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FACTORS AFFECTING QOL OF THE HOME-BOUND ELDERLY DISABLED

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INDEXING WORDS

quality of life (QOL); home-bound patients; PGC morale scale; home-based care; community-based rehabilitation (CBR)

SYNOPSIS

The purpose of this study was to clarify the factors affecting the quality of life (QOL) of the elderly home-bound patients. Data were collected from 56 chronically disabled elderly persons (mean age of 76.7 years) who needed a long-term home-based care. They were assessed on QOL, range of activity, functional capacity, and capacity of family care functioning as well as socio-economic condition. The QOL was evaluated by using Philadelphia Geriatric Center Morale Scale (PGC Morale Scale). The activities of daily living (ADL) and handicaps were evaluated by the Barthel index and the ESCROW profile, respectively. The capacity of family care functioning was also recorded according to the "Family Care Scale" developed by Hamamura. As a result, there was a significant difference between PGC Morale Scale score and Barthel index score ($P<0.05$), and we found a negative correlation between PGC Morale Scale score and ESCROW score ($P<0.05$). It was also revealed that the factors affecting the QOL of the home-bound elderly disabled were determined by the motivation,

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functional capacity, and capacity of family care functioning ($P<0.05$). These results suggest that in order to improve their QOL, ADL must be improved, therefor, rehabilitation should be continued to maintain their function after discharging from hospitals and that we should take these factors into consideration, such as living environments and social conditions of the family care. The results also indicate how the patient's independence in the daily life influences social and economic status, and consequently it affects the quality of life.

INTRODUCTION

Some patients with severe disabilities require further rehabilitation service after the treatment and the rehabilitation in the hospital, and others require help in carrying out daily living activities at home due to problems associated with family and economic conditions or lack of caregivers. The number of disabled people who need total care at home and require the help of medical and social welfare programs, such as post-discharge rehabilitation, is increasing. In some areas, due to lack of adequate rehabilitation services, patients have no other help but to be maintained at home.

Compounding these problems, the population of the aged is increasing rapidly, resulting in an alarming increase in the number of bedridden elderly in Japan. According to a 1992 survey conducted by Statistics and Information Department, Minister's Secretaries, Ministry of Health and Welfare of Japan, 0.4% of people between 65 and 69 years old are bedridden at home, and this rate increases to 1.3% among people between 70 and 79 years old, and is markedly higher to 5.6% among people between 80 and 89 years old. Furthermore, the number of the elderly who requires care is expected to reach 2.8 million in the year 2000, 3.9 million in the year 2010, and 5.2 million in the year 2025. [8] Consequently, the focus of rehabilitation has been shifting from hospitals and medical institutions to community-based rehabilitation (CBR) centers. The goal of CBR is to improve the quality of life (QOL) of disabled people and to help them function within their community. However, only few studies have been made, to our knowledge, on an issue that affects the subjective QOL of disabled elderly patients confined to home. [7,17,22]

This study attempts to find factors affecting the subjective QOL of the home bound elderly patients.

MATERIALS AND METHODS

Fifty-six disabled elderly persons who were able to answer the questions were surveyed. They consisted of 26 males (means age of 76.1±8.3 years) and 30 females(mean age of 77.3±11.0 years) and their mean age was 76.7±9.7 years. The majority of recipients were persons with cerebral vascular accidents (53.6%) and the remainders were with rheumatoid arthritis (12.5%), or with Parkinson's disease (5.4%). In addition, 46 were being treated as outpatients or seeing a physician, and of these 46 subjects, 10 were receiving rehabilitation training at a hospital or community health center as part of functional training service, and another 10 were receiving care only from a visiting public health nurse.

The duration from the onset of their disabilities to the time of this study were as follows: 13 patients were within 3 years, 21 were 3-10 years, 10 were over 10 years and 12 were too long to be specified the period.

