

Research Article

Chronic Illness Influences Health-Related Quality of Life of Caregivers of Patients with Dementia

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Abstract

Aim: Caregivers who live with dementia patients have lower Quality of Life (QOL) than those who do not, yet few studies have identified factors that affect caregiver Health-Related Quality of Life (HRQOL). The present study aimed to identify factors that affect HRQOL in caregivers of community-dwelling patients with dementia.

Methods: We conducted a cross-sectional survey among 52 older caregivers of patients with dementia to assess their HRQOL

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using the 36-item Short Form Health Survey (SF36). A bivariate correlation matrix and logistic regression analysis were used to examine associations of HRQOL with chronic illnesses and caregiver burden as measured by Zarit Burden Interview (ZBI). The number of chronic illnesses and ZBI scores were compared between caregivers with standard HRQOL and those with low HRQOL using the unpaired t-test.

Results: Mean SF-36 subscale scores and SF-36 summary scores were all below the national standards. Physical component summary scores were negatively correlated with the number of chronic illnesses ($r = -0.344$, $p < 0.05$). Caregivers with lower HRQOL showed significantly higher ZBI scores than those with standard HRQOL.

Conclusion: The present findings highlight the importance of managing chronic illnesses that may affect caregiver HRQOL.

Keywords: Caregiver burden; Chronic illness, Dementia; Health-Related Quality of Life (HRQOL)

Introduction

Caregivers who live with individuals with dementia (i.e., care recipients) have Lower Quality of Life (QOL) than those who do not [1]. Caregivers are often family members of the patient, and studies have found that those caring for a spouse have low QOL [2]. In addition, the strong relationship between caregiver and Patient With Dementia (PWD) can predict both positive and negative effects on the physical health and emotional happiness of the caregiver [3]. There has been an increase in the number of patients afflicted by Alzheimer's type dementia [4], which is associated with a higher sense of care burden due to psychiatric symptoms and decreased cognitive function [5]. Caregivers of PWDs experience more stress as well as psychological and physical health issues [6], report a higher care burden [7], are more prone to hypertension [8], and are more vulnerable toward developing physical illnesses [9], relative to caregivers of patients without dementia. Poorer physical status, lower life satisfaction, and higher degrees of depression and anxiety relative to those prior to becoming a caregiver are associated with higher caregiver burden [10]. One in three caregivers experiences depression, the rate of which is much higher among caregivers of PWDs than caregivers of patients with other chronic illnesses [11]. In addition, female caregivers of PWDs exhibit a higher propensity of developing headaches and higher blood coagulability, compared to their male counterparts [12]. Key factors known to influence caregiver burden include sex of the PWD, behavioral and psychological symptoms and decline in everyday functioning of the PWD, as well as the sex of the informal caregiver, their relation to the PWD, and whether or not they live with the PWD [13]. Several other factors that may affect caregiver health include caregiving stress, worsening of sleep quality, decreased overall physical activity, particularly with regard to leisure-time activity [14], irregularities in daily routines, and a less structured daily lifestyle. Any and all of these may explain decreases in caregiver QOL.

A positive correlation was previously reported between the feeling of self-efficacy in caregivers of PWDs and their Health-Related QOL (HRQOL) [15]. However, very few studies have identified factors that influence the HRQOL of caregivers of PWDs. The present study aimed to identify factors that influence HRQOL among community-dwelling caregivers of PWDs.

Methods

Participants

Participants were caregivers aged >65 years living with patients with dementia of the Alzheimer's Type (DAT) diagnosed according to DSM-IV [16] criteria by experienced geriatricians in a university hospital. While healthy caregivers were targeted, we also included some with chronic illnesses such as hypertension, diabetes, and dyslipidemia, all of which were adequately controlled by periodic treatment. Caregivers with severe cardiac disease (e.g., angina, myocardial infarction and heart failure), symptomatic cerebrovascular disease, uncontrolled blood pressure, renal failure, or uncontrolled diabetes were excluded.

