

A Discussion of Social Support for Dementia Elderly People and Family Carers

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Abstract

In this research, we revealed the living conditions of dementia elderly people and family carers and considered how social support would be provided for them. Targeting, family carers of dementia elderly people, we requested a few questions about actual living conditions of dementia elderly people with a paper questionnaire or interview. Then we considered about social support from three perspectives, “emotional support,” “tangible support,” and “informational support”.

As a result of this research, many of dementia elderly people have problems of ADL as well as complications. In social support, family members played an important role in “emotional support”, but welfare and medical personnel played little part in social support. Rather, according to the interview of this research, “tangible support” related to medical care and welfare might lead to mental peace of caregivers. On the other hand, about informational support, since there is not enough information about nursing care, and some caregivers think they do not know the way to care or to attend to, enhancing social services such as nursing care classes is needed.

Key Words: Social Support, Dementia Elderly People, Family Carers

1. Introduction

According to the estimate of the Ministry of Internal Affairs and Communications, as of October 2017, the elderly population of 65 and above, which serves as index of aging, is 34,610,000. The percentage of elderly in the total population accounts for 27.3%, both reached the highest number ever¹⁾. As the aging in Japan is advancing, elderly people requiring care are increasing rapidly beyond expectation/anticipation. People who had certified as requiring care or support in the Long-Term Care Insurance System is 6,340,000 as of May 2017. Compared to 4,420,000 in total as of May 2007, the number had increased by 1,920,000 in 10 years²⁾. For such as this rapid increase of elderly people requiring care, Long-Term Care Insurance System was enforced in 2000. It could be said that systems of care service for elderly people had changed significantly, as it allowed people to receive care services of non-family member with simpler procedures compared to before. However, we still have many problems, as greater-than-expected increasing of the number of elderly people requiring care services, a rise in nuclear family tendency, and a low birthrate progress. It is reported that the burden of nursing care of dementia elderly people

is great above all. The number of dementia elder increases due to further aging of society. The population of dementia elderly people is estimated as 15% in the elderly people of 65 and above, approximately 4,620,000 as of 2012³⁾. The Ministry of Health, Labour and Welfare announced “Japanese Dementia Strategy (New Orange Plan)” in January 2015, and in this strategy, the number of dementia people in 2025 is estimated to be more than 7,000,000. According to this, it is estimated that one in five of elderly people of 65 and above would be contracted dementia. Changes and disorder in language, emotion, behavior, and personality would be found in dementia elderly people. These symptoms were complexly intertwined, and occur individually and unevenly.

Furthermore, symptoms fluctuate widely in each individual, and patients could have other disease as well, which might make it difficult to certificate Needed Long-Term Care appropriately. Cases that it is difficult to receive enough services suitable for the symptoms could often be seen. Under these circumstances, this research would examine ways to support carers of dementia elderly people, focusing on the actual living conditions and social support.

The purpose of this research is to enable dementia elderly people and their carers to continue caring them at home and to have a high QOL.

Firstly, the following hypotheses were set up.

1. As environmental condition to lighten the burden of caring, social support has important meaning.
2. Understanding the actual living conditions and social support of dementia elderly people and considering assistance measures could improve the QOL of main carers.

Based on the recognition above, this research would also consider approaches focusing on the actual living conditions and social support.

<Definition of Terms>

Dementia: It is defined as “a medical condition that cognitive functioning which had once developed normally becomes worse gradually by acquired brain damage, interferes basic activities of daily or social life. It is observed as consciousness is not affected.”

4)

Dementia elderly people: It means elderly people over 65 years old who develop dementia.

Social support: support exchanged in social relationship. It works to maintain health behavior and decrease the influence of stressor⁵⁾. Social support could classified to four categories: ① emotional support, ② tangible support, ③ informational support, ④ companionship support. Depending on characteristics of the subjects, supports of ① ② and ③ would be analyzed in this research.

