

Family Strength Caring for the Elderly with Dementia: Engagements and Relationship Changes of Family Members

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Abstract

This study aims at clarifying engagements and relationship changes between people with dementia and their family caregivers to address psychosocial supports using family strength. Focus group interviews were used. Participants were 10 caregivers for people with dementia at home. Data was extracted concerning the relationship changes between family members and people with dementia.

As a result, five major categories were extracted from the relationship data: Emotional Involvements, ADL Support, Alternation of Caregivers, Supports for Specific Circumstances and Supportive Circumstance. Five major categories were extracted from the relationship changes data and divided into positive (Finding New Family Ties, Reconstruction of Life and Meeting New People) and negative (Changes of Life-Style, Change of life Designs) aspects.

Key words : strength, dementia, family relationship, caregivers

Introduction

Caring for elderly people with dementia requires a higher physical and psychological burden than that for those with other illnesses because of behavioral problems based on the deterioration of dementia. However, quite a large number of families continue offering care despite harsh circumstances. Clarifying what supports those families will contribute to offering high quality care-giving for elderly people with dementia and to improving quality of life for both caregivers and care-receivers. Adequate supports to enrich family strength will not only influence families' functional repairing but also maintain health status and

prevent deterioration of health status of both caregivers and care-receivers.

Stinnett *et al.*¹⁾ has established the Family Strength Scale with 47 items concerning family strength. Freidman²⁾ addressed family strength and lists communication skills, capacity for sharing strategies towards dealing with problems, supports within family members, self-care abilities and problem solving abilities as structural concepts of it.

Olson³⁾ established the Family Adaptability and Cohesion Scale as a family function scale and evaluated family function with the second dimension as Cohesion and Adaptability. Tachiki⁴⁾ has established the Family Adaptability and Cohesion Evaluation

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Table 1 Participant profiles

ID	Sex	Age (Y)	Family members living with	Duration of care-giving (Y)	Care-receiver's relationship	Care-receiver's Age(Y), ADL level, Problems
A	F	65	Husband, A daughter	3	Mother-in-law	90, totally dependent
B	F	56	Husband, A daughter, a son	7	Her mother	82, totally dependent
C	F	62	Son's family	3	Her father	85, wanders around
D	F	71	A daughter, a son	5	Her husband	75
E	M	73	Daughter's family	6	Wife	86, talks to oneself
F	F	66	Husband	2	Mother-in-law	86, lashes out
G	M	58	A daughter	3	Wife	61, sometimes delusional
H	F	62	Son's family	3	Her mother	85, totally dependent
I	M	60	Wife	5	His mother	82, totally dependent, lashes out against the caregiver
J	M	70	No one	5	Wife	71

Scale Kansai Gakuin to the Japanese family context based on Olson's Circumflex Model of Marital and Family Systems. He evaluated family functions from communication aspects such as cohesion(family ties) and adaptation(strength structure towards stress and roles).

In the nursing field, Feeley⁵⁾ identified that the family is capable of overcoming various life events and can grow. Furthermore, he advocated that family strength is identifying, providing, developing and calling forth strength. In Japan, Asano⁶⁾ interviewed families whose family members had developmental disabilities. She suggested that nursing intervention would enhance communication among family members to improve family strength based on results that families had enough abilities for self-care such as observing children and maintaining their health status, although some couples had inconsistent cognition for children's disabilities. However, few studies have addressed family strength especially families who took care of elderly family members. Understanding family strength focusing on families offering cares for elderly family members with dementia will contribute to establish support systems for families living with elderly people with dementia. Thus, the purpose of this study was clarifying engagements in caring and

relationship changes between elders with dementia and their family members to address family strength concerning family caregivers for elders with dementia.

Methods

Participants

Participants were 10 caregivers who took care of their family members with dementia at home and belonged to the group 'people with dementia and family members'. They were chosen as participants after consenting to this study.

Data collection

Focus Group Interview(FGI)(Flick⁷⁾ was used in a public place. The targeted subjects were 1) caring circumstances, 2) family member engagement in caring, 3) family relationship changes. The interviews were recorded and started with a self-introduction. Participants were encouraged to talk freely. The author intervened only when participants were off the targeted subjects and it took approximately two hours for an interview.

