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A life ability and care experience of the care family of the dementia elderly person who lives at home

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Abstract

The authors clarified quality of life from life ability and care experience of families that had dementia elderly. We discussed on supporting methods for improving their quality of life. We applied simplified family life ability assessment scale, and performed semi-structural interview for their care experience based on the interview guide for the ten families taking care of their at-home dementia elderly. As a result, four categories, which are [Influence on mental health with the care], [Family's lack of care support], [Sense of separateness of the caregiver holds], [Sense of separateness of the caregiver holds] and [Support of the care staff and appearances] have been extracted from the "star type" families. From the "box type" family, [Physical fatigue and mental fatigue with the care], [Uneasiness of the future of the care], [Heavy responsibility for the care of the caregiver], [Care role of the family] and [Care giver's shake of social support utilization] have been extracted. From the "full-moon type" family, [Family life with the dementia elderly person], [Good relation between the person with dementia elderly person and the family members], [Mutual support between the family] and [Family understands social support utilization] have been extracted. 13 categories were extracted. The result suggested that for the care experience according to the life ability pattern of the family who cares at home for a dementia elderly person, It is lacking in the physical health problem of the care family and the care support of the family, and when role allotment is not carried out smoothly the care support system was not set, and a care family felt uneasiness of the future, and the isolated thing that I knew was suggested.

Key words: dementia elderly, family caregiver, life ability, care experience

❖I Introduction

It is estimated that the number of dementia patients in Japan exceeded 5 million patients in 2015 and will reach 7 million patients by 2025[1]. In the community-based integrated care system, it aims to proceed an efficient/prioritized benefits[2], and accomplish the goal in the new orange plan describing as "The plan supports the realization of a society where persons with dementia are able to live in a pleasant and familiar local environment as long as possible while their opinions being respected"[1]. Nursing care may cause a lifestyle change due to an influence on job, housework, social activity, and leisure time[3]. These changes would possibly harm a family health[4]. The preceding studies reported many cases for family nursing care burden, family function[5], and a livelihood support of family caregiver[6~10]. Takami[11] mentioned that family caregivers for dementia patients may suffer a never-ending 24-hour nursing care as physical/metal fatigue or the chaos of family life while Yasuda[12] described a full usage of social resources and change in awareness for the solutions.

In recent years, a family structure has largely been changed due to nuclear family, women's social advancement, and increased divorce rate. It was also pointed out that a way of home care was changed with a decreased family nursing ability[13]. Some researches were conducted for nursing care and family function[14], family system[15], and assessment for ability of family caregiver[16]. Shimauchi et al.[17] defines a family living capacity as "A necessary integration of knowledge, skill, attitude, interpersonal relationship, behavior, and emotion for family healthy life". Some researches were also reported for a family living capacity model such as a hospital discharge support with use of the model[18] and a study on support for male caregiver[19]. However,

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there was no report for examining family living capacity and nursing care condition by targeting nursing family with dementia elderly at home. The study aims to clarify family living capacity and nursing care experience for dementia elderly (care receiver).

Definition of term

Family living capacity in the study means a necessary integration of knowledge, skill, attitude, interpersonal relationship, behavior, and emotion for family healthy life[17]. A nursing care experience will be an experience when providing nursing care to a care receiver[3].

❖II Study method

1. Selection of research subject

As selecting 10 primary caregivers for care receivers living at home, the study was referred to responsible persons working at 5 home-visit nursing stations in Prefecture S.

2. Research contents and data collection

The research was conducted by a questionnaire survey with interview for basic attributes and a simplified assessment scale of family living capacity (family living capacity)[20]. Basic attributes, degree of independence in daily life, and nursing care level for care receiver (dementia elderly) were transferred from the medical record. A semi-structured interview was conducted for nursing care experience on the basis of the interview guidance.