Scales and measured factors

Caregiver-related variables included age and sex of caregivers, number of co-caregivers living together, number of chronic illnesses, HRQOL and Zarit Burden Interview (ZBI) scores. To evaluate caregiver HRQOL, we used the SF-36® (36-item Short Form Health Survey). The SF36 is a measurement tool used widely to assess HRQOL, and has been shown to be scientifically reliable and valid. National standard values have been established for the SF-36v2. Any score exceeding the national standard score of 50 can be interpreted as indicating favorable HRQOL and scores below 50 as indicating poor HRQOL. The SF-36 comprises multiple survey items used to measure eight aspects of health. The eight subscales of the SF-36 include: 1) Physical Functioning (PF), 2) Role Physical (RP), 3) Bodily Pain (BP), 4) General Health (GH), 5) Vitality (VT), 6) Social Functioning (SF), 7) Role Emotional (RE) and 8) Mental Health (MH). A 3-component scoring method has been developed, which added a role/social component to the physical component and mental component of the SF-36v2 [17]. Summary scores for each of the three components are referred to as the Physical Component Summary (PCS), Mental Component Summary (MCS), and Role/Social Component Summary (RCS). These scores are calculated after each is weighted according to the factorial structure of the eight subscales, and reflect physical, mental and role/social components. Given the need to clarify the HRQOL of caregivers and understand their physical, mental, and social aspects, we defined HRQOL based on the eight subscales of SF-36 and 3-component scoring.

Using the Excel version of the SF-36v2™ scoring program, scores of 0-100 were re-calculated such that the national standard value of the general Japanese population would be 50, with a standard deviation of 10. These scores are considered international standard scores for the SF-36v2.

To assess the sense of caregiver burden among caregivers, we used the ZBI [18], a measurement tool that assesses 22 items pertaining to the mental aspect, physical aspect and social tension of a caregiver's life. Higher ZBI scores indicate higher sense of caregiver burden (0-88 points). With regard to PWDs, we assessed the degree of cognitive

impairment using the Japanese version of Mini-Mental State Examination (MMSE) [19], with lower scores indicating impaired cognition (0-30 points).

Statistical analysis

Descriptive statistics were used to analyze the characteristics of caregivers and PWDs. A bivariate correlation matrix was constructed to analyze factors related to caregiver HRQOL and the associated Pearson's correlation coefficients. Internal correlations among caregiver variables, including the presence of co-caregivers living together, number of chronic illnesses, and ZBI scores, were calculated. Another bivariate correlation matrix was used to analyze the number of chronic illnesses, ZBI, and the three component summary scores for SF-36. The mean total score (range, 0-8) of the eight subscales of SF-36 was 5.288. Accordingly, using 5 as the cut-off score, caregivers for whom the total eight subscale score on the SF36 was ≥ 5 were considered to have a low HRQOL, while those with < 5 were considered to have a standard HRQOL. Following this classification, an unpaired t-test was performed to assess statistically significant differences in total number of chronic illnesses, ZBI, sex, and age of caregivers between the standard HRQOL group and low HRQOL group. To identify factors predicting HRQOL and determine the extent to which each factor was explanatory, logistic regression analysis was performed with SF-36 subscale scores and SF-36 summary scores as dependent variables, and caregiver age, sex, number of chronic illnesses and caregiver sense of burden as covariates. Statistical analyses were performed using SPSS Ver. 25.

Ethical considerations

This study was approved by the Ethics Committee of Nagoya University Graduate School of Medicine. Written informed consent was obtained from all caregivers who participated in this study. Ethical measures were taken, including clarifying that participation in this study was voluntary.

Results

Of the 52 participants, more caregivers were female than male, and 42 participants reportedly had no cohabiting family members or relatives helping with the care, while 10 had family members helping them with caregiving. For the evaluation of HRQOL, mean SF36 subscale and SF36 summary scores were all below or equal to the national standard score of 50. Six of the SF-36 subscale scores (PF, RP, GH, SF, RE and MH) and 2 summary scores (PCS and RCS) were ≥ 40 but lower than 45 (the national standard). Meanwhile, two subscale scores (BP and VT) and one summary score (MCS) were ≥ 45 but lower than 50. Our evaluation of the cognitive function of PWDs revealed a MMSE score of 17.9 ± 7.4 , demonstrating a moderate level of dementia (Table 1).