Data Analysis

Audio data was converted into text files. Meaningful

Table 2 Categories: Family member engagement in caring

Categories	Subcategories	Extracted codes
Emotional Involvements	Emotional Attitudes	<ul style="list-style-type: none"> • unconsciously raises voice and shouts • understands problems but difficult to control anger • harsh with demanding tone
	Negative Emotions	<ul style="list-style-type: none"> • avoid exposure the care-receiver to neighbors • siblings never admit the care-receiver with dementia
	Sympathy	<ul style="list-style-type: none"> • helps with everything because of sympathy towards the care-receiver • intervenes with everything even though the care-receiver is able
ADL Supports	Helping Care-receiver's Self-care	<ul style="list-style-type: none"> • cleans up care-receiver's toilet mess • sleeps beside the care-receiver • helps with bathing
	Supports for Independence	<ul style="list-style-type: none"> • maintains the care-receiver's current abilities • tries not to intervene with the things which the care-receiver is able to do • maintaining independence is good rehabilitation
Alternation of Caregivers	Occasional Cooperation	<ul style="list-style-type: none"> • relieve the caregiver if ill and help with housekeeping • relieve the caregiver when out and help with housekeeping • accompany the caregiver to see a doctor
	Regular Cooperation	<ul style="list-style-type: none"> • daughter becomes relief caregiver for 4 days twice a year • help caring once a month
Supports for Specific Circumstances	Illness Control	<ul style="list-style-type: none"> • stoma management • diabetic meal preparation and help • medicine management
	Fall Prevention	<ul style="list-style-type: none"> • pay attention for falls from steps • guide to walk slowly • pay attention for falls to avoid being bedridden
Supportive Circumstance	Providing Information	<ul style="list-style-type: none"> • bring information from city halls • offer information from neighboring caregivers • offer information from internet
	Encouragements	<ul style="list-style-type: none"> • I am able to do my best as a caregiver with daughter's encouragement • alert oneself to burnout • show worries towards the caregiver when she/he is not in good shape
	Consultation	<ul style="list-style-type: none"> • give advice concerning care-giving • listen anytime to the care-receiver's complaints and worries • talk freely about care-giving

sentences were extracted and coded, and then, each code was compared to the context and categorized.

Ethical consideration

This research protocol was reviewed and approved by the Research Ethics Committee of Saitama Prefectural University (No.21036).

RESULTS

Participant profiles

Table 1 shows the participant profiles. They were 4 men and 6 women, and the average age was 64.3 (range 56-73) years old. Four of them did their own parents, two did parents-in-law and four took care of

their spouses. The average care-giving length was 4.2 years.

Family member engagement in caring

Table 2 shows the categories for the theme 'family member engagement in caring'. Five major categories and 12 subcategories were extracted. The following signs were used: major categories [], subcategories < > and extracted codes [].

【Emotional Involvements】 was composed of 3 subcategories. Five of the participants recounted <Emotional Attitudes>.

Mr. I: I understand that my mother is ill but I unconsciously respond [acridly with demanding tone because she repeatedly asks the same

thing over and over again.

Three of them talked about 〈Negative Emotions〉.

Mrs.F: [Siblings never admit the care-receiver with dementia] and she says that she can't be helped because of aging. She will be shocked if she admit her mother with dementia.

Four of them talked about 〈Sympathy〉.

Mrs.A: Sister-in-law [helps with everything because of sympathy] towards mother-in-law and [intervenes with everything even though she is able] when the mother stays at sister-in-law's house. So, it is really difficult to take care of herself after coming back to the mother's house because she forgets what she has learned.

The category [ADL Supports] was composed of 2 subcategories. Nine of them recounted 〈Helping Care-receivers' Self-care〉.

Mrs.H: My husband has plenty of time after his retirement, so he [cleans up his mother's toilet mess] and helps cleaning the toilet even around midnight. So, he helps me. He might feel care-giving is a hard job for me.

Four of them talked about 〈Supports for Independence〉.

Mrs.B: [Try not to intervene with the things which mother is able to do] otherwise; elderly people can easily lose abilities for self-care. My Children try to do the same.

Mrs.D: My mother is still capable of doing a lot of things. I try to [maintain her current abilities] during walking and exercising together.

The category [Alternation of Caregivers] was composed of 2 subcategories. Four of them talked about 〈Occasional Cooperation〉.

Mrs.C: My daughter usually isn't interested in care-giving but she [relieved me when I was ill and helped housekeeping]. I believe my daughter is reliable when something happens.

Two of them talked about 〈Regular Cooperation〉.

Mr.J: My son lives far away but he [helps caring once a month].

The category [Support for Specific Circumstances] was composed of 2 subcategories. Two of them were

recounted 〈Illness Control〉.

Mr.G: The category [Medicine management] is very important for a diabetic patient, so I should not forget giving medicine 10 minutes before meals.

Mrs.H: I ask my husband for [diabetic meal preparation and help] when I am out and late for meals.

Eight of them talked about 〈Fall Prevention〉.

Mr.E: I have to [pay attention for falls from steps] because my wife fell about twice when I didn't pay attention to her. But I was relieved that she didn't fracture anything.

The category [Supportive Circumstance] was composed of 3 subcategories. Four of them were recounted 〈Providing Information〉.

Mrs.B: My son sometimes [brings information] from a variety of sources and says that you have to read them.

Three of them talked about 〈Encouragements〉.

Mrs.A: Siblings encourage me to do my best but not work so hard because they know me very well. So, I [alert myself about burnout].

Five of them talked about 〈Consultation〉.

Mr.E: My daughter [gives advice concerning care-giving] because she is working in a nursing home and I have tried to take her advice but failed many times.

