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For the Betterment of the Family Care for the Aged with Dementia

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To investigate the feeling of burden and needs in care, a questionnaire was made which consists of "feeling of burden in care" (family Maslash Burnout Inventory for care or M.B.I. in short) and "family needs" (own making). It was mailed to ninety-nine caregiver of the family with the aged with dementia who cared them at home utilizing day-care service at a special nursing home for the aged, and attended family class once a month. 67 Valid answers were obtained. The average age of caregiver was 57.0 years; seventy-six percent of them were female. Their difficulties were own health condition and lack of a cooperator for care. The main component analysis of family M.B.I. for care showed that fatigue was the main factor, indicating that it is very important to provides the families with mental support. Many caregivers thought that their care were useful and worthy; however score of "emotional exhaustion" were higher and score of "self attainment" were lower.

According to the official statistics by the Department of Welfare, there are approximately one million the aged people with dementia in Japan in 1990, and there will be two million nine hundred twenty thousand in 2020[1)](Ministry of Welfare,Bureau of Health and Welfare for Old People 1994. About 70 percent of them are cared at home by their families[2)]. Recently, the structure of family is changing greatly due to the urbanization and the increasing percentage of nuclear families, making it more difficult to support such patients only by the family. There are studies on the interaction between the aged with dementia and caregiver, the feeling of burden in care, and of its attainment, and the health condition of caregiver [3), 4)] (Kikuko Ota 1996,Noriko Yamamoto 1996). However, there are few studies on the support for the family education which is given by community to assist those who have the aged with dementia. In this study, feeling of burden and needs at the time of care were investigated of the families attending family class and using day-care service at a certain installation for the aged; the results were compared with a similar study, and the significance of community's support in community for such family is discussed.

High aging of population is a worldwide tendency. In Japan, people over 65 amounted to 13.5 percent in 1993, and will amount to 25.8 percent in 2025[5)] (Association for Welfare and Statistics 1994). And most of the aged have chronic illnesses and disabilities, often overlapping at a time. The ratio of the people with symptoms, and that of the people attending hospital are increasing as the age increase; people over 65 who have more than two illnesses amount to 45.5 percent of those who attend hospitals or clinics periodically. Under these circumstances, to care the aged at home is difficult and is a serious problem. It was reported that in 1990 seven hundred thousand of people over 65 years old were bedridden for more than six months. The population of the bedridden is estimated to be two million three

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hundred thousand in 2025[1)] (Ministry of Welfare,Bureau of Health and Welfare for Old people 1994).

It is who reported that main causes of the bedridden are cerebrovascular disease and dementia[6)] (Kashu et al 1977). The number of the people with senile dementia was approximately one million in 1990, and will be two million nine hundred twenty thousand in 2020[1)]. People, foreseeing their own aging, say that senile dementia is one of the greatest anxieties as well as being bedridden[7)] (The Economic Planning Agency 1994) .

Under the present circumstance of Japan, this study is expected to offer important materials for those who are playing active roles in community, such as medical professionals, welfare professionals, and public health nurses.

Firstly, care for the aged with dementia will remain to be the important issue hereafter. The increase of the aged people of population and bearing fewer children will make it more difficult to care for the aged at home.

Dementia like the other various illnesses of the aged who need care, dementia, causes the more difficult situation.

Secondly, the aged who used to be cared in community will increase in number. As the Law of Insurance System for Care has been enacted, researches on the care for the aged will be the more strongly demanded. It is an urgent issue for medical professionals, including public health nurses, to examine how to support such families. This study is to assess the present situation and to make the better care available.

Table 1. Patient age and gender distribution

age	male	female	total
-69	3 (18.7)	8 (15.6)	11 (16.4)
70-74	4 (25.2)	7 (13.7)	11 (16.4)
75-79	3 (18.7)	11 (21.6)	14 (20.9)
80-84	3 (18.7)	11 (21.6)	14 (20.9)
85-89	3 (18.7)	9 (17.7)	12 (18.0)
90-	0 (0.0)	5 (9.8)	5 (7.4)

MATERIALS AND METHODS

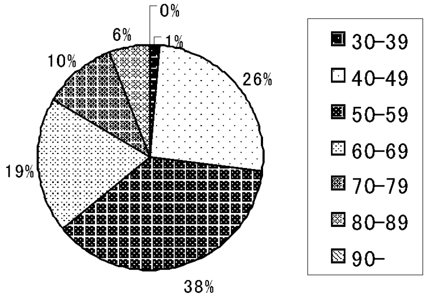
The quantitative and description methods were used; questionnaires were mailed to the main caregiver of each family who is caring the aged with dementia at home.