Table 2 presents results from the bivariate correlation matrix analysis of factors related to caregiver HRQOL. We found a weak correlation ($r=0.284$, $p<0.05$) between the number of chronic illnesses and age of the caregiver, which suggested a possible association between these two factors. PCS scores were inversely correlated with the number of chronic illnesses in the caregiver ($r=-0.344$, $p<0.05$, Table 3).

Table 4 shows comparisons of the low HRQOL group (in which the total number of subscales having a national standard value < 50 from among the eight subscales of the SF-36 is ≥ 5) and standard

HRQOL group (in which the total number of subscales having a national standard value <50 from among the eight subscales of the SF-36 is <5). Caregivers in the very low HRQOL group scored lower than the national standard for five subscale scores (PF, RP, SF, RE and MH) and one summary score (RCS), which had mean national standards of <40. For the remaining SF-36 scores, the fairly low HRQOL group scored lower than the national standard values for three subscale scores (BP, GH and VT) and two summary scores (PCS and MCS), which had mean national standard values of ≥40 but under 45.

	Mean	S.D.
Caregivers		
Sex, Male / Female (N)	23 /	29
Age	75.4 ±	5.0
Absence of someone helping with caregiving Yes / No (N)	42 /	10
Total number of caregiver's chronic illnesses	1.3 ±	0.9
ZBI total score	28.8 ±	16.1
SF36 subscales		
Physical Functioning (PF)	42.0 ±	14.9
Role Physical (RP)	40.8 ±	13.5
Bodily Pain (BP)	45.3 ±	10.2
General Health (GH)	44.1 ±	9.7
Vitality (VT)	45.6 ±	10.5
Social Functioning (SF)	42.8 ±	13.5
Role Emotional (RE)	42.5 ±	13.4
Mental Health (MH)	42.8 ±	9.2
SF36 summary scores		
Physical component summary: PCS	44.7 ±	15.4
Mental component summary: MCS	46.9 ±	9.0
Role/Social component summary: RCS	42.5 ±	16.1
Patient with dementia		
Age	77.2 ±	6.1
MMSE score	17.9 ±	7.4

Table 1: Background information of caregivers and patients with dementia.

S.D, standard deviation; ZBI, Zarit Burden Interview; SF36, 36-item Short Form Health Survey; MMSE, Mini-Mental State examination.

	1.	2.	3.	4.	5.	
1. Age	r	1				
	p					
2. Sex	r	-.228	1			
	p	.103				
3. Caregiver support person (cohabiting family members or relatives)	r	-.058	-.155	1		
	p	.684	.273			
4. Total number of chronic illnesses	r	.284*	-.084	-.004	1	
	p	.041	.555	.976		
5. ZBI	r	-.057	.261	-.207	-.117	1
	p	.687	.061	.141	.408	

Table 2: Bivariate correlations among factors related to caregiver Health-Related QOL (HRQOL).

*p<0.05, **p<0.01.

Note: ZBI, Zarit Burden Interview; r, Pearson's correlation coefficients; p, two-tailed significance.

	1.	2.	3.	4.	5.	
1. Number of chronic illnesses	r	1				
	p					
2. ZBI	r	-.117	1			
	p	.408				
3. PCS score	r	-.344*	-.005	1		
	p	.012	.972			
4. MCS score	r	-.208	-.030	-.002	1	
	p	.140	.835	.989		
5. RCS score	r	.197	-.548**	-.208	-.264	1
	p	.161	.000	.139	.059	

Table 3: Results of bivariate correlation matrix analysis of the number of chronic illnesses, ZBI and SF-36 summary scores.

Note: r, Pearson's correlation coefficient. p, two-tailed significance. *: p<0.05; **: p<0.01.

ZBI, Zarit Burden Interview; PCS, Physical Component Summary; MCS, Mental Component Summary; RCS, Role/Social Component Summary.

Meanwhile, caregivers in the standard HRQOL group did not score above the national standard values for two subscale scores (PF and RP) and one summary score (RCS), with somewhat low HRQOL mean national standard values of ≥48 but under 49.9. None of these scores were as high as the national standard values. All other SF-36 scores had mean national standard values of ≥50 but under 53, which were not high, but rather standard values. Relative to the standard HRQOL group, the low HRQOL group showed significantly lower national standard values for many of the SF-36 scores. ZBI scores were significantly higher in the low HRQOL group relative to the standard HRQOL group. No group-dependent difference was observed for the number of chronic illnesses.