Subjective QOL, volition for coping with disablement, range of activity, activity of daily living (ADL), severity of handicaps, the capacity of family to provide care were assessed. In addition, their sex, age, duration from their onset, family member, the number of caregivers, and the main caregiver were asked.

We then investigated how these factors influence the subjective QOL of these disabled elderly patients. In this study, 3 physical therapists were involved and all procedures of investigation were compromised beforehand not to happen interexaminer difference.

We assessed the subjective QOL of the subjects using the Japanese version of the Philadelphia Geriatric Center Morale Scale (PGC)[10] items from 1 through 17 translated by Maeda et al. [13] The PGC consists of four factors: the first affects optimism and positive outlook, the second affects psychological stability, the third affects the sense of health and usefulness, and the fourth affects attitude towards aging.

Volition for coping with disablement was evaluated by three grades (passive, medium, and active) based on reactions and answers given by the subjects during the interview. Passive volition was defined as the state of mind of patients who were psychologically confined by their disabilities, and did not act on their own or voice their opinions. Active volition was defined as the state of mind of

those who accepted their disabilities and actively went about anything, and medium was somewhere between passive and active.

The range of activity was also recorded according to three grades: in bed, indoors and outdoors.

ADL was assessed with respect to 13 items according to the Barthel Index (BI) modified by Granger et al [4] excluding the use of braces or prostheses.

In addition, the degree of handicap was evaluated using the ESCROW Profile (EP).[5] This profile consists of 6 factors, and each was independently assessed and scored from 1 (most independent or best) to 4 (most dependent or worst). The 6 factors are Environment (suitability of housing location and arrangement), Social interaction (personal contact versus reliance on social agency supports), Cluster of family members (availability of competent family members to support the patient), Resources (financial situation), Outlook (general ability of the person to make decisions) and Retirement status (roles in the household or community; scored from 1 to 3). The sum of the subscores was assembled into ranges from 6 (best) to 23 (worst).

The capacity of family to provide care was recorded according to the "Family Care Scale" designed by Hamamura. [6] This scale consists of the following ten items: "Health of caregiver", "Amount of free time", "Acceptance of disability", "Understanding of care", "Personality", "Ability of family members to help one another", "Human relations", "Economic status", "Family environment", and "Support from neighbors". On a scale of 1 to 15, the higher score means the higher family care functioning.

The effect of sex differences and main caregiver (differences between a spouse and daughter) on QOL was analyzed using a student's t-test. The differences between QOL and factors such as duration from their onset, volition for coping with disablement, activity range were evaluated using statistical analysis of variance. Multiple comparison was performed to investigate correlation among these factors using Tukey HSD method. Furthermore, the relationship between QOL and factors such as age, ADL, the degree of handicap, family member, the number of caregivers and the extent of care were analyzed using Spearman's rank order correlation test. The statistical significance was considered when a p value was less than 0.05. The data analyzed using a microcomputer soft "Statistica" (Stat Soft. Inc, Oklahoma, USA).

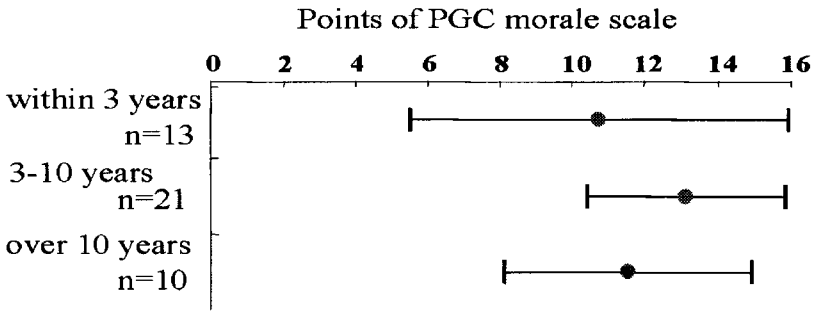

Figure 1. Relationship between the duration from their onset and QOL.