- ① Emotional support: attitudes of others such as supporting an individual under stress with empathetic or receptive manners.
- ② Tangible support: also called instrumental support. It includes financial assistance, material goods, or services.
- ③ Informational support: to provide technique or information to help problem-solve.

2. Research Method

2.1 Selection of subjects

The subjects of this study are main carers of dementia elderly people living in prefectures of Hyogo, Nara, Mie, and Aichi.

The respondents are as follows.

- (1) The questionnaire survey: Valid response was 138 (200 distributed, 69% response rate).
- (2) The interview survey: 30 of the subjects of the questionnaire survey. Valid response was 30 (100% response rate).

2.2 Research methods

The questionnaire sheets were distributed to the subjects who had agreed to cooperate when we had confirmed each of carer families' intent through care managers and daycare staffs of dementia elderly people living home. The answered questionnaire sheets were collected through staffs again, after sealing them strictly. In the interview survey, the researchers had requested the family members of dementia elderly people among the facility users who had cooperated the questionnaire survey to conduct interview at their home or when the users visited the facility, through staffs with the permission of the facility director, in advance in leaving method. The survey subjects and the researchers arranged time and place, and the survey was conducted. The place for the survey was rooms of the subjects' home or a room in the facility which could protect privacy. The survey time was kept within 30 minutes as long as possible.

The time period for this research was a year from August 2015 to August 2016.

2.3 Basic attributes

The average age of the dementia elderly people was 84.89 years old (± 7.24 years old), 84 female (60.9%), 50 male (36.2%), 4 non-responses (2.9%), 138 people in total.

2.4 Survey items

The survey items in this research were nursing care level, relationship to the main carer, period of care, other disease of the dementia elderly person, condition of ADL and troubles of house as questions about the actual living conditions of dementia elderly people and their family, and emotional support, tangible support, informational support, and what they expect welfare to be in the future as questions about condition of social support.

2.5 Ethical considerations”

From request to cooperate on the research, collection and analysis of data to publication of the result, the researchers strove to guarantee the basic rights below:

- 1) Right not to gain a profit

The subjects and candidates are promised that whether they would cooperate on this research or not would never affect services they would receive in the future, nor inflict any loss. They are also explained that it would be possible to decline after giving their consent and to refuse their cooperation temporarily.

- 2) Right to know the purpose and methods of the research

The positions of the researchers, the methods and the specific content of cooperation are explained to candidates for subjects sufficiently both in writing and orally. All the subjects are given the contacts of the researchers, and they would be informed clearly if any questions, opinion, or

request to know the results of the research are proposed.

3) Right to self-determination

Subjects are emphasized that intent of the subject himself/herself to determine whether cooperate or not has the highest priority and guarantee enough time if needed to make a decision.

4) Right of privacy, anonymity, and confidentiality

It was promised that the information obtained through this research would not use other than research purpose and would be maintained confidentiality. The obtained information was coded and maintained anonymity not to identify an individual. Subjects are interviewed in a place their privacy was protected, and informed they needed not to talk what they would not like to. This research is already approved by ethical review of Naragakuen University (approval number:27-005).

3. Result

3.1 Actual living conditions of dementia elderly people

1) The nursing care level of the dementia elderly people

Requiring help 1: 2 subjects (1.4%), Requiring help 2: 9 subjects (6.5%), Long-term care level 1: 29 subjects (21%), Long-term care level 2: 29 subjects (21%), Long-term care level 3: 27 subjects (20%), Long-term care level 4: 17 subjects (12.3%), Long-term care level 5: 18 subjects (13%), unknown: 7 people (5%).

2) Main carers

The largest number of the main carers were 46 daughters (33.3%), then 34 wives (24.6%), 20 daughter-in-laws (14.5%), 18 husbands (13.0%). The percentage added the daughters, the wives, and the daughter-in-laws was 72.4%, which meant female carers were more than 70%.

