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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
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. 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.

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. 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. However, fewer elderly individuals use computers and the Internet compared to younger people. 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. In addition, intervention trials with relaxation techniques in caregivers of dementia patients were shown to improve stress, depression, and negative bias scores. 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. 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...
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          | 8 | 10.0         | 80.0     | -639 | 0.523 |
|                              | 8 | 7.0          | 56.0     | -639 | 0.523 |
|                              | 5 |              |          |    |      |
| Role Physical                 | 13| 8.8          | 114.0    | -766 | 0.444 |
|                              | 6 | 12.7         | 76.0     | -766 | 0.444 |
|                              | 2 |              |          |    |      |
| Bodily Pain                   | 9 | 6.7          | 60.0     | -414 | 0.679 |
|                              | 7 | 10.9         | 76.0     | -414 | 0.679 |
|                              | 5 |              |          |    |      |
| General Health                | 8 | 8.4          | 67.5     | -.785 | 0.432 |
|                              | 10| 10.4         | 103.5    | -.785 | 0.432 |
|                              | 3 |              |          |    |      |
| Vitality                      | 9 | 7.1          | 64.0     | -1.970 | 0.049 |
|                              | 3 | 4.7          | 14.0     | -1.970 | 0.049 |
|                              | 9 |              |          |    |      |
| Social Functioning            | 6 | 6.0          | 36.0     | -.672 | 0.501 |
|                              | 7 | 7.9          | 55.0     | -.672 | 0.501 |
|                              | 8 |              |          |    |      |
| Role Emotional                | 6 | 7.3          | 43.5     | -.140 | 0.889 |
|                              | 7 | 6.8          | 47.5     | -.140 | 0.889 |
|                              | 8 |              |          |    |      |
| Mental Health                 | 10| 10.1         | 100.5    | -.524 | 0.600 |
|                              | 11| 11.9         | 130.5    | -.524 | 0.600 |
|                              | 0 |              |          |    |      |
| SF-36 summary scores          |   |              |          |    |      |
| Physical component summary    | 12| 11.0         | 132.0    | -.574 | 0.566 |
|                              | 9 | 11.0         | 99.0     | -.574 | 0.566 |
|                              | 0 |              |          |    |      |
| Mental component summary      | 10| 11.0         | 110.0    | -.191 | 0.848 |
|                              | 11| 11.0         | 121.0    | -.191 | 0.848 |
|                              | 0 |              |          |    |      |
| Role/Social component summary | 12| 10.8         | 129.5    | -.487 | 0.627 |
|                              | 9 | 11.3         | 101.5    | -.487 | 0.627 |
|                              | 0 |              |          |    |      |

Change after intervention (Δ) = post-intervention value – baseline value.
Table 3. Comparison of ranks in the intervention group after intervention

| Ranks                          | SF-36 scale          | Positive/tied ranks (N / %) | Negative ranks (N / %) |
|-------------------------------|----------------------|----------------------------|------------------------|
| 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%                 |
| 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%                 |

More positive/tied ranks than negative ranks

More negative ranks than positive/tied ranks

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          | 10 | 8.00         | 80.00    | -633 | 0.527 |
| Negative ranks                | 6  | 9.33         | 56.00    |     |    |
| Positive ranks                | 4  |              |          |     |    |
| Tied ranks                    | 5  |              |          |     |    |
| Role Physical                 | 9  | 5.94         | 53.50    | -1.092 | 0.275 |
| Negative ranks                | 8  | 12.44        | 99.50    |     |    |
| Positive ranks                | 4  |              |          |     |    |
| Tied ranks                    | 4  |              |          |     |    |
| Bodily Pain                   | 9  | 9.17         | 82.50    | -504 | 0.614 |
| Negative ranks                | 10 | 10.75        | 107.50   |     |    |
| Positive ranks                | 2  |              |          |     |    |
| Tied ranks                    | 2  |              |          |     |    |
| General Health                | 8  | 8.75         | 70.00    | -308 | 0.758 |
| Negative ranks                | 9  | 9.22         | 83.00    |     |    |
| Positive ranks                | 4  |              |          |     |    |
| Tied ranks                    | 4  |              |          |     |    |
| Vitality                      | 11 | 11.25        | 45.00    | -855 | 0.393 |
| Negative ranks                | 11 | 6.82         | 75.00    |     |    |
| Positive ranks                | 6  |              |          |     |    |
| Tied ranks                    | 6  |              |          |     |    |
| Social Functioning            | 8  | 9.19         | 73.50    | -525 | 0.600 |
| Negative ranks                | 10 | 9.75         | 97.50    |     |    |
| Positive ranks                | 3  |              |          |     |    |
| Tied ranks                    | 3  |              |          |     |    |
| Role Emotional                | 7  | 6.86         | 48.00    | -683 | 0.495 |
| Negative ranks                | 8  | 9.00         | 72.00    |     |    |
| Positive ranks                | 6  |              |          |     |    |
| Tied ranks                    | 6  |              |          |     |    |
| Mental Health                 | 7  | 5.86         | 41.00    | -1.683 | 0.092 |
| Negative ranks                | 10 | 11.20        | 112.00   |     |    |
| Positive ranks                | 4  |              |          |     |    |
| Tied ranks                    | 4  |              |          |     |    |

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 pro-
grams 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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