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ARTICLE

Effects of Free Time on Quality of Life in Elderly Caregivers

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ABSTRACT

Caregivers who contribute to health care of their patients are significantly more likely to experience emotional difficulty, physical difficulty, and financial difficulty, than caregivers who do not contribute. This study aimed to examine the effects of free time on health-related quality of life among elderly caregivers of dementia patients. In the intervention group, caregivers set aside free time every 30 minutes three times a week, while continuing to care for patients. During the free time, caregivers were free to spend time at home and do whatever they wanted. The control group received only usual care. The intervention period was six months. The Vitality subscale score of the SF-36 decreased significantly in the intervention group, despite more than half (57.1%) of participants showing improvements or no change in the rank of this subscale relative to baseline, as assessed by the Wilcoxon signed-rank test (not significant). Caregivers indicated that daily caregiving resulted in an accumulation of physical fatigue, and they continued to have little mental leeway. Caregivers also had difficulty securing free time, which may have hindered improvements to their vitality. There is a need to develop a home-based program that can alleviate caregiver stress and improve their quality of life.

1. Introduction

Family caregivers of dementia patients experience considerable burden [1]. Almost half of dementia patient caregivers reportedly experience stress at levels in moderate to very severe ranges [2]. Moreover, caregiving for dementia patients is associated with depression [3,4], and older caregivers are especially at increased risk of severe depressive symptoms [5].

Caregivers who contribute to health care of their patients are significantly more likely to experience emotional difficulty, physical difficulty, and financial difficulty, than caregivers who do not contribute. Compared to caregivers who do not contribute to health care activities, those who provide substantial contributions were more than five times as likely to experience participation restrictions in

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valued activities, and more than three times as likely to experience work productivity loss [6].

Intervention studies targeting caregivers of dementia patients found that psychoeducational intervention by telecommunication or face-to-face interviews improved quality of life (QOL) relative to a control group [7,8,9]. These methods hold promise in terms of providing remote support when people are restricted from going outside, for example, to care. Support via telemedicine using video conferencing has been shown to improve the resilience and well-being of both patients and caregivers compared to telephonic support [10].

Internet interventions for informal dementia caregivers can improve various aspects of caregiver well-being, for example, confidence, depression, and self-efficacy, provided that they comprise multiple components and are tailored to the individual [11]. Similarly, web-based interventions have the potential to reduce depressive symptoms, anxiety, stress, and distress among informal caregivers of chronically ill adults in the community [12]. However, fewer elderly individuals use computers and the Internet compared to younger people [13]. Therefore, other methods are needed to improve the health of the elderly at home.

Decision support for the selection of respite services by caregivers of patients with dementia was reported to be less burdensome [14]. In addition, intervention trials with relaxation techniques in caregivers of dementia patients were shown to improve stress, depression, and negative bias scores [15]. Previous studies have reported on relationships between free time and QOL among caregivers, as well as interventions aimed at ensuring free time for caregivers. These studies suggest that incorporating free time into the lives of caregivers may improve their QOL.

The purpose of this study was to examine the effects of free time on the QOL of elderly caregivers of dementia patients.

2. Methods

2.1 Research Design

This study was a randomized controlled trial. After consent was obtained from caregivers, they were randomly assigned to the intervention group or control group. In the intervention group, free time was set aside every 30 minutes three times a week while caregivers continued to provide routine care. During the free time, caregivers were free to spend time at home and do whatever they wanted. Caregivers of the control group received only usual care. The intervention period was six months.

2.2 Participants

The target population was elderly caregivers living with dementia patients.

2.3 Caregiver Assessments

The main outcome for caregivers was QOL after six months of intervention, as assessed by the SF-36, a measurement tool widely used to assess health-related QOL [16]. QOL was compared between the intervention and control groups at baseline and six months after initiation of the intervention.

2.4 Statistical Analysis

The Mann-Whitney U test was used to analyze data of the intervention and control groups at baseline. The Wilcoxon signed-rank test was used to analyze post-intervention data from the two groups. All statistical tests were two-tailed, with the significance level set at 5%.

2.5 Ethical Considerations

This study was approved by the ethics committee of Nagoya University Graduate School of Medicine. Caregivers who provided informed consent were included in the study and were informed that participation was voluntary.

3. Results

Table 1 summarizes the characteristics of caregivers of dementia patients. In the intervention group, 11 participants were female and the median care time was 6.0 hours. In the control group, 14 participants were female. In the intervention and control groups, the median number of family members living together (including the dementia patient) was 2.0, and relatives helping with care lived separately. In the intervention group, Physical Functioning, Bodily Pain, and Social Functioning subscale scores of the SF-36 were above the national norm, while Role Physical, General Health, Vitality, Role Emotional, and Mental Health subscale scores were below the national norm. In the control group, total SF-36 scores were generally lower than the national norm, and Role Physical and Mental Health subscale scores were much lower than the national norm.