3) Age of the main carers

Table 1. About troubles of house

<i>An extract of data</i>
<i>difficult to take a bath, steep stairs, difficult to cook with gas stove, a slope in front of the house, far between a dining room and a bedroom, anxious to trouble residents who live next to and downstairs of the apartment with noise. Impossible to build handrails along a graveled path and to use a walking assist instrument there, need more handrails</i>

Table 2.Details of the answers who did not know appropriate ways to care

<i>An extract of data</i>
<i>-how to deal with dementia. For example, when the patient shows no response or was emotional. -excretion assistance -I joined a kind of training but did not understand well. -I do not know conversations or how to answer. -personal long-term care and independence (the way to handle by oneself) -I do not know how to have a conversation, I cannot communicate with the patient well -I am anxious about the way to care the patient in case the symptoms would progress in the future.</i>

Table 3. The specific answers about “few information about caring”

<i>An extract of data</i>
<i>Only few people tell me information about caring. -I do not know where to ask for advice. -They would not tell us information unless we ask. Organization we would go for advice is Sunday and Holidays (closed to business) -different ways of caring depends on various diseases (especially when the patient have a complication) -There is no carer around me, so I get information only by TV and newspapers. -I would like them to tell us, just once a month, a place where I could get information about caring, or how they would take care of my husband (the person requiring care) and where I could ask for his care if I got sick. -I would like to have information about mental care of carers. -I believed that only bedridden people whose stage of long-term care need is high could use service. I wish I could have been able to take advice in the early stages. -There are only a few carers in the neighborhood so I am uncertain how to care when the symptom would progress. I have few chances to talk about caring. I would like to listen to other carers as I have not had a chance. -system of caring (I am not sure if I do not know it or if I do not understand) -I would like to listen to carers of dementia people. -I would like to know information of service such as short stay for long-term care. -I wonder if there is some information I do not know, and if I know every information. -I do not know clearly and specifically. -There is few means to acquire special knowledge. -I would like to have information to deal with small things of daily life.</i>

The average age of the main carers was 66.33 years old (± 12.3 years).

4) Period of care

About the period of care, 51 people answered 3-10 years, which was the largest (37.0%), then 48 people 1-3 years (34.8%). From these numbers, 1-10 years of care was 71.8%, which was more than 70%. 1-3 years and 3-10 years were about 30%, almost the same percentage.

5) Other diseases

About other diseases, 56.8% of the subjects answered "they had other diseases," and 22.5% answered "they did not." As the other diseases, 20 subjects answered heart failures, which was the largest number (15%), then 18 apoplexies (13%), others were high blood pressure, diabetic, bed sore, COPD, etc.

6) Daily condition of care (ADL of the dementia elderly people)

- (1) Walk: 23 subjects answered "total assistance" (16.7%), and 18 subjects answered "assistance was mostly needed" (13.0%). Approximately 30% of the subjects had severe gait disturbance.
- (2) Going out: 53 subjects answered "total assistance" (38.4%), and 27 subjects answered "assistance was mostly needed" (19.6%). Approximately 60% of the subjects had difficulties with going out.
- (3) Meal: 12 subjects answered "total assistance" (8.7%), and 13 subjects answered "assistance was mostly needed" (9.4%). Approximately 20% of the subjects needed much assistance.
- (4) Bath: 43 subjects answered "total assistance" (31.2%), and 33 subjects answered "assistance was mostly needed" (23.9%). More than 50% of the subjects needed much assistance.
- (5) Dressing: 26 subjects answered "total assistance" (18.8%), and 25 subjects answered "assistance was mostly needed" (18.1%). A little less than 40% of the subjects needed much assistance.
- (6) Defecation and urination (using diapers): 69 subjects answered "use diapers" (50.0%), and 12 subjects answered "sometimes use diapers" (8.7%), 3 subjects answered "use diapers only when going out" (2.2%), 48 subjects answered "not use diapers" (34.8%). Approximately half of the subjects used diapers.
- (7) Defecation and urination (using bathrooms): 33 subjects answered "total assistance" (23.9%), and

18 subjects answered "assistance was mostly needed" (13.0%). Approximately a little less than 40% of the subjects needed much assistance.