Family living capacity consists of questions from 9 areas 60 items such as health maintenance ability, coping ability for health problem, nursing care ability, utilization ability for social resources, housework ability, role reallocation/complementary ability, relation adjustment/integrating ability, adjustment ability for living environment, management ability for economy/household budget. Achievement rate (%) will be calculated for appropriate scores on the basis of "Quick chart by achievement rate" after adding up scores by each area. It can be categorized into 4 patters (Full-moon type, Box type, Star type, and Fist type) after plotting the fulfillment rates on a radar chart as a form of diagram. "Full moon type" represents an approximately-circular shape with a stable nursing care and a high achievement rate. "Box type" represents two or more paralleled sides as connecting two or more areas with overlapped health problems. "Star type" represents 3 or more acute angles with aggravated health problem. Lastly, "Fist type" represents a small shrunken circular shape with a lower achievement rate[3)21)].

Nursing care experience includes "How a person considers a first symptom and deals with it", "How other family members consider the symptom", "How a cooperation with other family members and their roles are changed", and "What is a current problem" as the interview guidance. We conducted the interview at a designated place requested by a research subject along with his/her consent after having an appointment in advance and explaining the interview time as approximately 60 minutes.

3. Analysis method

The study graphically categorized family living capacity with 4 patterns (Full-moon type, Box type, Star type, and Fist type). The interview data was qualitatively analyzed by the 4 patterns. The study extracted and coded the phenomena describing as nursing care experience according to the literal record. We also summarized codes in subcategory by confirming the meaning of data context. Furthermore, the subcategory's common abstraction levels were arranged and named as categorization. In the main text, the study indicated【】as category, < > as subcategory, " " as data, and ( ) as description. Then, it compared the characteristics of nursing care experience by a family living capacity pattern. In addition, the analysis contents secured face validity with the examination by 4 specialists from the family nursing area.

4. Ethical consideration

We provided oral and written explanation for the study purpose/contents to the research subjects, and a study participation or cooperation was totally decided on a voluntary basis without any advantage/disadvantage by the decision. We carefully handled the personal data to avoid any information leakage by data anonymization and no data usage other than the research. The present study was carried out with an approval from the S University Ethics Review Committee.

❖III Result

1. Summary of the research subjects and care receivers

The research subjects were 10 persons at the age of 48-86. The care receivers were 1 male and 9 females at

the age of 81-95 (Table 1).

2. Category and achievement rate for a family living capacity pattern

Figure 1 shows Average achievement rate of family living capacity in 9 areas by a family living capacity pattern. “Fist type” was not recognized in the Figure. Table 2 shows the achievement rate of family living capacity by the research subject.

3. Nursing care experience by a family living capacity pattern (Table 3)

1) Nursing care experience of “Star type” family

【Influence on mental health by nursing care】consisted of <I feel pain in dealing with dementia> <There is no time for myself because of nursing care>. There were also descriptions as “I have a palpitation because of stress caused by care receiver’s behaviors” and “Because a care receiver looks for me all the time, I do not have time even for hobby and shopping”.【Lack of nursing care support by family members】consisted of <Family members do not understand my symptom> and <Family members do not understand the necessity of nursing care cooperation>. There was a situation of absence of secondary caregiver such as “Nobody sympathizes with me because of no knowledge of dementia” and “People visit me but I can not find a person whom I can ask for nursing care”.【A sense of isolation by caregiver】consisted of <I can not find anyone to replace me for nursing care> and <I feel responsible as a caregiver>. In addition, one person takes responsibility for both nursing care and housework because of lack of understanding by other family members such as “I can not ask for nursing care to other family members due to lack of knowledge for nursing care” and “Nursing care is my duty”.【Support by nursing care staff and public decency】consisted of <Nursing care staff are sympathizers for nursing care> and <I am worried about public decency when utilizing social resources>. Nursing care staff plays an important role as an adviser giving encouragement and concerned expression for caregiver”. On the other hand, caregivers complain that “it is difficult for caregivers to consult with other family members to use social resources as additional care services”.