1) The subjects were ninety-nine caregivers who care the aged with dementia at home, using day-care service which are given by the special nursing home and attending family class once a month. They are living in Kita-Ward, Nishi-Ward, Tarumi-Ward of Kobe City. This family class provides them with information about care, diseases, and medical systems, according to the annual theme. They also discuss their own problems in the class.

2) The period of the study was April 31st 1995 through October 31st of the same year. Feeling of burden of family was investigated with the questionnaire of family, Maslach Burnout Inventory (M.B.I.), which Nakatani used for his study for care. Family M.B.I. consists 8 items of "emotional exhaustion (EE)" which 4 items of "depersonalization (DP)", 4 items of "feeling of poor attainment (PA)", which 16 items in a total. Each item was assessed in a 4-grade system of Likert's scale ranging from "I think that is quite true" to "I do not think so at all"(Table 2). And another questionnaire for investigation was given on family needs such as physical condition of caregiver, his or her caring situation, future plan

for the care, caregiver's difficulties in care, how to use of social resources and their future demands (free description).

Statistical analyses were made on family M.B.I. for care, and several items of “family needs” were chosen. Family M.B.I. main component analysis was also made in order to grasp the subjective feeling of burden in care. Subjects were asked to describe “future demands” in their own words, and the answers were categorized.



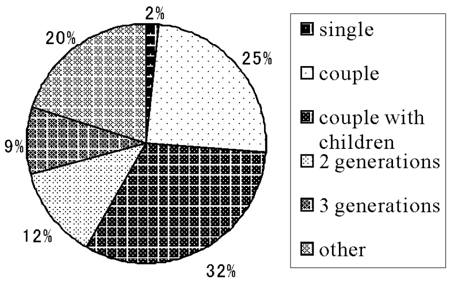
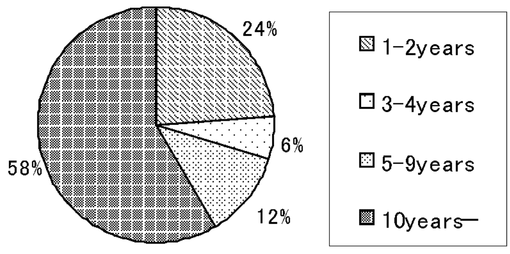


FIG. 1 (Left) Carefiver age. The age of caregiver was 57.0 years, as shown in it.

FIG. 2 (Right) Family structure. Family structures were shown in it; “couple with children” amounted to 32 percent followed by “couple”.

FIG.3 Patients’ A.D.L.. Aspects of Activities of Daily Living were shown in it; Many answered “Capable by oneself” about the items of “eating” and “walking”, many answered “incapable” about “dressing” and “bathing”.



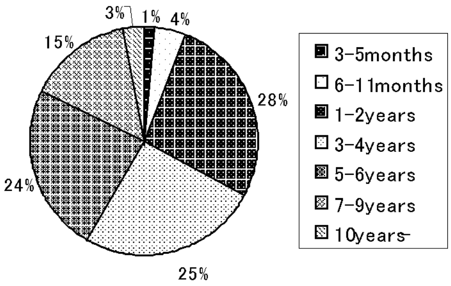


FIG. 4. (Left) Duration of residence together. Duration of residence together with caregiver was shown in it; “residence together for more than ten years” was majority and amounted to 60 percent.

FIG. 5. (Right) Duration of the care. Duration of the care was shown in it; from 1 year to less

than 2 years" was vast majority and average was 6.2years.

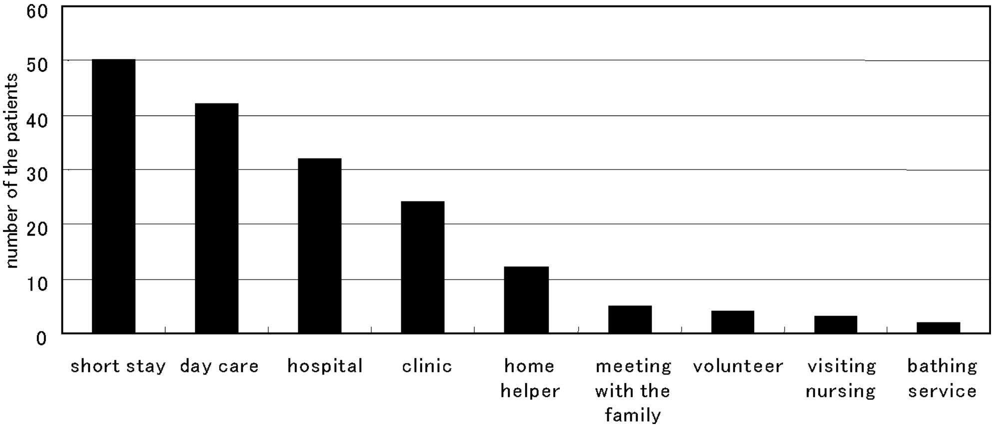
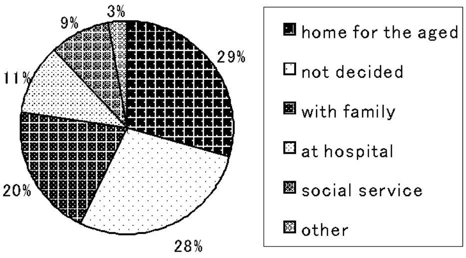


FIG.6. Use of services. Use of services were shown in it; many used short stay, day - care, and hospitals. A few used volunteer, visiting nursing,and bath service.