- (8) Communication (conversations, gestures, hand signals): 13 subjects answered "impossible" (9.4%), and 28 subjects answered "possible a little" (20.3%). Approximately 30% of the subjects had problems of communication.
- (9) Waking up at night for caring: 63 subjects answered "they do" (45.7%).
- (10) Times of waking up at night: (only among the subjects who answered they wake up at night) 18 subjects answered that they woke up twice a night, which was the largest number (28.6%), then 15 subjects answered once a night (23.8%). The subjects who answered three times were 11 (17.5%), and the subjects who answered more than three times were 11 (17.5%).
- (11) Reason of waking up: (multiple responses) 38 subjects answered excretion (60.3%), 11 subjects answered prowling (17.5%). Other reasons were anxiousness, panic state, etc.

7) Troubles of house

51 subjects answered "there are steps" (36.9%), 9 subjects answered "difficult to remodel" (6.5%), 12 subjects answered "there is no elevator" (8.7%). (multiple responses) The detailed answers mentioned in (others) are shown in Table 1.

3.2 Social support

1) Emotional support

- (1) Advisor for caring (multiple responses, N=138)

93 subjects answered "care managers," 79 subjects answered "family, relatives," 35 subjects answered "doctors of clinics and hospitals," 32 subjects answered "nurses," 21 subjects answered "helpers," 19 subjects answered "care workers," 16 subjects answered "neighbors, friends," 10 subjects answered "social workers," 4 subjects answered "others," 3 subjects answered "none," 1 subject answered "public health nurses."

- (2) Moral support (which have high priority as moral support)
82 subjects answered "family" (59.4%), the largest number, and next was 15 answers of "care workers" (10.9%), then 13 subjects answered "medical workers" (9.4%), and others were approximately 20%.

2) Tangible support

- (1) Whether there is a doctor who would give advice or make

Table 4a. What they would like government to do in the future.

