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# A longitudinal study on sleep, ambulatory blood pressure and fatigue of family caregivers providing home care

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## Abstract

**PURPOSE**: We prospectively followed family caregivers to examine changes in sleeping patterns, ambulatory blood pressure, and fatigue status three years after the initial survey.
**SUBJECTS**: 67 family caregivers who enrolled in the first survey conducted between 2001 and 2004.
**METHODS**: We asked the participants to enroll in the follow-up survey by mail. We interviewed care condition and asked to write self-reported activity recording for those who gave the written informed consent. An actigraph was used to determine sleep status and ambulatory blood pressure was monitored for 24-hour period. The Cumulative Fatigue Symptoms Index-Housewife was used. The research proposal was approved by the ethics committee of the faculty of Medicine, Kanazawa University.
**ANALYSIS**: The changes in the first and second survey results were tested by the Wilcoxon matched-pairs signed-ranks test according to presence of continuation of home care.
**RESULTS**: Of 67 eligible participants, 66 were alive. Of those, two were hospitalized, and 24 remained as primary caregivers. Thirty-three participants agreed to enroll in the second investigation. Fourteen participants continued home care and 19 ceased to provide care because of the death or hospitalization of care receivers. Of 14 caregiving participants, no significant changes were found for sleep status, blood pressure measurements, and fatigue status although the number of participants with hypertensive treatment increased by two.
In 19 non-caregivers group, nap time in the daytime became significantly longer and the mean duration of nap increased by 54 minutes, and chronic fatigue was relieved significantly. No significant changes in the blood pressure measurements were detected although additional two people were under hypertension medication.
**DISCUSSION**: This study did not show any clear difference of health condition between those continuously engaged in home care and those who had discontinued giving care. In the 19 former caregivers, the daytime nap time was significantly increased with a reduction in the feeling of fatigue. These results may be attributable to the cessation of home care.
**CONCLUSION**: The cessation of caregiving activities led to increased nap time and contributed to the reduction of chronic fatigue. The increasing number of participants with hypertensive treatment suggests additional care is necessary for aging participants, especially for those continue to provide care.

## Key words

Family caregiver, Ambulatory blood pressure, Fatigue, Sleep

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## Introduction

Some time has passed since the increasing cost of advancing medical technologies and providing care to an aging of population became a major policy issue in Japan. Although home care has been advanced as one measure to address the issue, the increased burden of caregivers, including the provision of care for the elderly by elderly individuals has become a problem.

Elderly caregivers have to manage their own health and burden of providing care[1]. The previous research focus has been mainly on the mental health aspect of the care[2-6] or the self-reported impacts of the care burden on physical health[7-9]. However, it is necessary to specifically examine what kind of care becomes what kind of burden to reduce burden in the provision of nursing care.

We focused on burden in the provision of nighttime nursing care and clarified the relationship among nighttime sleeping conditions of family caregivers, changes in daily blood pressure, and fatigue[10-12]. However, it is also necessary to conduct longitudinal research on the same subjects to clarify the impact of blood pressure dynamics and fatigue on health as well as the impact of confounders such as aging and content of nursing care. Such longitudinal research on the health of family caregivers has not been carried out either at home or abroad.

Our purpose is to prospectively follow family caregivers to examine changes in sleeping patterns, ambulatory blood pressure, and the fatigue status three years after the initial survey.

## Methods

### 1. Subjects & Survey period

Sixty-seven family caregivers who enrolled in the first survey conducted between 2001 and 2004. This survey was conducted between 2004－2007 excluding the summer for three years after the initial survey.

### 2. Methods

The visiting nurse stations cooperated in the follow-up survey to verify the status of the care receiver and care givers three years after the first survey. The participants were asked to enroll in the follow-up survey by mail, and those who returned the informed consent form were recruited in the 2nd survey. The following data were obtained by visiting the participants' home. The research proposal was approved by the medical ethics committee of Kanazawa University.

**1) BMI, alcohol consumption, smoking, medication, and the care recipient's health conditions (those continuously engaged in home care)**

**2) Self-reported activity recording**

The 24-hour record of caregiving and other activities of the caregivers were filled out by self.