2) Nursing experience for the family of “Box type”

【Physical and mental exhaustion by nursing care】consisted of <I can not be involved with any social activity due to nursing care> and <No family member understands the hardship of nursing care for dementia>. The research subjects faced a difficult social life as “I can not get out of the house” and “I am late for work”. Then, they started thinking “I am the only one who extremely suffers in such situations” (where other family members were suspicious about the symptom as “Is it really dementia?”)【Future concern for nursing care】consisted of <I am concerned about the requirement of more nursing care in future> and <I have a difficulty to

Table 1. Summary of research subjects

Research subjects	Summary of primary caregiver				Summary of care receiver				Family structure
	Sex	Age	Relation	Occupation status	Sex	Age	Category of care need	Degree of independence in daily life for dementia elderly	
A	Female	48	Son’s spouse	No	Female	89	Level 1	IIa	Son & daughter-in-law, 2 grandchildren
B	Female	62	Son’s spouse	No	Female	91	Level 2	IIa	Son & daughter-in-law
C	Female	75	Wife	Yes	Male	81	Level 2	IIIa	Wife, son & daughter-in-law, and 2 grandchildren
D	Female	52	Daughter	Yes	Female	82	Level 1	IIb	Daughter and 2 grandchildren
E	Female	61	Daughter	Yes	Female	95	Level 1	IIb	Oldest daughter and son-in-law, grandchild in couple, 1 great-grandchild
F	Female	53	Son’s spouse	Yes	Female	87	Level 1	IIb	Son & daughter-in-law, and 1 grandchild
G	Female	61	Son’s spouse	No	Female	85	Level 1	I	Husband
H	Female	60	Daughter	No	Female	86	Level 2	I	Daughter and son-in-law
I	Male	86	Husband	No	Female	86	Level 2	IIb	Husband
J	Male	81	Husband	Yes	Female	81	Level 1	I	Husband

Table 2. Achievement rate by family living capacity's assessment scale index for each research subject

Research subjects	Achievement rate by family living capacity index (%)									Family living capacity pattern
	Health maintenance ability	Coping ability for health problem	Nursing care ability	Utilization ability for social resources	House-work ability	Role reallocation/ complementary ability	Relation adjustment/ integrating ability	Adjustment ability for living environment	Management ability for economy/ household budget	
A	70	100	91.7	100	100	80	100	100	100	Full moon type
B	80	100	83.3	100	100	80	100	100	100	Full moon type
C	75	50	91.7	100	100	80	100	100	100	Box type
D	100	62.5	83.3	100	80	80	40	100	100	Box type
E	70	87.5	100	100	100	100	100	100	100	Full moon type
F	80	62.5	75	60	80	40	20	100	100	Box type
G	60	62.5	75	100	100	60	40	100	100	Box type
H	60	87.5	41.7	100	60	40	20	100	100	Star type
I	70	100	83.3	100	100	80	100	100	100	Full moon type
J	60	75	75	100	100	100	100	100	100	Full moon type
Average achievement rate by index	71.0	78.8	80.0	96.0	92.0	74.0	72.0	100.0	100.0	

Table 3. Characteristics of nursing care experience with a family living capacity pattern

Type	Category	Subcategory
Star type	Influence on mental health by nursing care	Feel pain to deal with dementia No time for myself due to nursing care
	Lack of nursing care support by family members	Family members do not understand my symptom Family members do not understand the necessity of nursing care cooperation
	A sense of isolation by caregiver	I can not find anyone to replace me for nursing care I feel responsible as a caregiver I can not find anyone to replace me for housework
	Support by nursing care staff and public decency	Nursing care staff are sympathizers for nursing care I trust nursing care staff I am worried about public decency when utilizing social resources
Box type	Physical and mental exhaustion by nursing care	I can not be involved with any social activity due to nursing care No family member understands the hardship of nursing care for dementia I am the only person who is exhausted by nursing care and housework Stress can be manageable
	Future concern for nursing care	I am concerned about the requirement of more nursing care in future I have a difficulty to deal with dementia Family members are frustrated by dementia
	A huge burden on caregiver's nursing care	Nursing care is carried out mainly by one person There are some cooperation for housework and nursing care by other family members I do not feel any necessity to discuss nursing care in the family Family members do not want to provide nursing care for dementia I can not ask my daughter-in-law for my spouse's nursing care
	Family roles in nursing care	Nursing care would smoothly be achieved if family members are involved Family members are aware of nursing care for dementia elderly I motivate myself for nursing care
	Emotional swings in utilization of social resources by caregivers	Family members show understanding for utilizing social resources I am concerned about family when utilizing social resources I feel I am assessed by nursing care staff about nursing care
Full moon type	A life with care receiver as a family member	Reviewing a life with care receiver up to the present A desire to live with care receiver I hold care receiver in esteem Consideration to care receiver
	A good relation between care receiver and family	There is a cooperation for nursing care and housework by other family members I consult with other family members for nursing care Family members hold a relationship with care receiver
	Mutual support in the family	Consideration to primary caregiver by other family members Nursing care is mutually understood among family members I can be emotionally strong with assistance from other family members
	Understanding for utilization of social resources by family	I will have time for family by utilizing social resources Family members understand to utilize social resources Existence of nursing care staff becomes a mental support