<p><i>An extract of data</i></p> <p>1. About admission</p> <ul style="list-style-type: none"> -I would like government to increase facilities which could use at ease. -I would like government to be able for everyone who hope to be admitted to. -We have economical problem to enter. I would like government to help only when we do not have enough at least. Two of us could live at our home, but when the two must live separated, we could not afford living expenses for two places. -We cannot reserve short stay for long-term care (it would take about two months). -We have a problem of shortened hospitalization. -The standards for admission is strict. -Though unit-type private room is very popular, I would like government to build new geriatric welfare home for the elderly with cheap multi-bed room for 2-4 people. -the judgment meeting for admission takes a long time. -It is difficult to be admitted for someone without introduction. -It is difficult to be admitted for people who had diseases. -I would like government to increase facilities to admit pensioners. <p>2. Improvement of systems about usage</p> <p>Cost and burden of expenses</p> <ul style="list-style-type: none"> -I would like government to make self-pay rate of Long-Term Insurance equal. -I hope facilities which would give appropriate care at reasonable price for everyone could pay to receive their service would be built. -I would like government to improve systems to allow us to use them continuously. -Cost for caring burdens us. -I hope burden of expenses to be decreased. As amount of pensions had reduced, we could not receive services at ease when we have no money to spare. I would like government to consider amount of the burden charge depends on income. -I hope them to increase subsidies for communities and in-home care. -As most of elderly people is nuclear families, 'elderly care by the elderly' or living alone. If they ruin their health, it interfere their daily life in a moment (going to the hospital, shopping, having meals, taking a bath, management of money, etc.) -There are people who separate households because they cannot care their elderly with national pension. -Some separate household and live a better life (better care services) with life insurance. It is conflicted. <p>Treatment of staffs</p> <ul style="list-style-type: none"> -Work of care workers is hard. I hope treatment of nursing care professions would improve. -I hope government to pay care workers more wages and increase the number of staff. <p>Incomprehensiveness of systems</p> <ul style="list-style-type: none"> -I hope them to change systems simpler. -The Long-Term Care Insurance System is complicated. (terms of use, procedures, etc.) -I think it would be good if there are services which would reduce carer's burden or an administrative service which could be received regardless of residential area. -I hope valuable attempts of the city or services which require applications to be informed more simply. I also hope more I information of services which require applications. <p>For better services</p> <ul style="list-style-type: none"> -I hope them to improve understanding of support for people who do not seem to be weak physically (people who need the long-term care visibly). -I hope them to check sites of nursing care of each nursing facility (including staffs, salaries, equipment, financial affairs, management policies, communications among employees, etc.), and to try to improve services based on comparison through the whole country. -I would like to have an opportunity for carers to talk with other carers about mental care or nursing, if there are ones for young carers. -I would like to get information. I have internet, but I want information based on the actual situation of the area from the administration. <p>Future prospects.</p> <ul style="list-style-type: none"> -As there would be usual in the future that family members would care their elderly while working, I hope them to establish a welfare service for working carers to continue their work with no worries. -Care for living alone (feeling lonely). What form our local communities should take, establishing salons (within the walking distance), age-friendly town planning. -Services to support elderly to live at their home. 24 hour service in case a problem happens. I think home is the best. It would be good if there is a place elderly people and children can interact each other. -A town that people can live in their familiar house without worries (elderly people, handicapped people, dementia people). <p>Understanding of local people.</p> <ul style="list-style-type: none"> -Having calm and safety life. I think better services could be provided by review of the systems, improvement of wages and treatment of nursing care staffs. -I think it is impossible to improve welfare without change in awareness and demonstrate of ability to take action of young people. -People do not understand dementia enough. Mental burden of carers is large. -I hope flexible services, such as getting dental treatment during short stay. <p>Hoping the Administration to lead to the future</p> <ul style="list-style-type: none"> -Though dementia people do not have productivity, I hope systems to be built to pass away as an important person as when they were born. I would like young people to think about "importance of family," and "view of life including their old age." I am worried about phenomenon to avoid "dirty" things extremely, getting used to life in the affluent society. I hope a society which kindness as human being is needed rather than high academic ability. I hope the Administration to lead to the future through education. <p>The Administration do not understand the actual situations</p> <ul style="list-style-type: none"> -It seems to me that the Administration do not understand the actual situations. They do not know problems in front of them. They do not interact with inhabitants enough. As well as future, I would like them to focus on "current problems." Such as levels of care managers (different depending on managers in charge), overcapacity of community comprehensive care centers (foster family care).

Table 4b. What they would like government to do in the future.

<p><i>An extract of data</i></p> <p>Necessity of any support when it is really needed, regardless of points</p> <p>-It would take long to care dementia patients because they could get angry or refuse suddenly, so it often happens that carers and family members do not have their own time. Dementia patient would go out without permission, not know how to open a lock he/she had locked, or walk a long ways without thinking of the distance to the destination for several times. Family members feel like carrying the burden for 24 hours, so I want any support when it is really needed, regardless of points.</p> <p>-I want them to relax the restrictions of the long-term care services, as we can use depends on the condition and situation.</p> <p>-I hope them to educate staffs to give consideration to feelings of each patient, not treating everyone alike.</p> <p>-I would like information elderly people can understand, not through internet.</p> <p>3. Anxiety about the future</p> <p><i>Anxiety about maintenance of systems</i></p> <p>-It is alright now, but I am anxious very much whether the administration like the current one would be maintained or not after 20 years when I would receive the nursing care.</p> <p>-I am worried about the possibility that it would be unable to use caring facilities and services. I hope the current policy to be maintained.</p> <p>-I am worried how it would be in the future. Dementia prevention, dealing with disease prevention. I hope the Administration to lessen the burden of elderly people such as consumption tax.</p> <p><i>Anxiety about continuing of caring</i></p> <p>-There is no other caregiver, so I cannot break down no matter what happens.</p> <p>-I do my best while sacrificing myself. I am worried how long I can continue, as it is very hard physically to change diapers, etc.</p> <p>-Since I had quit my job to care the patient so I have no income, and I am unmarried, I do not have anyone to take care of me in the future, nor savings enough to be admitted to nursing home.</p> <p>-I am at a loss as to what to do since my father was not admitted to nursing home. It was because the limited number of staffs would not allow them to attend my father alone all the time when he would not sleep prowling all night long, and he would raise his voice.</p> <p>-The patient has a diabetes as well who needs insulin shots, and cannot urinate by himself so he has IDC (Indwelling Catheter) inserted. So it is very difficult to find facility that would admit the patient.</p> <p>-They had the patient move to a private room because they insisted the noise of sucking sputum was annoying..</p>
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Table 5. Measures in case the disease worsens; other comments