**3) An actigraph was used to monitor the sleep/awake status for a 24-hour period**

An actigraph (Micro Mini; Ambulatory Monitoring, Ardsley, NY, USA) was applied to the non-dominant wrist[13] and the activity level during the 24-hour period was measured in the zero crossing mode with a sampling time of 1 min. ACT2000 software (Ambulatory Monitoring, Ardsley, NY, USA) was used to analyze the results. The sleep/awake status was determined with Cole's method[14,15], which was used for calculating the number of interruptions of sleep, duration of sleep, actual duration of night sleep, and actual duration of sleep during a 24-hour period[11].

The following sleeping index was calculated[11]

ⅰ) **Total sleep time** = 24 h − awake status h, excluding h spent on naps in the daytime.

ⅱ) **Actual night-time sleep time** = h in bed − h of sleep, excluding sleep interruptions and periods when the participants were in bed but not asleep.

**4) Ambulatory blood pressure was monitored for a 24-hour period**

The blood pressure and heart rate were monitored during the 24-hour period by means of an ambulatory blood pressure monitoring system (ABP90217; Spacelabs Medical, Issaquah, WA, USA)[16]. Values during daytime activities (except blood pressure during a nap) and nighttime sleep (except blood pressure in a conscious state) were calculated based on the actigraph data[11].

**5) The Cumulative Fatigue Symptoms Index-Housewife (CFSI-H)**

The Cumulative Fatigue Symptoms Index-

Homemaker (CFSI-H) was developed by us and validated[17]. The CFSI-H was slightly modified the CFSI in order to measure care burden. The CFSI was developed to measure chronic fatigue in workers and validity and reliability of the CFSI were tested[18,19]. The scale of the CFSI comprises eight subcategories: general sense of fatigue, chronic fatigue symptoms, physical disorders, depression, anxiety, reduced mental energy, irritation, and reduced motivation for work[18,19].

### 3. Analysis

The Wilcoxon rank sum test, $\chi^2$ test, or Fisher exact test was used to analyze differences between those who continued to give care and those who quit care giving. The Wilcoxon matched-pairs signed-ranks test was used to examine the changes between the first and second survey results according to the presence of the continuation of home care. SPSS V14.0 J was used for analysis.

## Results

### 1. The outcomes and a comparison of the initial survey results by the status of home-care continuation at 3 years in 67 family caregivers (Table1)

Of the 67 family caregivers, 24 (35.8%) were

Table 1. The outcomes and a comparison of the initial survey results by the status of home-care continuation at 3 years in 67 family caregivers

| | Those continuously engaged in home care n=24 | Those who discontinued giving care n=43 (1 death, 2 inpatients) | Wilcoxon rank sum test $\chi^2$/Fisher exact test p-value |
|---|---|---|---|
| Gender | 17 females (70.8%), 7 males (29.2%) | 31 females (72.1%), 12 males (27.9%) | 1.000 |
| Relationship with care receiver | 12 spouses (50.0%), 2 daughters-in-law (8.3%) 10 children or parents etc. (41.7%) | 23 spouses (53.5%), 14 daughters-in-law (32.5%) 6 children or parents etc. (14.0%) | 0.012* |
| Age (years) | 63.8±8.9 | 66.6±9.2 | 0.209 |
| Body mass index (kg/m$^2$) | 23.5±3.3 | 23.4±3.6 | 0.819 |
| Hypertensive medication | 7 (29.2%) | 15 (34.9%) | 0.787 |
| Duration of home care (months) | 75.4±91.5 | 68.5±54.0 | 0.534 |
| Hours providing care/day (hours) | 7.9±8.5 | 7.9±7.9 | 0.813 |
| Characteristics of care receivers | | | |
| Age (years) | 71.5±18.9 | 80.4±9.7 | 0.129 |
| Care level[1)] | Ⅰ1; Ⅱ1; Ⅲ4; Ⅳ6; Ⅴ8; Others 4 | Ⅰ1; Ⅱ3; Ⅲ7; Ⅳ6; Ⅴ25; Other 1 | 0.180 |
| Dementia | 8 (33.3%) | 20 (46.5%) | 0.317 |
| Blood pressure[2)] | | | |
| Systolic Nighttime rate of reduction[3)](%) | 11.6±11.2 | 16.8±7.0 | 0.045* |
| Diastolic Nighttime rate of reduction[3)](%) | 14.0±9.8 | 18.6±7.7 | 0.038* |
| Diastolic Value during nighttime sleep (mmHg) | 71.9±11.5 | 65.3±8.3 | 0.009** |