* *"Dementia elderly" will be described as "Care receiver" in the table.*

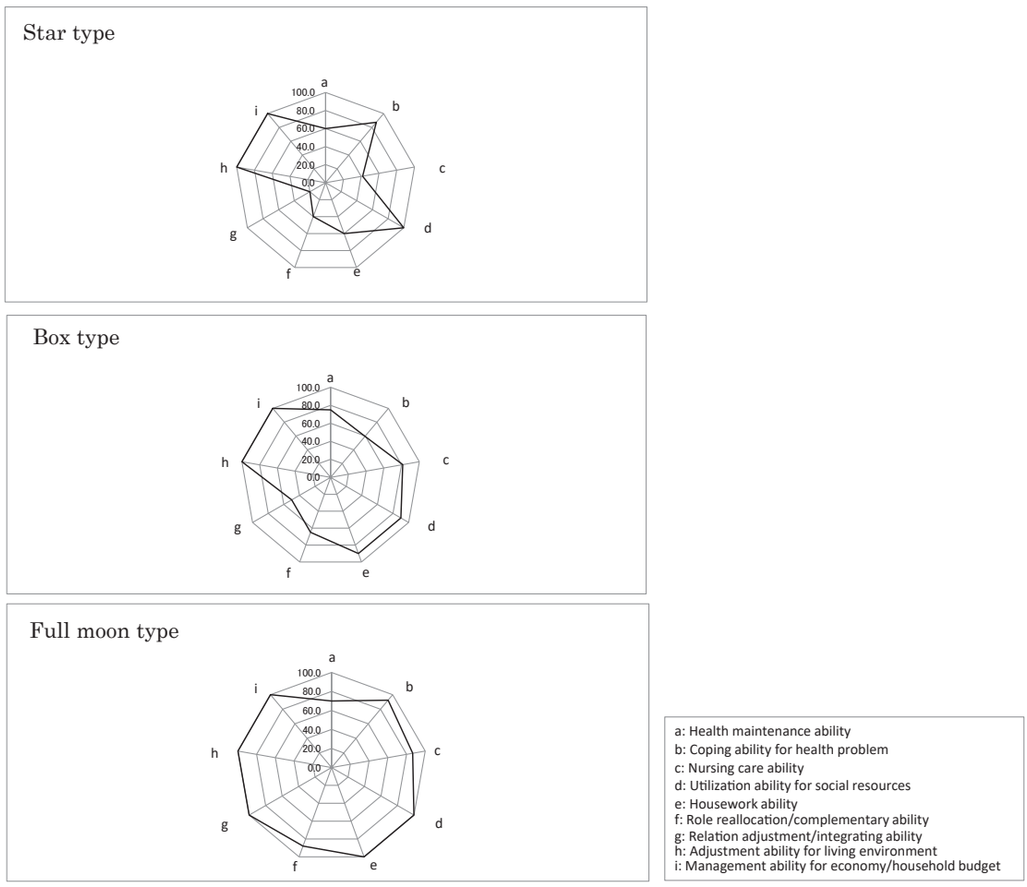

Figure 1. Average achievement rate of family living capacity in 9 areas by a family living capacity pattern