<p><i>An extract of data</i></p> <p>-I think it would be good to discuss with the patient when such case actually happens.</p> <p>It would be good if the patient himself/herself hoped to move into facility, but we might give up if not.</p> <p>-The patient would eventually go into hospital if the condition of the disease worsened and become impossible to care at home.</p> <p>-I hope to continue caring to the end as long as my (the carer) physical strength lasts.</p> <p>-Hoping to care at home first, then to go into hospital or facility. Considering the patient's own intention and burden for family.</p> <p>-I hope to care at home as long as possible. Going into hospital if it was impossible.</p> <p>-The patient would go into hospital just in case, but I would like to care him/her at home if it became better even a little</p>
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- a house call or not
- About family doctor, 111 subjects answered “they have” (80.4%), which was approximately 80%.
- (2) Whether there is a hospital which would admit them in emergencies
- 82 subjects answered “there is” (59.4%), which meant approximately 60% answered that they would be admitted in emergencies.
- (3) Ways to care (multiple responses)
- 82 subjects answered, “using day care etc.,” 37 subjects answered “with family living together helping each other,” 25 subjects answered “caring almost whole day,” 21 subjects answered “using home care service,” 16 subjects answered “others,” 12 subjects answered “with family living separately in turn,” 11 subjects answered “using certified care workers,” 1 subject answered “with neighbor’s help.”
- (4) About receiving welfare service (multiple responses)
- 92 subjects answered “outpatient (day service),” 53 subjects answered “rental of welfare aids (bed, wheelchair, handrail, etc.),” 39 subjects answered “short stay service for long-term care,” 31 subjects answered “visiting nursing (dispatch of helpers),” 24 subjects answered “visiting nursing (hospital nurses, etc.),” 18 subjects answered “day care rehabilitation,” 16 subjects answered “visiting medical management in home (doctors etc. visit home and give management and guidance),” 12 subjects answered “visiting rehabilitation,” 7 subjects answered “visiting bathing care.”
- (5) Whether there is someone who would help to care or not
- About family members who help the main carer to care, 90 subjects answered “there is” (65.2%), which meant approximately more than 60% were assisted by helpers to support care-giving (deputy carer).
- (6) Number of helper to support care-giving (deputy carer)
- 59 subjects answered there was one helper to support care-giving (42.8%), 24 subjects answered there were two helpers (17.4%), which meant that approximately 60% were assisted by one or two deputy carers.
- 3) Informational support

- (1) Do not know appropriate ways to care
18 subjects answered “agree” (13.0%), 34 subjects answered “agree a little” (24.6%), which showed that approximately 40% answered that they didn’t know.
- (2) Few information about caring
12 subjects answered “agree” (8.7%), 28 subjects answered “agree a little” (20.3%), which showed approximately 30% subjects answered there was few information about caring. Table 3. shows details of the specific answers about “few information about caring.”
- (3) Measures to be hoped in case disease or disorder of the care-receiver worsen
79 subjects answered “hope to be admitted to hospital or facility” (57.2%), which meant approximately 60% hoped to be admitted to hospital or facility. Also, 35 subjects answered “receive services and live in own home” (25.4%), 10 subjects answered “continue caring at home” (7.2%), which shows approximately 30% hoped to stay at home. Table 5. shows other comments.