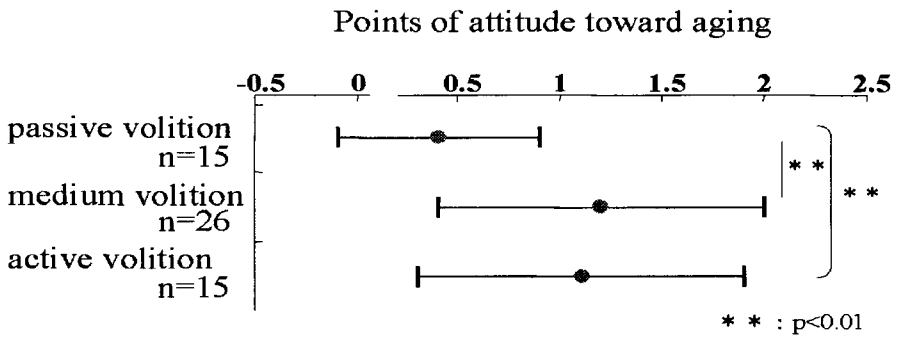

Figure 2. Relationship between the attitude toward own aging and volition of coping with disablement.

RESULTS

1. *Situation of the recipients*

The average PGC score of the subjects was 11.5±3.7. The subjects' average BI score was 58.4±38.5, and thus, although not bedridden, their ADL was restricted to some degree. The average EP score was 10.8±3.2, indicating that most subjects were not affected by a high degree of handicap.

2. *Relationships between QOL and age, sex and time from onset.*

No statistically significant correlation was found between age and total PGC score, or each of the four factors. Gender had no affect on the results as the average PGC score of the female subjects (12.4± 3.9) was not significantly different from that of the males (10.6±3.2).

There was no statistically significant difference between duration from their onset and PGC score (within 3 years:10.7±5.2, 3-10 years:13.1 ±2.7, over 10 years:11.5±3.4) (Figure 1).

3. *Relationship between QOL and volition for coping with disablement, and activity range.*

No significant difference was found between volition for coping with disablement and the average PGC score (patients with passive volition was 10.2, and those with active or medium volition was 12.0). Analysis of the relationship between volition for coping with disablement and each of four PGC factors indicated that the degree of satisfaction of the fourth PGC factor (attitude towards aging) was significantly higher for those with active (1.1±0.8) or medium (1.2± 0.8) volition for coping with disablement than those with passive volition (0.4±0.5) ($p<0.01$) (Figure 2).

No statistically significant difference was observed between the range of activity and total PGC score or each of the four PGC factors.

4. *Effect of independence in ADL on QOL*

Total QOL score was significantly affected by the degree of patients' independence in ADL, and those with independent ADL showed higher QOL score ($p<0.05$).

Analysis of the relationship between the total BI score and each of the four PGC factors indicated that the degree of satisfaction for the first factor (affects optimism and positive outlook) and the fourth factor (affects attitude towards aging) were significantly higher for those patients with a higher degree of independence in ADL ($p<0.05$). Analysis of the relationship between each BI activity and each PGC factor revealed that, except for two activities (excretion and walking on a flat surface), the degree of satisfaction for the fourth factor (affects attitude towards aging) was significantly higher for those patients with a higher degree of independence. Furthermore, when the degree of independence for performing such activities as dress upper body, dress lower body, bowel continence, sitting on a chair, going to the bathroom, taking a bath and climbing stairs was high, the degree of satisfaction for the third factor (affects the sense of health and usefulness) was significantly higher ($p<0.05$) (Table 1).

Table 1. Correlation between the disablement and QOL.