Mean±standard deviation *p<0.05, **p<0.01
1)Level of long-term care required: Ⅰ, <65 min of care time; Ⅱ, 65-100 min; Ⅲ, 100-135 min; Ⅳ, 135-170 min; Ⅴ, ≧170 min; Other, medical insurance.
2)Only blood pressure levels with a significant difference between the groups are presented. No significant difference was noted in sleeping time and the feeling of fatigue.
3)(Value during daytime activity−value during nighttime sleep)/value during daytime activity×100

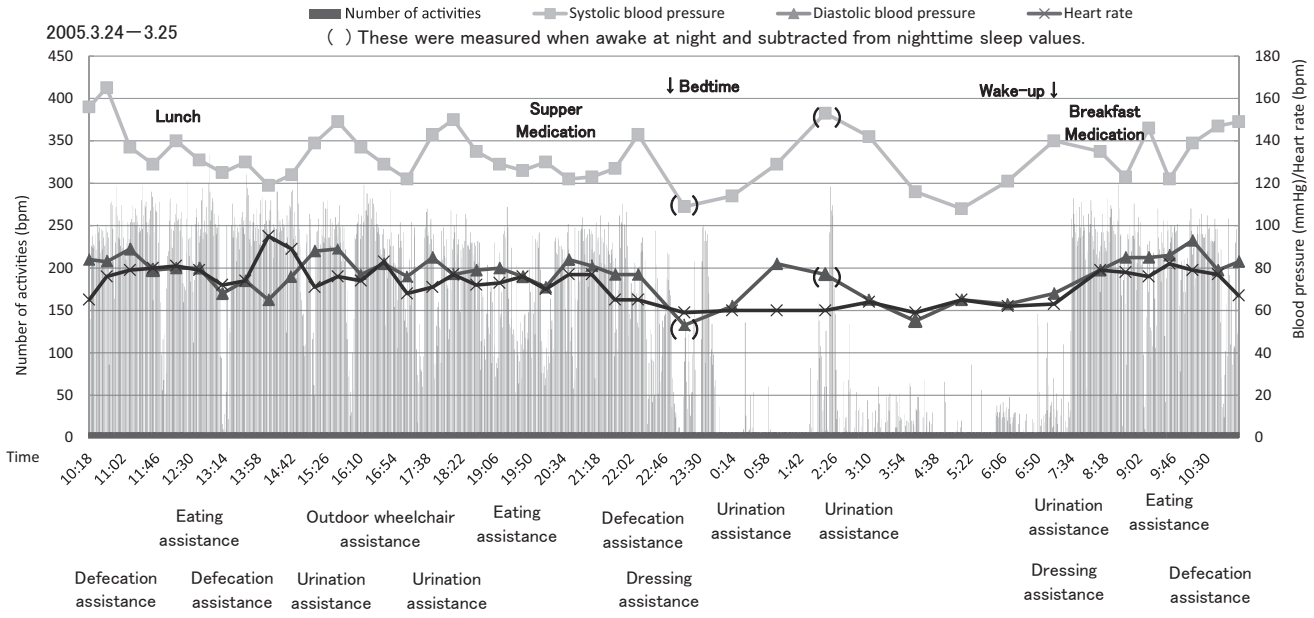



Figure 1. Diurnal variation in the care activities, sleep status, and blood pressure of an active caregiver (wife, 65) taking antihypertensive

continuously engaged in home care, and 43 (64.2%) had discontinued giving care within 3 years after the first survey. Among the 43 ex-caregivers, one had died and two were hospitalized, and those who had received care from the remaining 40 ex-caregivers had died (32) or were hospitalized (8).

**2. Results of the follow-up survey at 3 years in 33 family caregivers**

Figure 1 shows the amount of activities, sleeping status, and changes in daily blood pressure of a female caregiver who is 65 years of age and taking antihypertensive drugs as a sample data.

**1) A comparison of the follow-up survey results between 14 active caregivers and 19 ex-caregivers**

Thirty-three participants agreed to enroll in the second investigation, including 14 continuously engaged in home care and 19 who had discontinued giving care. No significant difference was observed in gender, age, BMI, the rate of drug ingestion, sleeping time, and the feeling of fatigue between the 14 active caregivers and the 19 ex-caregivers. Blood pressure levels in the initial survey showed certain differences as in the comparison by the home-care continuation status in 67 caregivers, while those in the follow-up survey did not significantly differ.