deal with dementia>. The study found a poor mental health for the research subjects when they felt concern and became impatient with specific behaviors by dementia patients such as “Toileting assistance is a difficult task and I do not know what I should do if the frequency of stool is increased” and “Putting a half-eaten food back into a pot and calling a gas company”.【A huge burden on caregiver’s nursing care】consisted of <I do not feel any necessity to discuss nursing care in the family> and <Family members do not want to provide nursing care for dementia>. The research subjects had a helpless feeling as “Family members help me for housework but I solely provide nursing care (as primary caregiver)” and “Family members avoid to see and talk about dementia”.【Family roles in nursing care】consisted of <Family members are aware of nursing care for care receiver> and <Nursing care would smoothly be achieved if family members are involved>. The subjects experienced that nursing care would successfully achieved with assistance from other family members as “Care receiver would obediently accept or take nursing care when a grand child is worried”. The research subjects motivated themselves for daily nursing care by “I (primary caregiver) should be mentally strong as long as I provide nursing care”.【Emotional swings in utilization of social resources by caregivers】consisted of <I am concerned about family when utilizing social resources> and <I feel I am assessed by nursing care staff about nursing care>. The research subjects were facing and providing nursing care with emotional ss as “I am afraid I would be blamed (by other family members) if sending a care receiver to an institution” and “Nursing care staff might think that family members totally leave nursing care tasks to other people or non-family members”.

3) Nursing experience for the family of “Full moon type”

【Care receiver and family life】consisted of <I would like to live with care receiver> and <I hold care receiver in esteem>. The research subjects held care receivers in esteem as a family member and value spend-

ing time with them as "We walk through a life together as leaning on each other" and "I avoid leaving a care receiver alone but I do not provide any help for a thing that a care receiver can do by himself/herself". 【A good relationship between care receiver and family】consisted of <There is a cooperation for nursing care and housework by other family members> and <I consult with other family members for nursing care>. The research subjects recognized sufficient support from "Brothers/sisters or my children living near by will help me" and "I can consult with my husband for nursing care". 【Mutual support in the family】 consisted of <Consideration to primary caregiver by other family members> and <I can be emotionally strong with assistance from other family members>. The research subjects felt "Since a grand child worries about a health condition of caregiver or a medication to take on the day, family members already understand each other by discussion" and "I feel secured because someone will come at the time of emergency". 【Understanding for utilization of social resources by family】 consisted of <I will have time for family by utilizing social resources> and <Family members understand to utilize social resources>. The subjects recognized a good nursing care condition as "Other family members ask me (caregiver) to use social resources for reducing care burden" and "Using a daycare facility helps me to spend more time with family".

❖IV Discussion

1. Characteristics of nursing care experience and life quality for "Star type" family

Star type indicated 【Influence on mental health by nursing care】and physical symptom such as palpitation appeared due to a painful burden by dementia. Caregivers who recognize their own unhealthy conditions may hold a sense of a significant care burden[21]. Mental distress was recognized as an unhealthy condition along with a lower achievement rate of "health maintenance ability" in family living capacity. It was expected to face a difficult situation to maintain a healthy life due to built-up stress of nursing care and a limitation on time for hobby or time to interact with friends. In addition, because the achievement rate for "Nursing care ability", "Housework ability", "Role reallocation/complementary ability", and "Relation adjustment/integrating ability" was lower, it would indicate 【A sense of isolation by caregiver】 due to 【Lack of nursing care support by family members】. When there is no cooperative situation due to no opportunity for discussing nursing care among family member, it would generate an imbalanced role allocation in family and eventually cause a problem in continuation of nursing care. Cooperation from family members and relatives will enhance a continuation of home care[11]. It is important to carry out a flexible role reallocation/complementary ability without forcing specific family members to work for nursing care and housework. While consulting nursing care with trusted-nursing care professionals, family members had an emotional conflict with 【Support by nursing care staff and public decency】 when they desired to increase care services but were concerned with a public decency.