	Factors of PGC morale scale				
Barthal Index	Ⅰ	Ⅱ	Ⅲ	Ⅳ	Total
Drink from cup/feed from dish	0.368**	0.097	0.076	0.380**	0.329*
Dress upper body	0.223	0.027	0.289*	0.489**	0.284*
Dress lower body	0.250	0.046	0.328*	0.528**	0.318*
Grooming	0.267	-0.042	0.263	0.428**	0.254
Wash or bathe	0.295*	-0.080	0.217	0.367**	0.257
Bladder continence	0.319*	-0.121	0.243	0.233	0.234
Bowel continence	0.290*	-0.116	0.286*	0.307*	0.241
Care of perineum/clothing at toilet	0.254	-0.171	0.223	0.399**	0.214
Transfer, chair	0.261	-0.052	0.323*	0.388**	0.274*
Transfer, toilet	0.227	-0.126	0.156	0.357**	0.184
Transfer, tub or shower	0.256	-0.141	0.280*	0.320*	0.213
Walk on level 50 yards or more Wheel chair/50 yards-only not walking	0.084	-0.299	0.061	0.225	0.003
Up & down stairs for one flight or more	0.227	-0.101	0.276*	0.360**	0.200
Total	0.302*	-0.110	0.270	0.463**	0.276*

*:p<0.05 **:p<0.01

Ⅰ: first factor Ⅱ: second factor Ⅲ: third factor Ⅳ: fourth factor

Table 2. Correlation between the severity of handicap and QOL.

	Factors of PGC morale scale				
ESCROW Profile	Ⅰ	Ⅱ	Ⅲ	Ⅳ	Total
Environment	-0.174	0.064	-0.209	-0.340*	-0.210
Social interaction	-0.433**	0.029	-0.152	-0.566**	-0.386**
Cluster of family members	-0.130	0.081	0.123	-0.142	-0.032
Resourcers	-0.108	-0.419**	-0.009	0.151	-0.163
Outlook	-0.175	-0.162	-0.172	-0.227	-0.247
Retirement status	-0.324*	-0.053	-0.439**	-0.297	-0.388**
Total	-0.227	0.028	-0.142	-0.291	-0.241

*:p<0.05 **:p<0.01

Ⅰ: first factor Ⅱ: second factor Ⅲ: third factor Ⅳ: fourth factor

5. *Correlation between the severity of handicap and QOL*

When relationship between the PGC score and severity of handicap was investigated, it was found that the higher PGC score reached, the significantly lower the scores for social interaction and role at home or within a community became ($p<0.01$). Negative correlation was observed between the first PGC factor and social interaction, and retirement status, and the second PGC factor and resourcers, and third PGC factor and retirement status, and the fourth PGC factor and environment, and social interaction ($p<0.05$) (Table 2).

Table 3. Correlation between the capacity of family to provide care and QOL.

	Factors of PGC moral scale				
	I	II	III	IV	Total
Capacity of family to provide care	0.223	−0.165	0.384*	0.135	0.213

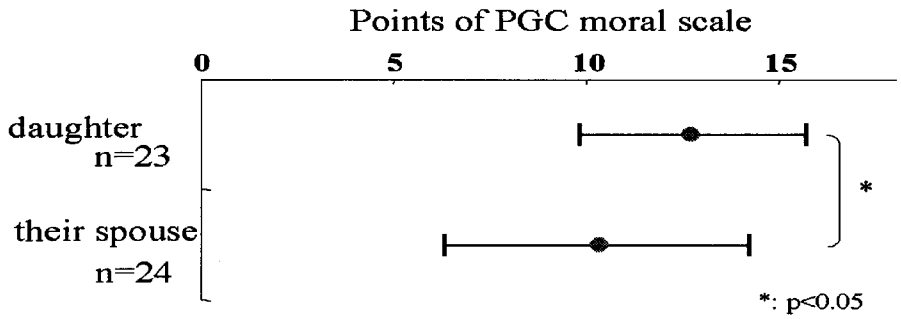

Figure 3. Relationship between difference of their chief care-givers and QOL.

6. *Relationship between QOL and family member, the number of caregivers, capacity of family to provide care and main caregiver.*

No statistically significant differences in PGC score were observed between QOL and family member as well as the number of caregivers and ability to provide care. However, the patients who were provided with higher care show the higher degree of satisfaction for the third factor (affects the sense of health and usefulness) ($p<0.05$) (Table 3).