**2) Changes in the initial and follow-up survey results of 14 active caregivers (Table 2 and 3, Figure 2)**

No significant difference was observed in the sleep status between the initial and 3-year-later follow-up surveys. Although no significant difference was observed in blood pressure, the number of those taking antihypertensive drugs increased from 6 to 8. Likewise, while no significant difference was observed in the chronic feeling of fatigue, the CFSI-H score increased regarding various aspects during the 3 years.

Table 2. Changes in the sleep status of active caregivers between the initial and follow-up surveys (n=14)

| | Initial survey | Follow-up survey at 3 years |
|---|---|---|
| Nighttime frequency of leaving bed (times) | 1.9±1.9 | 1.5±1.2 |
| Time in bed during the night[1)](hours) | 7.45±1.37 | 7.53±1.34 |
| Time in bed before entering sound sleep[2)](hours) | 0.41±0.36 | 0.35±0.46 |
| Actual nighttime wake time[3)](hours) | 1.30±0.86 | 1.11±0.90 |
| Actual nighttime sleep time[4)](hours) | 6.15±1.06 | 6.42±1.13 |
| Actual daytime nap time[4)](hours) | 0.71±1.12 | 0.84±0.90 |

Mean±standard deviation

Note) The Wilcoxon matched-pairs signed-ranks test showed no significant difference in the results of the initial and 3-year-later follow-up surveys.

1) Determined based on the bedtime and rising hours estimated from the actigraph data and self-reported activity recording.

2) Determined based on the bedtime hour in the self-reported activity recording, and the time of entering sound sleep estimated from the actigraph data.

3) The period of not sleeping soundly in bed was estimated from the actigraph data.

4) The period of sleeping soundly in bed was estimated from the actigraph data.

Table 3. Changes in the systolic blood pressure of active caregivers between the initial and follow-up surveys (n=14)

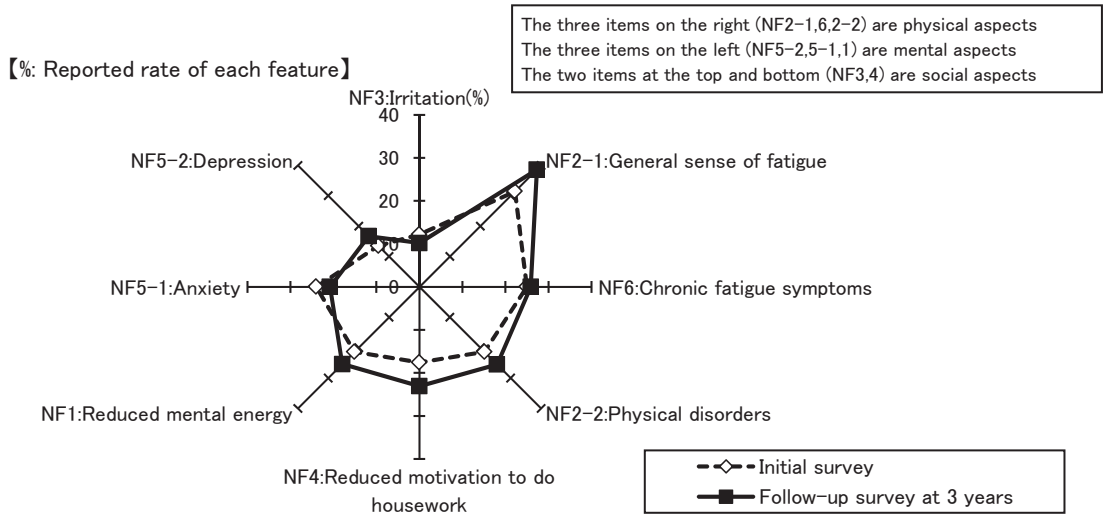
| (mmHg) | Initial survey | Follow-up survey at 3 years |
|---|---|---|
| 24-hour value | 138.5±14.2 | 132.8±14.9 |
| Maximum value | 176.2±18.0 | 169.8±22.1 |
| Range[1)] | 73.3±13.1 | 69.7±16.0 |
| Coefficient of variation[2)] | 12.0±1.9 | 12.8±2.3 |
| Value during daytime activity | 141.8±15.0 | 137.5±16.1 |
| Value during nighttime sleep | 126.7±16.6 | 119.1±14.0 |
| Nighttime rate of reduction(%) | 10.5±9.0 | 13.1±6.9 |

Mean±standard deviation

Note) The Wilcoxon matched-pairs signed-ranks test showed no significant difference in the results of systolic and diastolic blood pressure of the initial and 3-year-later follow-up surveys.