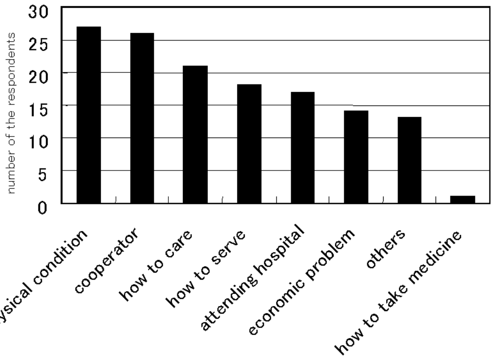


FIG .7. (Left) Future plan for the care. Future plan for the care was shown in it; many selected home nursing for the aged, and many answered "not decided".

FIG.8. (Right) Difficulties in the care. Caregiver's difficulties in care were shown in it; "his or her own physical condition" were the most and amounted to 40 percent; "want to cooperator", "how to care", and "how to serve" were in order.

RESULTS

From 99 subjects we could obtain 67 valid answers; the rate was 67.7 percent. The average age of the patients was 77.1 years, as shown in Table 1. There were 16 males (23.9 percent) and 51 females (76.1 percent). The average age of caregiver was 57.0 years, as shown in Figure 1. There were 7 males (10.4 percent) and 60 females (76.1 percent). Family structures were shown in Figure 2; "couple with children" amounted to 32 percent followed by "couple". Causes of diseases of the aged with dementia were given; dementia of Alzheimer's type and dementia of cerebral accident type both amounted to about 30 percent, making approximately 70 percent in total.

Aspects of Activities of Daily Living (A.D.L.) were shown in Figure 3; many answered "capable by oneself" about the items of "eating" and "walking", many answered "incapable" about "dressing" and "bathing". Duration of residence together with caregiver was shown in Figure 4; "residence together for more than ten years" was the majority and amounted to 60 percent. Duration of the care was shown in Figure 5; "from 1 year to less than 2 years" was

Table 2. Answer distribution of family M.B.I. for care (%)

		I think that is quite true.	I think that is a little true	I do rather not think so.	I do not think so at all.	unknown
(EE1)	I feel worn out with care.	35.8	56.7	3.0	1.5	3.0
(EE2)	I feel tired out at the end of day.	37.3	52.2	6.0	3.0	1.5
(PA1)	I think that my care is useful for the aged.	59.7	37.3	3.0	0.0	0.0
(DP1)	I am indifferent to the change of the aged.	9.0	25.4	14.9	38.8	11.9
(DP2)	I handle the aged as an object.	1.5	17.9	25.4	55.2	0.0
(EE3)	It is hard and worrisome to spend time with the aged.	44.8	41.8	6.0	4.5	3.0
(PA2)	I think that I am dealing well the problems of care.	16.4	58.2	14.9	3.0	7.5
(DP3)	I treat others harshly after the beginning of care.	3.0	28.4	35.8	29.9	3.0
(EE4)	I feel fatigue in the morning to think that another day of care began.	25.4	47.8	11.9	10.4	4.5
(PA3)	I can see precisely how the aged feels.	23.9	46.3	17.9	7.5	4.5
(EE5)	I feel burned out with care.	14.9	38.8	35.8	7.5	3.0
(EE6)	I feel irritated with care.	31.3	58.2	6.0	1.5	3.0
(DP4)	I feel that I am insensitive as I care.	10.4	37.3	26.9	22.4	3.0
(PA4)	I think that to care is worthy.	47.8	41.8	4.5	3.0	3.0
(EE7)	I work too hard in care.	25.4	38.8	28.4	4.5	3.0
(EE8)	I feel that I realize limitation to care for myself.	20.9	40.3	32.8	6.0	0.0

EE: emotional exhaustion (8 items) DP: depersonalization (4 items)
PA: poor self attainment (4 items)

the vast majority and average was 6.2 years. Use of services were shown in Figure 6 ; many used short-stay, day-care, and hospitals; a few used volunteer, visiting nursing, and bathing service. Future plan for the care was shown in Figure 7; many selected home nursing for the aged; and also many answered “not decided”. Caregiver's difficulties in care were shown in Figure 8; “his or her own physical condition” were the most and amounted to 40 percent; “want of cooperator”, “how to care”, “how to serve” were in order.