Most of the main caregiver were 24 spouses (42.9%), 23 daughter (41.1%, 20 were daughter-in-law). The difference between the PGC scores and a key-person who mainly took care of the patient indicated that the degree of satisfaction were significantly higher when the main caregiver was a daughter (12.7 ± 3.0) rather than a spouse (10.3 ± 4.0) ($p<0.05$) (Figure 3).

DISCUSSION

Rehabilitation programs have to begin as soon as possible after the onset to reduce impairments and disabilities, and ideally, the

long-term follow-up study is significant in order to improve their levels of function to the maximum after discharge from the hospital. Enhancement of levels of function and acquirement of higher quality of life are the essential and intrinsic goal of the rehabilitation process for home-bound elderly patients. In addition, to maintain the daily living activities of the patients, various types of disuse atrophy must be prevented, and to maintain residual functions, continuous functional training must be provided. Nonetheless, in order for patients to maintain functional training for a long time, a program should be designed and implemented to be integrated into the lifestyle of each patient. However, when residual functions cannot be maintained or improved by daily living activities, an appropriate function-training program is necessary. If their caregivers make a mistake in the method of functional-training program and care, they might cause the misuse syndrome such as pain, bone fracture, and ectopic ossification. To prevent the misuse syndrome, correct training and complication management techniques should be explained to patients and their family members. If functional disorders and ADL can not be improved, the lifestyle of the patient should be altered. For example, when an elderly patient spends most of his or her day in the living room, arrange him or her to the place from where the streets can be looked on easily so that the patient can have social interaction and stimulation. Furthermore, elderly patients should be encouraged to interact with people even when he or she is confined to a wheel chair, or to get to the room where other family members gather even if the patient has to move by prone kneeling or kneeling. To ease the effect of disabilities, patients should be encouraged to participate with people at the day-care centers and to practice functional-training programs so that they will not be left in the house and lose their volition for coping with disablement. Psychological support should also be provided to patients so that their opportunities for social interaction increase.

Family members play an important role in the feasibility of disabled elderly patients living at home, however, as the number of the nuclear family has been increasing problems have started to emerge, such as a lack of caregivers, and the caregivers have also become elderly and poor in health. Consequently, the society as a whole must try hard to support disabled people. In addition, instead of considering family members only in terms of an entity that helps the disabled, a disabled elderly patient and their family should be regarded as a single

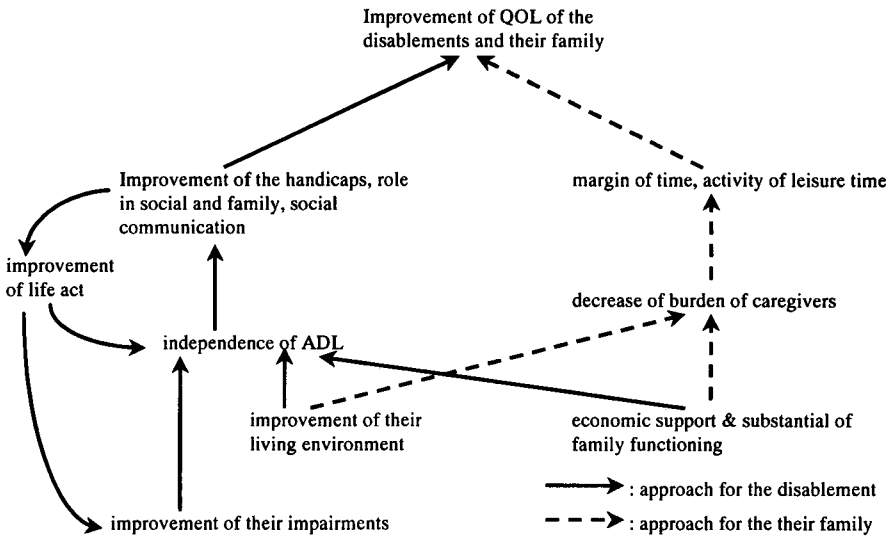

Figure 4. Approach for improvement of QOL of the disablement and their family.

unit, so as to maintain and improve the QOL of both patients and caregivers. Moreover, since the elderly population has been rapidly increasing in Japan, living environments should also be reorganized by modifying their houses and providing support economically so that disabled elderly patients can live safely with some degree of independence in ADL (Figure 4).

