL evaluation scale for dementia developed by Logsdon et al. [6]. Matsui et al. [12] studied the reliability and validity of the Japanese version of the QoL-AD in 150 elderly people living at home and with mild to moderate dementia. The study also involved their family caregivers. In this study, most people with dementia living in care facilities could rate their own QoL (82%). This study included 34% of people with severe cognitive dysfunction with MMSE scores of 10 or less. Consistent with previous studies [8,9,16], about one-third of these individuals could rate their own QoL. There were significant differences in the MMSE and the Barthel Index scores between the group that was able to participate and that which was not able to participate in the QoL-AD. The results of this study indicate that severely impaired cognitive function prevents them from completing the QoL-AD. However, the cognitive function of non-completers was very low, with ten points or much less.

In this study, we found a significant difference between self-rated and staff-rated QoL that indicates that caregivers tend to underestimate residents' QoL

as compared to patients' self-perception. In the lowest scoring of the 13 items in self-rated and staff-rated QoL, low correlations were observed between the evaluations of 'living situation' and 'family', and there were no significant correlations in the other 11 items. Several studies have performed one-to-one comparisons of the QoL-AD score between people with dementia and their caregivers [8-10, 12, 15]. Logsdon et al. [6] first studied people with dementia and their family caregivers and reported strong correlations between both evaluations. However, two studies investigating patients in care facilities reported that such correlations were noted in only 4 or 5 of the 13 items, with no significant correlation in the total score of QoL-AD [8, 9]. These discrepancies have also been reported in home settings [23, 24]. In line with previous research, people with dementia rate their own QoL highly than that perceived by the caregiver [6, 8, 9, 15, 23, 24]. It is noteworthy that this discrepancy is not observed exclusively in dementia patients, so it is not reasonable to ascribe it to subject error caused by cognitive impairment or lack of insight. Many individuals with chronic conditions consistently rate their own QoL highly. This 'disability paradox' is a well-established concept [25,26]. In addition to patient condition, caregiver characteristics such as caregiver burden, education, and support received may seem to influence the staff ratings [27,28]. Caregivers may find it more difficult to evaluate the QoL from the perspective of dementia patients than as proxies giving their opinion on the QoL of such people.

When the lowest scores of the 13 items were compared in this study, the scores of both ratings for 'memory' and 'ability to perform household chores' were found to be the lowest. In contrast with this study, 'memory' and 'ability to perform household chores' usually had higher scores among people with dementia in home settings [6,8,9,14, 24]. It has been reported that people with dementia tend to score low on 'ability to do household chores' in self and staff ratings [8, 9]. This suggests that owing to the fact that they are living in a care facility, patients are quite aware of suffering from memory dysfunction and the staff performing the household chores for them. The staff at care facilities should be aware of this point, and it may be effective to introduce intervention to improve the patients' self-acceptance.

A multivariate regression analysis showed that the self-rated QoL-AD was significantly predicted by functional status and depression, while staff-rated residents' QoL was significantly predicted by ratings of severity of dementia and

some behaviour symptoms. A number of other studies have investigated the potential predictors of self-rated QoL of people with dementia. The most consistent predictor was depression [6, 8-11, 23, 24], while other predictors included functional status [6] and behaviour symptoms [15]. The severity of cognitive impairment was concluded to be generally unrelated [6, 8-11, 12 15, 23, 26]. In line with several previous studies, depression in the patient was the main clinical factor associated with lower QoL in patients themselves; however, the relationship between functional impairment and self-rated QoL was controversial [27]. Logsdon et al. [6] reported the correlation between self-rated QoL and caregivers' QoL scores and activity limitation. Hoe et al. [8] reported that the Barthel Index score correlated with the staff-rated QoL but not related with self-rated QoL of people with dementia in care facilities. In another study of people with severe dementia, Hoe et al. [16] reported statistically significant correlations between self-rated QOL-AD scores and scores of the Activities of Daily Living Inventory. This study indicates that dysfunction in basic daily living activities may be one of the predictive factors related to the QoL of people with dementia as perceived by the patients themselves. Indeed, depression and impaired activities of daily living are considered to be interrelated in elderly populations [29, 30]. Measures to improve the basic activities of daily living may positively impact not only the patients' measure of QoL but also their depressive symptoms.

In caregivers, the common clinical predictors associated with perception of residents' lower QoL were caregiver burden, dependency, depression, and behaviour problems [8-10 12, 15, 23, 27, 30]. In this study, the staff rating of their QoL was significantly predicted by rating of severity of dementia, agitation, and apathy, and inversely related with disinhibition. Severity of dementia and agitation are common causes of increasing caregiver burden among both family and professional caregivers [23, 30]. Apathy is a frequently occurring symptom of dementia [23,32], but life in the care facility may exacerbate the patients' apathetic state. Apathy may itself inhibit participation in living activities and may have a negative impact on the evaluation of QoL by the staff. It remains uncertain why disinhibition was inversely related to the staff rating of QoL. The disinhibition would be counterproductive to an active status.