Table 5 presents the results from the logistic regression analysis when national standard values of the HRQOL subscales were used as dependent variables. Associations were observed between PF and the number of chronic illnesses of the caregiver (OR: 2.309, 95%IC: 1.089-4.895), RP and ZBI (OR: 1.071, 95%IC: 1.019-1.124), BP and caregiver sex (OR: 0.269, 95%IC: 0.074-0.972) and number of chronic illnesses (OR: 3.074, 95%IC: 1.300-7.268), VT and ZBI (OR: 1.061, 95%IC: 1.010-1.116) and number of chronic illnesses in the caregiver (OR: 2.977, 95%IC: 1.100-8.060), SF and ZBI (OR: 1.046, 95%IC: 1.006-1.088), and RE and ZBI (OR: 1.080, 95%IC: 1.028-1.135). For SF-36 subscales, associations were observed between the PCS score and number of chronic illnesses (OR: 2.417, 95%IC: 1.089-5.362), the MCS score and number of chronic illnesses (OR: 2.120, 95%IC: 1.002-4.485), and the RCS score and ZBI (OR: 1.107, 95%IC: 1.044-1.174).

Discussion

The present study examined factors that influence the HRQOL of caregivers of PWDs. Our study results indicated that the number of chronic illnesses in caregivers and ZBI scores can decrease the QOL of caregivers of PWDs. This finding may help to improve caregiver QOL. Roughly 80% of caregivers examined in the present study had no one to help them with caregiving, and we found that in many cases, elderly patients were being cared for by another elderly individual. It is understandable that having no one to help in caregiving would be physically and emotionally demanding of an elderly caregiver.

Evaluation item	Caregivers with low HRQOL (N=36)			Caregivers with standard HRQOL (N=16)			P-value
	Mean	S.D.		Mean	S.D.		
Caregiver							
Age (years)	76.0	± 5.5		74.1	± 3.5		0.206
Sex Male/Female (N)	15	/	21	8	/	8	0.585
SF36 subscales							
Physical Functioning (PF)	38.6	± 16.3		49.7	± 6.6		0.012
Role Physical (RP)	37.3	± 13.6		48.7	± 9.6		0.004
Bodily Pain (BP)	42.5	± 10.6		51.7	± 5.8		0.002
General Health (GH)	40.3	± 8.0		52.6	± 7.4		0.000
Vitality (VT)	42.4	± 9.6		52.6	± 8.9		0.001
Social Functioning (SF)	38.8	± 12.8		51.8	± 10.3		0.001
Role Emotional (RE)	38.2	± 13.7		52.2	± 5.2		0.000
Mental Health (MH)	39.5	± 8.0		50.2	± 7.3		0.000
SF36 summary score							
Physical component summary: PCS	42.3	± 16.8		50.0	± 10.5		0.098
Mental component summary: MCS	44.3	± 8.3		52.6	± 7.8		0.001
Role/Social component summary: RCS	39.2	± 17.0		49.9	± 11.1		0.025
ZBI	32.7	± 16.4		20.0	± 11.5		0.008
Total number of chronic illnesses	1.4	± 1.0		1.2	± 0.8		0.525
Patient							
MMSE score	18.7	± 6.2		16.4	± 9.6		0.312

Table 4: Comparison of caregivers by HRQOL scores (at/above versus below the national standard).

Note: S.D, standard deviation; ZBI, Zarit Burden Interview; SF36, 36-item Short Form Health Survey; MMSE, Mini-Mental State examination.

Caregivers with low HRQOL were defined as those for whom the total number of subscales having a national standard value <50 from among the eight subscales of the SF-36 is ≥5. Caregivers with standard HRQOL were defined as those for whom the total number of subscales having a national standard value <50 from among the eight subscales of the SF-36 is <5.

Given that the mean total score (range, 0-8) for the eight subscales of SF-36 was 5.288, 5.0 was used as the cut-off. An unpaired t-test was used.