Constitution of QOL includes objective QOL and subjective QOL. [21] It is important for the elderly people to maintain the meaning and the worth of life, when they meet the loss of health both in mind and body, of the economical foundation, and of the social communication. [1] Therefore, QOL of elderly people should make allowances for subjective QOL in morale, life satisfaction and subjective well-being. The QOL in the aged people is an important issue that has been discussed for a long time and led to a number of studies. The relationship between subjective QOL of the aged and various factors was summarized in the article by R. Larson published in 1978 in the United States of America. [9] Among a variety of methods for measuring subjective QOL, the Life Satisfaction Index-A[16] and the PGC morale scales [10] are commonly used.

In the present study, the PGC morale scale was used to assess subjective QOL because this scale not only measures the current state of subjective well-being but also investigates the level, extent and structure of morale. [14]

Many reports have been published that utilize PGC to examine a sample of the elderly population. In Japan the factors such as health, ADL, activity level, depression, self-esteem, economic status, and social support have been reported to evaluate the subjective QOL of the elderly. [13,18,20] In the present study, the factors influencing the QOL of disabled elderly patients who are confined to home were considered in the issue such as volition for coping with disablement, level of ADL and ability of family members to provide care. Although statistically significant correlation was not found, findings in the present study show the general status of the elderly.

In Tokyo the average PGC score of the elderly persons (means age of 69.7±6.8 years), male was 11.6±3.8, and female was 11.2±4.0, respectively, and that of the elderly who were using the welfare centers for the aged (mean age of 72.9±6.3 years), male was 11.3±3.8 and 12.6±3.4, respectively. [20] Although the average age of the subjects in this study was slightly higher than that of the subjects of the report above, their average PGC scores can be comparable (males: 10.6±3.2, females: 12.4±3.9).

Similar to the studies of Liang et al, [11,12] Maeda et al [15] and Taniguchi et al [20], the present study clarified that age and sex do not influence the subjective QOL.

Regarding the duration from their onset of patients with cerebral apoplexy, Sugisawa et al and Harwitz et al suggested that their subjective well-being was shown to correlate significantly with time from onset. [7,17] However, we found no significant correlation between their duration from onset and QOL levels. The passage of time from onset was important factor to the acceptance of handicap by patients and to adjust to their new lifestyle, and it should be one of important factors influencing QOL. But in the case of the home bound patients, their QOL was determined not only by duration from their onset, but also by the acceptance of handicap by family members as well as their situation of the people around them.

The present study showed that no significant relation was found between volition for coping with disablement and PGC score, but the PGC scores of patients with active or medium volition tended to be

higher than those of patients with passive volition. In addition, the degree of satisfaction for the fourth PGC factor (affects the attitude towards aging) was significantly higher for patients with active volition for coping with disablement. In other words, in order to improve the QOL of disabled elderly patients, caregivers should encourage them to live with their disabilities rather than be confined by them, and should motivate them toward recovery.

Taniguchi et al [20] have reported the relationship between volition for coping with disablement and QOL. They found that the QOL levels of the healthy older people were higher, if they were on the higher activity level. Naturally, to improve the QOL of elderly patients who are confined to home, they should be encouraged to go out and socialize. [19] But, as shown in our study, the range of activity did not significantly correlate with the total QOL score. It is natural that the volition for coping with disablement should be one of important factors influencing ADL. But in the case of the home bound patients, their QOL was determined not only by function of their activity, but also by their living environment as well as their situation of assistance by the family.