There were 47 answers in free descriptions about the demands of medical treatment, nursing, and welfare; there were demands of medical system such as “We need a hospital and a system which admits the aged with dementia at the time of in case of emergency”, ”We need a special institute for the aged with dementia”; there were demands of welfare such as “We need more frequent day-care services”, “We need more satisfactory short-stay service”, ”We need to lessen our economic burden”. There were many demands of nursing and of support for caregiver such as “We need an institute and manpower which allow the aged with dementia to be cared when caregiver is ill”, “We would like to know the proper care and attitude toward the aged with dementia”.

About the family M.B.I. for care, as it is shown in Table 2, the item to which the most respondents answered the item “I think that my care is useful for the aged (PA1)” which

amounted to 59.7 percent gained the greatest number of the responses to “I think that is quite true”; item of “I think that care is worthy (PA4)”followed with 49.2 percent. Those who affirmed items ”emotional exhaustion (EE) 1,2,3,4,6”amounted to approximately 30 percent. Those who affirmed “depersonalization (DP) 1,2” amounted to approximately 3 percent. This study showed the tendency
of higher “emotional exhaustion (EE)” and lower “feeling of poor self attainment (PA)” compared with the study by Nakatani (1994) and Noji (1994), which dealt with the families of the aged with dementia or the bedridden cared at home.

In order to examine the situation of care by the home caregiver more precisely, main component analysis of family M.B.I. for care was given. The results were shown in Table 3; three factors, which made the sum square of factor loading more than 1.0 and cumulative contribution rate more than 0.52, were extracted. The first factor was related to the items “tired out” and ”worn out”, and was thought to be a factor of ”fatigue” elating to the “emotional exhaustion” shown in family M.B.I. for care by Nakatani[9)]. There were no correlations between the first factor and age of caregiver, period of care, degree of A.D.L. of the patients. The second factor was related to the items of ”I think that my care is useful for the aged” and “I think it is worthy to care”, and was thought to be a factor of “contribution”. The third factor was related to the items of “I feel that I become more insensitive as I care” and “I have been more indifferent to the change of the aged”, and was thought to be corresponded to the factor of ”depersonalization” shown in family M.B.I. for care by Nakatani[9)]. There were no correlations between the fourth factor and caregiver's age, period of care, degree of A.D.L. of the patients.

DISCUSSION

Firstly about the needs of caregiver, they pointed out the need for facility and a system to provide care for them when they became unable to care because of their own physical problem; this is an urgent matter. Secondly they pointed out the need of the knowledge and information about the care of the aged with dementia ; this shows there were difficulties of care in coping with the aged with dementia. The relation to the aged with dementia is not only difficult; but it is said that within the interrelation between the aged with dementia and caregiver, the latter have strong hostile feelings toward the caregiver, and respectfulness and intimacy toward the caregiver are not intensive [8)]. The family class that is held at by the nursing home should keep supporting home caregivers by giving information of the care, and also continue as a place for the family to advise the caregivers on their difficulties and worries. A public health nurse has to take part in care not only for the aged but also for caregiver or family, and has to play a significant role in promoting the better care and welfare system concerning the aged with dementia.

Compared with the studies by Nakatani[9)] (1994) and by Noji[10)] (1994),as shown in results of family M.B.I. for care, the caregivers played their role with the feeling of value in care similarly. The score of ”emotional exhaustion (EE)” was higher and the score of ”poor self-attainment (PA)” was lower. It is thought that this is because to care for the aged with dementia is deeply influenced by the mental state of caregiver because to care for the aged with dementia, and because there were much more difficulties in such care. The main component analysis of family M.B.I. for care showed that the first factor was “fatigue”. From these, it can be said that it was very important to support the families mentally, when a support was given to the families with the aged with dementia. And about 30 percent of the respondents described that ”I think that to care is worthy” and ”It is my role to care”. It is important for nurses to support such families with enough respect for these matters.

Distinctive features of the subject of this study were firstly living in a situation of a community, and secondly receiving day-care service of a special nursing home for the aged. In order to develop this study the future tasks should be taken up such as follows, 1) to assess the effects of the family class for care, 2) to practice the intervention to the support for families, and to examine it for better methods of nursing intervention,3) to put into practice the construction of care system in community for the aged with dementia and to assess its effect.

CONCLUSION

1) Caregiver at home for the aged with dementia were emotionally exhausted, and having poor feeling of self attainment.

2) The hospital and institution were needed in case of emergencies of the aged with dementia and in case of caregiver's difficulties in care giving.

3) Caregivers need the knowledge of proper care and proper attitude toward the aged with dementia these would be taken up as theme at the family class thereafter.

4) The construction of care system for the family of the aged with dementia at home is needed community as the responsibility of each.

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