Dependent variable	Variables (covariate)	B	OR	95% IC	P
PF	Total number of caregiver chronic illnesses	.837	2.309	(1.089-4.895)	.029
RP	ZBI	.068	1.071	(1.019-1.124)	.006
BP	Caregiver sex 1: male; 2: female	-1.313	.269	(0.074-0.972)	.045
	Total number of caregiver chronic illnesses	1.123	3.074	(1.300-7.268)	.011
VT	ZBI	.060	1.061	(1.010-1.116)	.020
	Total number of caregiver chronic illnesses	1.091	2.977	(1.100-8.060)	.032
SF	ZBI	.045	1.046	(1.006-1.088)	.024
RE	ZBI	.077	1.080	(1.028-1.135)	.002
PCS score	Total number of caregiver chronic illnesses	.883	2.417	(1.089-5.362)	.030
MCS score	Total number of caregiver chronic illnesses	.751	2.120	(1.002-4.485)	.049
RCS score	ZBI	.101	1.107	(1.044-1.174)	.001

Table 5: Logistic regression analysis with HRQOL subscales as dependent variables.

Note: B: partial regression coefficient. OR: odds ratio (95% confidence interval).

PF, physical functioning; RP, role physical; BP, bodily pain; GH, general health; VT, vitality; SF, social functioning; RE, role emotional; MH, mental health; PCS, physical component summary; MCS, mental component summary; RCS, role/social component summary. For the dependent variable, 0 was assigned to HRQOL subscales for which the national standard value was ≥50, and 1 for those with a national standard value <50.

The SF-36 subscale scores and summary scores were all lower than the national standards. Particularly low scores were noted for PF (Physical Functioning), RP (Role Physical), SF (Social Functioning), RE (Role Emotional), and MH (Mental Health). Caregivers of PWDs often develop depression [20,21], and caregiver HRQOL is

reportedly low [22]. Our study findings are consistent with these previous reports. One potential reason for the low scores on the subscales in the present study is that PF and RP decreased due to the physical and mental fatigue of daily caregiving, i.e., it is possible that work and daily activities were restricted and social life hindered. Lower SF

scores could indicate physical and emotional difficulties with social interaction, possibly due to a lack of physical strength caused by caregiving. Low RE values may be explained by the increased burden of caregiving for PWDs with lower MMSE scores, which in turn could have led to emotional problems in normal everyday activities. Low MH values are thought to have been caused by nervousness and the dismal feeling that developed from continued caregiving as the care burden increased. Moreover, mental and psychological fatigue from caring for patients with dementia who have low cognitive function, the tendency to accumulate stress due to the lack of cohabiting family members who can help with care, and the physical burden of caregiving due to aging of the caregivers themselves are thought to have contributed to sensitivity towards caregiver sense of burden. Each of these factors may significantly contribute to the decline in caregiver health and social participation. The present study found low MMSE scores among the PWDs; because of their high demand for care, caregivers had very little time for social participation, such that emotional interactions were difficult to have with others. In addition to being elderly themselves, caregivers were required to care for the patients, and thus, in addition to the physical pain, their physical function was likely decreased as well.

Caregiver age and number of chronic illnesses were found to be weakly correlated with HRQOL, demonstrating the possibility that chronic illnesses and age are related. Aging of the Japanese society has been accompanied by an increase in chronic illness onset [23]. In addition to the physiological changes associated with aging, aging caregivers have fewer and fewer opportunities for activity, leading to decreases in physical strength. Moreover, due to age-related decreases in physical reserve/recovery capacity, adaptability, and fatigue of caregiving, they become more prone to contracting illnesses, while also recovering from these less readily. Management that prevents the exacerbation of chronic illnesses is necessary.

An inverse correlation was observed between PCS score and the number of chronic illnesses in caregivers. Chronic illnesses may have had an impact on the physical aspects of caregivers, suggesting the need for illness management in patients with chronic illnesses to improve their physical function. Caregiver burden, as measured by ZBI, is significantly and negatively correlated with QOL [24]. Consistent with this, the RCS score and ZBI were negatively correlated in the present study. We surmise that caregivers felt the stress of the role required of them, which created a psychological burden that led to emotional problems in daily living. Our findings suggest the need to develop programs that would strengthen the psychological support for caregivers. With regard to ZBI scores, since caregiver sense of burden cannot be lessened simply by counseling caregivers, it is necessary to also demonstrate an understanding of their social aspects. As many caregivers fulfil their role without help, a caregiver support system needs to be established using social resources. In the present study, MMSE scores of PWDs indicated a moderate level of disease; this reflects just how difficult it is to care for PWDs. Educating caregivers about caregiving techniques according to the degree of disease (as reflected by MMSE score) may be necessary.