The subjective QOL of the elderly with a low independence in ADL has been shown to be lower than that of the elderly with a high independence in ADL. [18] In addition, Fujita et al [1] found that, although the correlation between subjective QOL and physical ADL was strong, that between subjective QOL and instrumental ADL was weak among the elderly in the community. The results of the present study showed that QOL was significantly higher for those patients with a higher degree of independence in ADL, in agreement with previous studies. Thus, in order to improve the QOL of disabled elderly patients who are confined to home, the independence of patients must be improved. Although elderly patients need to receive continuous rehabilitation to maintain and even improve the degree of independence in ADL, 82% of the patients in the present study were not receiving such therapy. Analysis of the relationship between each activity of BI and each PGC factor revealed that the degree of satisfaction for the fourth factor (affects the attitude towards aging) was significantly higher, if the patients have a higher degree of independence in excretion and walking on a flat surface. Furthermore, when the degree of independence for performing such activities as sitting on a chair, going to the bathroom, taking a bath and climbing stairs was high, the

degree of satisfaction for the third factor (affects the sense of health and usefulness) was significantly high. This emphasizes that to increase the degree of satisfaction regarding the attitude towards aging and to improve their confidence in the health and usefulness of elderly patients, ADL must also be improved. As stated by Fukuya, [3] it is important to ensure the transfer functioning of elderly patients, utilizing whatever means available.

The subjective QOL correlates to social factors, such as family member, marriage, interpersonal relationships and visits with neighbors as reported by Fujita et al. [1] The results of the present inyestigation on the relationship between disabilities and QOL showed that the higher the PGC score, the significantly lower the scores for social interaction and roles at home or within the community. This suggests that the QOL of the elderly was determined by social factors, such as social interaction or social roles. If social interaction was diminished, elderly patients tend to stay home and rely more on their family members, thereby losing their role at home and subsequently reducing their QOL. Therefore, to increase the QOL of these people, their opportunities for social interaction must be increased, so that their social roles can be maintained.

A lack of the ability for family members to care for the disabled has been shown to correlate with disruption. [2] In the present study, the score for the third PGC factor was significantly higher for patients with a sound support system (e.g., good main caregiver, favorable family environment, reliable helpers), suggesting that the ability to provide care affects the subjective QOL of elderly patients. Thus, sound caregivers, family environment, financial stability, and care support system are important in maintaining the QOL of disabled elderly patients. Furthermore, the QOL of elderly patients who were taken care of by a daughter and daughter-in-law have significantly higher satisfaction than that of patients cared by their spouse. This is unique in Japan, as the sense of happiness or loneliness experienced by the elderly is affected more strongly by contact with their children rather than their spouse, despite the fact that a daughter-in-law is not a blood relative. [23]

As a conclusion of this study, QOL of home-bound disabled elderly patients depend on their volition for coping with disablement, level of ADL, socioeconomic status, and ability of family members to provide care, though QOL is not influenced by these factors alone. This

kind of study could be necessary to establish an appropriate home-care program in response to the criticism that this type of service has not been scrutinized for its effectiveness. It is thought that QOL of home-bound disabled elderly patients and their families need to be analyzed how it is affected by their living environment or social environment in future.

Finally, these results suggest that in order to improve their QOL, ADL must be improved, therefor, rehabilitation should be continued after discharging from hospitals to maintain their function and that we should take these factors into consideration such as living environments and social conditions of family care. The results also indicate how the patients' independence in their daily life influences social and economic status, and consequently these affect their quality of life. In particular, their transfer functioning in ADL must be guaranteed, utilizing whatever means available. It leads to improve their sociality such as social interaction, participation in day-care centers and functional-training programs, therefore, improvement of their QOL becomes possible. In addition, we need to understand about care environment when their disablements increase by aging.

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