Post-intervention changes in the intervention group are shown in Table 2. The Vitality subscale score was significantly decreased post-intervention relative to baseline, while other subscale scores did not significantly differ between baseline and post-intervention. Table 3 compares ranks in the intervention group after the intervention using

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the Wilcoxon signed-rank test. The Vitality subscale had a positive rank of 3, a tied rank of 9, and a negative rank of 9, which did not significantly differ from baseline, but the subjects improved (N=3). Positive and tied (positive/tied) ranks comprised 57.1% of the total. Physical Functioning and General Health subscales had positive/tied ranks in 61.9% of participants, and Social Functioning and Role Emotional subscales had positive/tied ranks in 71.4% of participants. Subscale and summary scores with more positive/tied ranks than negative ranks were observed for the following: Physical Functioning, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health, and Mental component summary. The following had more negative ranks than positive/tied ranks: Role Physical (61.9%), Physical component summary (57.1%), and Role/Social component summary (57.1%).

Changes relative to baseline after the intervention in the control group are shown in Table 4. The Physical component summary (66.7%) had more negative ranks, while other subscale and summary scores had more positive/tied ranks.

Table 1. Baseline characteristics of caregivers

	Intervention		Control		
	Median	IQR	Median	IQR	P
Age	75.0	72.0-78.0	77.0	73.0-80.0	0.073
Gender Male/Female (N/%)	10 / 11		7 / 14		0.351
Care hours per day (hours)	6.0	2.5-14.5	8.0	2.0-16.0	0.561
Number of family members living together	2.0	2.0-2.5	2.0	2.0-2.0	0.499
SF-36 subscales					
Physical Functioning	50.6	43.4-54.2	47.0	29.0-54.2	0.221
Role Physical	45.8	34.2-55.7	39.1	22.5-55.7	0.378
Bodily Pain	50.1	40.3-54.6	44.7	35.4-49.7	0.075
General Health	44.2	39.2-52.2	41.5	37.8-50.9	0.503
Vitality	49.8	45.0-54.7	43.4	35.4-49.8	0.030
Social Functioning	50.6	34.5-57.0	44.1	31.2-53.8	0.236
Role Emotional	43.6	35.3-54.0	43.6	29.0-56.1	0.600
Mental Health	43.8	41.1-50.5	38.4	37.1-45.2	0.059
SF-36 summary scores					
Physical component summary	47.8	42.6-56.3	48.9	33.1-56.4	0.563
Mental component summary	49.2	40.2-57.1	44.1	36.4-51.2	0.242
Role/Social component summary	45.1	33.8-57.3	41.9	28.3-52.0	0.428

Notes: The SF-36 score represents the national norm. Data are presented as median. The number of family members living with the patient includes the dementia patient. IQR, interquartile range.

Table 2. Changes in the intervention group after intervention relative to baseline

Change after intervention (Δ)		N	Average rank	Rank sum	Z	P
SF-36 subscales						
Physical Functioning	Negative ranks	8	10.0	80.0	-.639	0.523
	Positive ranks	8	7.0	56.0		
	Tied ranks	5				
Role Physical	Negative ranks	13	8.8	114.0	-.766	0.444
	Positive ranks	6	12.7	76.0		
	Tied ranks	2				
Bodily Pain	Negative ranks	9	6.7	60.0	-.414	0.679
	Positive ranks	7	10.9	76.0		
	Tied ranks	5				
General Health	Negative ranks	8	8.4	67.5	-.785	0.432
	Positive ranks	10	10.4	103.5		
	Tied ranks	3				
Vitality	Negative ranks	9	7.1	64.0	-1.970	0.049
	Positive ranks	3	4.7	14.0		
	Tied ranks	9				
Social Functioning	Negative ranks	6	6.0	36.0	-.672	0.501
	Positive ranks	7	7.9	55.0		
	Tied ranks	8				
Role Emotional	Negative ranks	6	7.3	43.5	-.140	0.889
	Positive ranks	7	6.8	47.5		
	Tied ranks	8				
Mental Health	Negative ranks	10	10.1	100.5	-.524	0.600
	Positive ranks	11	11.9	130.5		
	Tied ranks	0				
SF-36 summary scores						
Physical component summary	Negative ranks	12	11.0	132.0	-.574	0.566
	Positive ranks	9	11.0	99.0		
	Tied ranks	0				
Mental component summary	Negative ranks	10	11.0	110.0	-.191	0.848
	Positive ranks	11	11.0	121.0		
	Tied ranks	0				
Role/Social component summary	Negative ranks	12	10.8	129.5	-.487	0.627
	Positive ranks	9	11.3	101.5		
	Tied ranks	0				

Change after intervention (Δ) = post-intervention value – baseline value.