2. Characteristics of nursing care experience and life quality for "Box type" family

Box type includes 【Physical and mental exhaustion by nursing care】. Because family members do not show understanding of physical exhaustion and mental stress caused by a limit of social activity due to hardship in nursing care. Caregivers with a health problem and a higher burden by nursing care may easily cause a limit on work or daily life activity[22]. It was clarified that the achievement rate of "Coping ability for health problem" in family living capacity indicated lower. 【Future concern for nursing care】 was also recognized due to increasing concern for excessive workload of nursing care in future such as toilet support meals. A risk in continuing care was predicted since family members would be confused and frustrated by dementia treatment. Family members also considered that nursing care should be provided mainly by one family member (not depending on daughter-in-law) due to a hesitation by a relation between daughter-in-law and mother-in-law. The study recognized 【A huge burden on caregiver's nursing care】 without a necessity of discussion for nursing care among family members. It was clarified that a cooperative structure for nursing care and housework is insufficient, and an achievement rate for "Role reallocation/complementary ability" and "Relation adjustment/integrating ability" in family living capacity was lower respectively. A caregiver could be encouraged when other family members consider care receive even a little. The importance on family nursing was confirmed with the recognition of 【Family roles in nursing care】 as mentioned previously.

While understanding the utilization of social re-

sources with some hesitation to other family members, caregivers did not want to give a negative impression to nursing care staff as negligence.【Caregiver's emotional swings in utilization of social resources】was recognized for caregivers. Nursing care family can adjust care amount by acquiring social supports, and it is necessary to restructure emotional feelings through self-observation in family members themselves[12]. It was suggested that utilization of social resources would include emotional feelings not only for reduction in nursing care burden but also for a desire to recognize a heavy responsibility in nursing care practice.

3. Characteristics of nursing care experience and life quality for "Full moon type" family

It was recognized that the achievement rate was over 80% in 8 areas except "Health maintenance ability" of family living capacity. Labor and mental support in a family role allocation could provide time/pleasure to family and eventually lead to continuation of nursing care[20]. By focusing on and reviewing for【A life with care receiver as a family member】, it would pay a regard to such existence and contribute to form a good relationship between care receiver and family. Family members would foster respectful spirits or favors in daily life and such emotional affinity may possibly lead to continuation of nursing care[23].【A good relationship between care receiver and family】became【Mutual support in the family】. It seems that mutual understanding in family holds a strong emotion as spending time together or helping each other in nursing care. This would lead to consideration to caregiver's mind and provide an actual feeling to live together through daily nursing care. Social resources tend to be utilized more in case of a high burden on nursing care[15], but even a care receiver with mild disability in our study had a favorable nursing care environment with【Understanding for utilization of social resources by family】for reducing a nursing care burden and securing time for family. It was suggested that a fulfillment of cooperative activity for nursing care and housework generates an affluent life, and caregivers also hold a sense of satisfaction with nursing care under such circumstance. Although the degree of independence in daily life was lower in Full moon type compared to other types, the achievement rate for family living capacity was higher due to the nursing care practice by family.

❖V Conclusion

From a viewpoint of nursing care experience by family living capacity pattern for dementia elderly at home, it was suggested that a nursing care support system would not be properly arranged and family members may feel uncertainty or even isolation in future when physical health issue for nursing family, lack of nursing care by family, and role allocation are not smoothly solved. For maintaining a home-care life, it will be important to have supports as teaching a family health maintenance/dementia care, adjusting a role allocation of nursing care and housework by carefully determining a relationship among the family members, and encouraging cooperation by individual family member.

❖VI Conclusion and limitation for the present study

The study targeted 10 family cases living with dementia elderly. When using a family living capacity model with these cases, there would be a limitation to comprehend an entire family only by an interview with one family member. Moreover, it may be difficult to generalize suggestions from the research with only one case of Star type in family living capacity. Thus, it is necessary to make a further examination by considering those issues and expanding research subjects in future.

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