1)Maximum-minimum during the 24-hour period.

2)Standard deviation/mean value×100




＊The Wilcoxon matched-pairs signed-ranks test showed no significant difference in the results of the initial and 3-year-later follow-up surveys.

Figure 2. Changes in the feeling of fatigue (CFSI-H score) of active caregivers between the initial and follow-up surveys (n=14)

**3) Changes in the initial and follow-up survey results of 19 ex-caregivers (Table 4 and 5, Figure 3)**

Regarding the sleep status, the nap time in the daytime became significantly longer, and the mean nap duration increased by 54 minutes during the 3 years between the initial and follow-up surveys. Although no significant difference was observed in blood pressure, the number of those taking antihypertensive drugs increased from 6 to 8. Concerning chronic fatigue, the CFSI-H score significantly decreased in 2 aspects during the 3 years.

## Discussion

To analyze the psychosomatic factors of caregivers that affected their continuation of home care, health conditions 3 years ago were compared

Table 4. Changes in the sleep status of ex-caregivers between the initial and follow-up surveys (n=19)

| | Initial survey | Follow-up survey at 3 years |
|---|---|---|
| Nighttime frequency of leaving bed (times) | 1.6±1.5 | 1.7±1.2 |
| Time in bed during the night (hours) | 7.77±1.23 | 7.63±1.19 |
| Time in bed before entering sound sleep (hours) | 0.21±0.14 | 0.32±0.33 |
| Actual nighttime wake time (hours) | 1.26±1.31 | 1.22±0.98 |
| Actual nighttime sleep time (hours) | 6.52±1.11 | 6.41±1.16 |
| Actual daytime nap time (hours) | 0.39±0.53 | 1.29±1.77＊ |

Mean±standard deviation　＊$p<0.05$ (The Wilcoxon matched-pairs signed-ranks test)

Table 5. Changes in the systolic blood pressure of ex-caregivers between the initial and follow-up surveys (n=19)

| (mmHg) | Initial survey | Follow-up survey at 3 years |
|---|---|---|
| 24-hour value | 130.5±21.2 | 131.0±17.8 |
| Maximum value | 167.4±30.6 | 166.5±23.1 |
| Range | 72.2±24.9 | 71.5±19.9 |
| Coefficient of variation | 12.8±3.6 | 12.2±2.7 |
| Value during daytime activity | 135.6±21.8 | 135.5±18.3 |
| Value during nighttime sleep | 111.3±18.6 | 115.4±20.3 |
| Nighttime rate of reduction(%) | 17.7±7.4 | 14.9±9.5 |

Mean±standard deviation

Note) The Wilcoxon matched-pairs signed-ranks test showed no significant difference in the results of systolic and diastolic blood pressure of the initial and 3-year-later follow-up surveys.

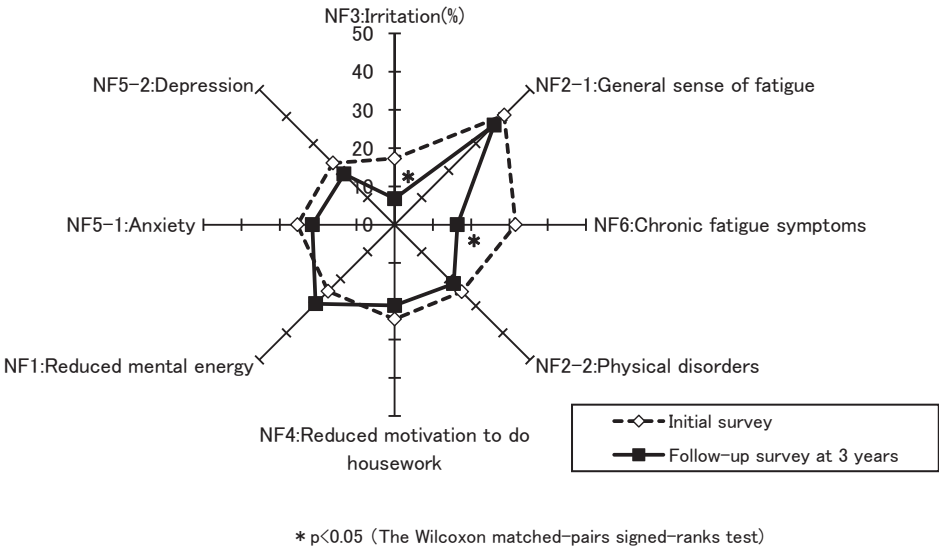



Figure 3. Changes in the feeling of fatigue (CFSI-H score) of ex-caregivers between the initial and follow-up surveys (n=19)