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Table 3. Comparison of ranks in the intervention group after intervention

Ranks	SF-36 scale	Positive/tied ranks (N / %)	Negative ranks (N / %)
More positive/tied ranks than negative ranks	Physical Functioning	13 / 61.9%	8 / 38.1%
	Bodily Pain	12 / 57.1%	9 / 42.9%
	General Health	13 / 61.9%	8 / 38.1%
	Vitality	12 / 57.1%	9 / 42.9%
	Social Functioning	15 / 71.4%	6 / 28.6%
	Role Emotional	15 / 71.4%	6 / 28.6%
	Mental Health	11 / 52.4%	10 / 47.6%
	Mental component summary	11 / 52.4%	10 / 47.6%
More negative ranks than positive/tied ranks	Role Physical	8 / 38.1%	13 / 61.9%
	Physical component summary	9 / 42.9%	12 / 57.1%
	Role/Social component summary	9 / 42.9%	12 / 57.1%

Table 4. Changes in the control group after intervention relative to baseline

Change after intervention (Δ)		N	Average rank	Rank sum	Z	P
SF-36 subscales						
Physical Functioning	Negative ranks	10	8.00	80.00	-.633	0.527
	Positive ranks	6	9.33	56.00		
	Tied ranks	5				
Role Physical	Negative ranks	9	5.94	53.50	-1.092	0.275
	Positive ranks	8	12.44	99.50		
	Tied ranks	4				
Bodily Pain	Negative ranks	9	9.17	82.50	-.504	0.614
	Positive ranks	10	10.75	107.50		
	Tied ranks	2				
General Health	Negative ranks	8	8.75	70.00	-.308	0.758
	Positive ranks	9	9.22	83.00		
	Tied ranks	4				
Vitality	Negative ranks	4	11.25	45.00	-.855	0.393
	Positive ranks	11	6.82	75.00		
	Tied ranks	6				
Social Functioning	Negative ranks	8	9.19	73.50	-.525	0.600
	Positive ranks	10	9.75	97.50		
	Tied ranks	3				
Role Emotional	Negative ranks	7	6.86	48.00	-.683	0.495
	Positive ranks	8	9.00	72.00		
	Tied ranks	6				
Mental Health	Negative ranks	7	5.86	41.00	-1.683	0.092
	Positive ranks	10	11.20	112.00		
	Tied ranks	4				
SF-36 summary scores						
Physical component summary	Negative ranks	14	9.25	129.50	-.487	0.627
	Positive ranks	7	14.50	101.50		
	Tied ranks	0				
Mental component summary	Negative ranks	8	11.81	94.50	-.730	0.465
	Positive ranks	13	10.50	136.50		
	Tied ranks	0				
Role/Social component summary	Negative ranks	8	12.00	96.00	-.678	0.498
	Positive ranks	13	10.38	135.00		
	Tied ranks	0				

Change after intervention (Δ) = post-intervention value – baseline value.

4. Discussion

This study examined the effects of free time on the QOL of elderly caregivers of dementia patients. Overall, setting aside free time did not improve QOL in home-based caregivers. In terms of post-intervention changes, the intervention group had a significant decrease in the Vitality subscale score of the SF-36, despite 57.1% of participants showing an improvement or no change in the score. Other subscale scores did not significantly differ between baseline and post-intervention.

In a previous intervention study, a program to support family caregivers suffering from above-average levels of depression and anxiety in the home management of dementia was implemented. After the six-month intervention period, neither the experimental group nor the control group showed improvements in these areas. However, the experimental group showed a clinically important improvement in QOL, experienced a slightly longer mean time to long-term institutionalization, found the caregiver role less problematic, and had greater satisfaction with nursing care than the control group [17]. Caregivers in the present study had QOL scores after intervention that were lower than baseline scores, indicating that caregivers were accumulating physical fatigue from daily caregiving and that they continued to have little mental leeway. These caregivers had difficulty securing free time, making it difficult for them to balance caregiving with their current situation, and this may have prevented them from improving their vitality. Through the intervention, caregivers hoped their vitality would improve and that they would become more energetic and motivated. The change in scores in the intervention group showed that some caregivers were able to improve or maintain their QOL, suggesting that the intervention may have had some effect. However, as a whole, the QOL of these caregivers decreased. These findings highlight the difficulty of developing a program to improve QOL without altering the care situation itself.

Home-based programs for caregivers of dementia patients have been reported to be important for QOL changes [18]. In this regard, developing programs that can maintain and improve the vitality of caregivers and enable them to lead their daily lives while caring for others in a lively and positive manner will be important. Home support has been reported to deepen the connection of caregivers to support [19]. Thus, exploring home-based intervention methods to improve caregiver QOL is meaningful. According to a previous study, respite care had no impact on care burden or mental health of caregivers, although there was a very high level of satisfaction [20]. This suggests the potential advantage of incorporating respite care into support programs and providing time away from caregiving so that the caregivers can rest and conserve energy.

Some caregivers in the control group showed improvements (albeit non-significant) in health-related QOL scores. The increased number of caregivers with an improved Vitality subscale score might be attributed to the Hawthorne effect. For instance, caregiver QOL may have improved due to the psychological support provided by act of participating in the study itself, rather than having free time. It was suggested that there is an urgent need to improve the program according to the health status of dementia caregivers in the future.

5. Conclusions

The results of the present study suggest the need to develop a home-based program that can alleviate caregiver stress and improve QOL. A long-term follow-up study with a larger sample size will be needed to plan further intervention studies according to the QOL status of caregivers.

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Disclosure Statement

The authors declare no conflict of interest.

Author's Contributions

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

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