Several longitudinal studies assess change in self-rated QoL over time in people with dementia and investigate possible predictors for future QoL [24, 26, 33, 34]. These studies also report that the perceived QoL of people with dementia does not decline during a follow-up period in spite of disease progression [24, 26, 33, 34]. Livingston et al. [26] reported that baseline mood and social relationships are predictors for future QoL for those living in the community with dementia. There is a growing consensus that individual QoL of patients with dementia is an important outcome for effective intervention. Self-ratings are a preferable means to measure the QoL of most dementia patients capable of appraising their own QoL; however, it remains a challenge in advanced dementia patients who are not able to communicate their perspective [35].

CONCLUSION

Our data suggest that the QoL-AD is a feasible way of measuring the QoL of people with dementia in care facilities. The staff showed a tendency to underestimate residents' QoL as compared to the patients' own perceptions of their QoL. To improve the QoL of people with dementia in care facilities, it is necessary to improve staff's awareness of factors related to the self-rated QoL of people with dementia.

CONFLICT OF INTEREST

None

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Table 1. Characteristics of subjects who did and did not complete QOL-AD

Variables	Completers (n = 116)		Non-completers (n = 25)		
	Mean (SD)	Range	Mean (SD)	Range	
Age (years)	86.2 (6.0)	66–102	87.7 (7.2)	71–100	
Length of stay (month)	19.8 (21.0)	1–110	10.5 (9.2)	1–36	
MMSE	15.1 (4.2)	5–24	5.4 (2.9)	1–10	**
CDR	2.0 (0.7)	0.5–3.0	3.0 (0.2)	2.0–3.0	**
NPI	7.3 (7.6)	0–34	12.8 (9.8)	0–48	**
Barthel Index	40.6 (26.2)	0–95	18.0 (17.2)	0–55	**
Staff rated QOL	27.0(4.7)	15–40	25.4(5.5)	15–37	

Abbreviations: Quality of life in Alzheimer's disease, QoL-AD; Mini Mental State Examination, MMSE; Neuropsychiatric Inventory 10 item version, NPI; Clinical Dementia Rating, CDR; SD, standard deviation. ** P < 0.01

Table 2. Mean scores, standard deviations, and correlations for residents' QoL -AD score

	self-rated QoL-AD (n=116)	staff-rated QoL-AD (n=116)	Correlation
	Mean (SD)	Mean (SD)	
1. Physical health	2.1 (0.84)	2.0 (0.68)	0.13
2. Energy	2.1 (0.80)	2.1 (0.72)	0.18
3. Mood	2.2 (0.80)	2.1 (0.61)	0.09
4. Living situation	2.5 (0.77)	2.1 (0.69)	0.28 **
5. Memory	1.8 (0.74)	1.9 (0.71)	-0.14
6. Family	2.5 (0.84)	2.5 (0.92)	0.25 **
7. Marriage	2.8 (0.85)	2.5 (0.79)	0.18
8. Friends	2.3 (0.88)	2.0 (0.76)	0.05
9. Self	2.1 (0.74)	1.9 (0.65)	0.02
10. Ability to perform household chores	1.8 (0.80)	1.6 (0.78)	0.13
11. Ability to engage in leisure	2.2 (0.81)	2.0 (0.84)	0.16
12. Money	2.3 (0.84)	1.9 (0.56)	0.04
13. Life as a whole	2.3 (0.81)	2.2 (0.57)	0.01
Total score	28.9 (6.0)	27.0 (4.7)	0.24 *

* $P < 0.05$, ** $P < 0.01$

Table 3. Correlation of QoL-AD with demographic data and related measures

Variables	Self-rated QoL-AD (n = 116)	Staff-rated QoL-AD (n = 141)
Sex	0.06	0.08
Age (years)	0.01	0.06
Length of stay (m)	0.05	-0.03
MMSE	-0.03	0.18 *
CDR	0.06	-0.23 **
Barthel Index	0.30 **	0.27 **
NPI total	0.02	-0.31 **
NPI-delusions	0.08	-0.05
NPI-hallucinations	-0.06	-0.11
NPI-agitation	0.07	-0.11
NPI-depression	-0.25 **	-0.16
NPI-anxiety	-0.01	-0.08
NPI-euphoria	-0.09	-0.06
NPI-apathy	-0.07	-0.30 **
NPI-disinhibition	0.18 *	0.16
NPI-irritability	0.06	-0.12
NPI-aberrant behaviour	motor 0.20 *	-0.04

Abbreviations: Quality of life in Alzheimer's disease, QoL-AD, Mini Mental State Examination, MMSE; Neuropsychiatric Inventory 10 item version, NPI; Clinical Dementia Rating, CDR. * P < 0.05, ** P < 0.01