4. Discussion

4.1 Actual living conditions of dementia elderly people

- 1) Main carers
According to “Current State and Trends on the Elderly and their Environment²⁾” of Aging Society white paper 2017 edition by the Cabinet Office (whole version), relationship between main caregivers and persons requiring long-term care was: spouse 26.2%, children 21.8%, and children’s spouse 11.2%. Besides, as gender is: male 31.3%, female 68.7%, there are more female caregivers, which was almost similar to the numbers in this research. As the result of this research, since many of dementia elderly people have problems of ADL as well as complications, it is considered that mental and physical support for caregivers depending on individual characteristic of dementia elderly people is needed.
- 2) Age of the main caregivers
It is reported that there are considerable number of cases so-called “nursing care of elderly by elderly” of late years²⁾. As the average age of of main caregivers is 66.33 years old (± 12.3 years) in this research, it is assumed that obviously there are existing state that old people providing care for old people.
- 3) Whether there is someone who would help to care or not
The result of this research shows that there are approximately 30% of people who cannot receive

assistance. Measure to support those who cannot receive assistance is considered to be an urgent issue.

- 4) Number of helper to support care-giving (deputy caregiver)
In this research, the result of the number of deputy caregiver was one in the 50% of the caregivers who had deputy caregivers. Since dementia elderly people have not only dementia but also various diseases, and they have various neuropsychiatric symptoms, in addition to physical care caused by lowered ADL, their mental burden is heavy. Based on these states, human resources of deputy caregivers is not enough, and during the trend toward the nuclear family, it poses a more serious problem hereafter.
- 5) Daily condition of care (ADL of the dementia elderly people)
30% of the dementia elderly people had severe gait disturbance, and approximately a little less than 60% had difficulties with going out. Approximately a little less than 20 % of the dementia elderly people needed assistance when having meals. About taking a bath, more than 50% needed much assistance. Also in dressing, a little less than 40 % of the dementia elderly people needed much assistance. Besides, in excretion, which is said to be the hardest burden of caring, 50% used diapers. A little less than 40% of those who used bathrooms required much assistance. It is assumed that the dementia elderly people who required assistance in dressing need the same level of assistance in excretion. Generally, problem behaviors of dementia elderly people are liable to be noticed, but support depending on individual characteristic for disorders of ADL is also needed.
- 6) Communication
30% people had problems that they cannot communicate with others enough. For dementia elderly people, it is revealed also in earlier studies⁶⁾ that being unable to communicate might lead not only to stressors such as to express their needs or not to be understood their feelings, but also to factors that cause problem behaviors. It could be heavy stressors for caregivers as well since it might hinder them from communicating each other. It is needed to endeavor to understand feelings and needs of dementia elderly people, using a communication board with letters or information which could obtain in daily observations.
- 7) Waking up at night for caring
In this research, it was found that approximately 50% of the caregivers wake up at night. The main reason was excretion and prowling. Except for excretion, analyzing of data from this interview shows that the fact that dementia elderly people would wake up at night is connected with

phenomenons which could be interpreted as a problem behavior. Considering that some of the caregivers complained that they must care the patient at night more than in the daytime, it was revealed that more studies about nursing care at night are needed to be developed, more in details than in this research.

Besides, the caregivers are worried not only about actual care-giving itself but also about physical problems such as fainting or getting into a panic. From these results, waking up at night would disturb sleep of dementia elderly people and their caregivers and lead to accumulation of exhaustion both physically and mentally.