between those continuously engaged in home care and those who had discontinued giving care. As is described here, there were almost no longitudinal research on the health conditions of caregivers and the individuals who had discontinued providing care. Although significant differences were observed in the nighttime blood pressure, both were within the normal ranges. According to the survey on a cohort conducted by Shaw et al[20], caregivers indicated the higher risk of developing hypertension than those who received nursing care; however, this study did not show any clear difference between them. The facts that the mean age of those who had received care from ex-caregivers was 80 years and caregivers were often the daughters-in-law of their care recipients imply the involvement of the aging of care recipients in their caregivers' discontinuation of home care.

To clarify the psychosomatic effects of continuing home care, changes in each caregiver during the 3 years between the first and follow-up surveys were analyzed. In the 14 caregivers continuously engaged in home care, there were 2 additional caregivers taking drugs for hypertension, newly diagnosed during the 3 years. Given the necessity of strict 24-hour control of blood pressure in the daily lives of hypertensive patients, the importance of the prevention and early detection of hypertension was suggested for caregivers to continue home care. Although no significant changes were noted in the feeling of fatigue, its level generally intensified during the 3 years, suggesting the accumulation of fatigue through care activities.

In the 19 ex-caregivers, the daytime nap time was significantly increased with a reduction in the feeling of fatigue compared to 3 years before. These results may be attributable to their cessation of home care.

## Conclusion

The cessation of caregiving activities led to an increased nap time and contributed to the reduction of chronic fatigue. The increasing number of participants receiving hypertensive treatment suggests that additional care is necessary for aging participants, especially for those continuing to provide care.

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# 家族介護者の睡眠と血圧日内変動と疲労感の追跡調査

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**要　　旨**

**【目的】**介護を長期間続けることによる心身への影響を明らかにするため、家族介護者の3年後の転帰と、同一者の3年後の睡眠、血圧日内変動、および疲労感の追跡調査を行った。
**【対象】**2001年から2004年に行った初回調査から3年経過した家族介護者67名。
**【方法】**対象者の転帰を郵送で調査し、再調査を依頼した。書面での同意を得た者に対し介護状況に関する面接調査と24時間自記式行動調査を行った。Actigraphにより24時間の睡眠時間を測定した。携帯型無拘束間接型血圧装置により24時間の血圧変動を測定した。疲労感はThe Cumulative Fatigue Symptoms Index-Housewifeより調査した。
**【分析】**初回調査と追跡調査の比較は、在宅介護の継続の有無別に、事例ごとに対応したWilcoxon符号付き順位検定を行った。
**【結果】**家族介護者67名の3年後の状況は、66名が生存しており、そのうち2名は入院、在宅介護を継続していた者は24名だった。64名中、追跡調査に同意した者は33名だった。そのうち在宅介護を継続していた者が14名、要介護者の死亡や入院により介護していなかった者が19名だった。在宅介護を継続していた14名の初回調査と追跡調査の結果を比較した結果、睡眠時間、血圧、疲労感には有意差がみられなかった。3年後の降圧剤内服者は2名増えて8名だった。介護していなかった19名は、3年後の方が日中の仮眠時間が有意に長く平均54分増えており、疲労感が有意に軽減していた。血圧には有意差がみられず、内服者は2名増えて8名だった。
**【考察】**本研究では、在宅介護継続者と介護を継続していなかった者との間に健康状態の有意な差は認められなかった。介護を中断していた19名は、日中の仮眠時間が有意に長く疲労感が軽減していた。このことは在宅介護を継続していなかったことに起因すると考えられる。
**【結論】**介護の中断は、仮眠時間が増えて疲労感の軽減に貢献することが示唆された。高血圧の治療者数の増加は、加齢、とくに在宅介護を継続していくためには、高血圧の治療の追加が必要であることを示していると考える。