Comparison of the low and standard HRQOL groups revealed significantly lower subscale scores for the eight SF-36 subscales in the low HRQOL group relative to the standard HRQOL group. The low HRQOL group had significantly higher ZBI scores than the standard HRQOL group. A previous study on SF-36 and ZBI found

a significant relationship between psychological health of caregivers and HRQOL [25]. Physical HRQOL was lower in female caregivers, those caring for more physically affected patients, and older caregivers, while mental HRQOL was lower in younger caregivers, those caring for more physically affected patients, and those caring for patients with abnormal behaviors [26]. The present study results are consistent with these previous reports. Our study found that the low HRQOL group had high ZBI scores. One reason for the low HRQOL scores may have been that both SF-36 and ZBI comprise similar items such as psychological components, physical components, caregiver's social role, and mental strain (tension), thus HRQOL and caregiver sense of burden may have influenced this.

The number of chronic illnesses and ZBI scores of the caregivers were found to influence HRQOL. Psychological/emotional stress is an independent risk factor for mortality among elderly individuals caring for their spouses, and those reporting caregiving-related stress reportedly have a 63% higher risk of mortality compared to their non-caregiving counterparts (relative risk, 1.63) [27]. Chronic stress from caregiving is known to cause adverse effects on blood pressure [28], can make one more prone to atherosclerosis, and increase the onset rate of cardiovascular disease [29]. From our present findings, we would surmise that caregivers may develop chronic illnesses more readily because 80% or more of our caregivers had no one helping them in their caregiving, and because they were constantly in an environment where psychological stress was easily felt because they were under constant and extreme stress from their caregiving role. Moreover, as they were alone in caregiving, they had fewer opportunities to get out and enjoy leisure activities. Fewer opportunities for social participation indicate that decreases in physical activity were also evident, making them more prone to chronic illnesses and the exacerbation of such. This demonstrates the importance of using social resources allotted to caregiving in order to offer respite care for elderly caregivers who are dealing with physical pain due to a chronic illness. In addition to offering psychological interaction, programs should be developed that would alleviate the physical pain of caregivers who have no caregiving assistance.

One factor that influenced Bodily Pain (BP) was caregiver sex. Compared to female caregivers, male caregivers were found to have less bodily pain. In studies that examined sex-dependent differences, over 50% of caregivers had high scores for anxiety and depression, and relative to their male counterparts and female caregivers exhibited a 3.39-fold higher risk for anxiety onset [30]. As caregiver anxiety is evidently sex-dependent, it will be important to consider the sex of the caregiver when interacting with them.

The study population of the present study was relatively small, and we were unable to obtain statistically significant results. Future studies should re-examine this question with a larger sample population. In addition, as this was a cross-sectional study, it is possible that causality cannot be confirmed. Longitudinal studies will be needed to clarify this point. The present study clarified that the number of chronic illnesses and ZBI of caregivers of PWD were two factors that influenced HRQOL. The low HRQOL of caregivers of PWDs was indicative of the high demands of caregiving placed on them. We anticipate that chronic illnesses will increase in caregivers as they age, as well as the stress of caregiving and burden on QOL. As chronic illnesses are more likely to develop as a result of caregiver fatigue and related factors, a healthy caregiving environment must be established

in order to allow for adequate management of chronic illnesses and delegation of caregiving duties.

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Disclosure Statement

The authors declare no conflicts of interest.

Author's Contributions

Akemi Hirano and Hiroyuki Umegaki conceived the idea and designed this study. Akemi Hirano carried out data analysis and interpretation. Akemi Hirano wrote the first draft and Yusuke Suzuki, Hiroyuki Umegaki, and Koichiro Ina critically discussed all versions of the manuscript. Yusuke Suzuki, Hiroyuki Umegaki, Koichiro Ina, Toshio Hayashi, and Masafumi Kuzuya recruited the participants, and Hiroyuki Umegaki contributed to the overall supervision of the present study.

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