8) Troubles of house

Troubles of house was difficulties with walking or taking a bath such as steps and stairs might lead to low ALD of dementia elderly people. About stairs, there would be problems that there is no elevator in old apartments. It might be difficult to solve problems of slopes and graveled paths personally, as environment of the local characteristics might affect them.

4.2 Social support

The importance of social support was pointed out in Europe relatively early on and longitudinal studies of social support based on areas have been continued^{7) 8) 9)}, but there are few systematic and empirical studies in Japan.

1) Emotional support

(1) Advisor for caring

In this research, the largest number of the answers as advisor for caring was care managers, while one subject answered public health nurses. Further study about teamwork of community medicine is needed.

(2) Moral support

As moral support for caregivers, “family” was 60%, each of “careworkers” and “medical workers” was approximately 10%. It is needed to build a relationship of trust to contribute to emotional support as professionals.

2) Tangible support

(1) Whether there is a doctor who would give advice or make a house call or not

20% of the cases answered “there is not.” The background of it would be needed to be clarified in further studies.

(2) Whether there is a hospital which would admit them in emergencies

As a result of this research, 40% of people had “anxiety.” It is needed to grasp medical environment of communities in further studies.

(3) About welfare services

In the results of this research, visiting nursing, visiting bathing care, hospitals, visiting rehabilitation, visiting medical management in home, outpatient (day service), day care rehabilitation, short stay service, and rental of welfare aids are used as welfare services through the Long-Term Care Insurance System. On the other hand, there were answers such as “caring with family living together helping each other,” “with family living separately in turn,” and “caring almost whole day,” which meant that not every caregivers make good use of welfare services based on the Long-Term Care Insurance System. Most of the dementia elderly people and their family caregivers had positive feelings to the services of facilities and careworkers. However, there were people who were worried about future continuity of welfare services, economical problems, problems if themselves could receive those services. It is important to provide more information about welfare services from the Administration.

3) Informational support

Caregivers who answered that they do not know how to care was a little less than 30%, and caregivers who thought that information about caring is too few was 30%, which would mean that information about caring is not enough. Since dementia elderly people have other complications, it was shown that informational support about understanding of each disease and its appropriate way to care is needed. Also, caregivers seemed to wait for active information by professionals, as opinions such as “they would not inform us until we ask,” “I would like to know the structure of the Long-Term Care Insurance System,” “I would like to listen to caregivers of dementia patients” were raised. There might be difficult situations for caregivers to raise their voices, or they might be too busy with their daily life, or it might be too difficult for elderly people to use internet. Therefore, the way to provide information is needed to be considered. Further studies are needed after finding out the reason why it is difficult to get information.

5. Research limits and problems

This research focused on life of dementia elderly people and caregiver and social support and considered plans to support life of dementia elderly people and their family. However, the concept of life is wide, and this research did not aim at every life factors. From such aspect, this research has limitation as well. In the future, the researchers would conduct further surveys of the current living

conditions of dementia elderly people and their family and consider how effective social support should be provided.

6. Conclusion

As a result of classifying social support broadly into “emotional support,” “tangible support,” and “informational support,” analyzing, and considering them, it was found that family was important in emotional support and that welfare and medical workers were not involved with it. Rather, according to the interview of this research, tangible support related to medical care and welfare might lead to mental peace of caregivers. Doctors who would give advice or admit patients into hospital in emergencies were essential as emotional support for dementia elderly people and their family caregivers who have a disease called dementia. In this research, approximately 40% of the caregivers are worried about dealing with dementia elderly people in emergencies, improvement of medical environment in communities would be needed.

On the other hand, about informational support, since there is not enough information about nursing care, and some caregivers think they do not know the way to care or to attend to, enhancing social services such as nursing care classes is needed. Besides, according to the results of this research, careful assessment of each cases and promotion of using appropriate services might be important, as it is supposed that not every caregivers make good use of welfare services based on the Long-Term Care Insurance System.

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<Profit reciprocity>

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