Family relationship changes

Table 3 shows the categories for the theme 'family relationship changes'. Five major categories and 11 subcategories were extracted.

The category [Finding New Family Ties] was composed of 2 subcategories. Nine of them were recounted 〈Deepened Family Ties〉.

Mrs.B: I haven't had enough time to talk to my children and didn't share common topics but we did to [have common topics] concerning caring after starting taking care of my mother.

Mrs.F: My husband currently [shares the housekeeping] even though he has never helped doing it. We have time to talk and I've got to know him again.

Three of them talked about 〈Emotional Changes

Table 3 Categories: Family relationship changes

Categories	Subcategories	Extracted codes
Finding New Family Ties	Deepened Family Ties	<ul style="list-style-type: none"> • family members show appreciation • realize family members can help when problems happen • share the housekeeping • family members help with housekeeping after their own duties • talk future life with family members • have common topics
	Emotional Changes towards Others	<ul style="list-style-type: none"> • naturally become kind towards other elderly people • show gentle attitudes toward others • naturally show appreciation toward own husband
Changes of Life -Style	Unable to Enjoy Life	<ul style="list-style-type: none"> • less opportunities for eating out • always think about care – receiver’s diaper • no time to go out for pursuable purposes
	Changes of Sleep Pattern and Quality	<ul style="list-style-type: none"> • easily wakes up from a small noise • unable to sleep because of worries about care-receiver’s diaper • lack of sleep satisfaction • always sleepy
Reconstruction of Life	Reviewing Life	<ul style="list-style-type: none"> • have to do something about current life • unable to continue current life • work hard to gain back to the previous life
	Obtaining New Roles	<ul style="list-style-type: none"> • obtain new qualifications with one’s spouse • newly engage in housekeeping after retirement • take care of others for the first time
	Changes of Diet	<ul style="list-style-type: none"> • main family diet was changed to vegetables • take soft foods
Changes of Life Designs	Unexpected Life Changes in Old Age	<ul style="list-style-type: none"> • unable to travel with one’s spouse and enjoy one’s life • unable to engage in one’s hobbies • unable to spend one’s life peacefully • care-giving is an unexpected role
	Anxiety for One’s Future	<ul style="list-style-type: none"> • wonders how long I am able to continue this life • wonders what will happen in own life
Meeting New People	Collecting Information from Others	<ul style="list-style-type: none"> • family members collect information from various people • obtain information from experts
	Meeting People with Same Circumstances	<ul style="list-style-type: none"> • meeting others with same problems • consult worries about care-giving • join family support organizations

towards Others).

Mrs.C: My children used to be delinquent when they were teenagers but they now [show gentle attitudes toward others] after their father’s dementia.

The category [Changes of Life Style] was composed of 2 subcategories. Three of them recounted (Unable to Enjoy Life).

Mrs.A: I used to eat out with my family members when mother-in-law was healthy. But she is not capable of staying alone. We have [less opportunities for eating out]. I feel like I’m losing my pleasurable time.

Four of them talked about (Changes of Sleep Pattern

and Quality).

Mr.I: I [easily wake up from a small noise] and I worry if something has happened to my mother and unable to go back to sleep after that.

The category [Reconstruction of Life] was composed of 3 subcategories. Two of them recounted (Reviewing Life).

Mrs.D: I feel like I’m [unable to continue current life] and feel burnout unless increasing opportunities to use welfare services.

Four of them talked about (Obtaining New Roles).

Mrs.H: I [obtained new qualifications with my husband] to help each other when one of us

becomes ill in the future. Our motivation towards the new qualifications was due to my mother.

Four of them talked about 〈Changes of Diet〉.

Mr.E: I used to take meat when I was younger, but [main family diet was changed to vegetables] because of health consciousness.

The category 【Changes of Life Designs】 was composed of 2 subcategories. Eight of them recounted 〈Unexpected Life Changes in Old Age〉.

Mrs.H: I dreamed about traveling with my husband after his retirement and living peacefully but I am [unable to travel with my husband and enjoy my life] because I have to take care of my mother unexpectedly.

Four of them talked about 〈Anxiety for One's Future〉.

Mr.J: I am not young anymore and my children live far away and I have to take care of my wife. I become anxious and [wonder how long I am able to continue this life].

【Meeting New People】 was composed of 2 subcategories. Nine of them recounted 〈Collecting Information from Others〉.

Mrs.B: All [family members collected information from various people] after starting to take care of my mother-in-law.

All participants talked about 〈Meeting People with Same Circumstances〉.

Mr.G: My daughter got information about a family support organization via internet. I joined it and I like [meeting others with the same problems]. The meeting eased my daughter's burden because she shares similar circumstances.

DISCUSSION

Family member engagement in caring

Cognitive functions are steadily deteriorating among elderly people with dementia. Thus, family members sometimes are unable to control emotional attitudes when they encounter wandering around, lashing out and behavioral problems among care-receivers. Noguchi⁸⁾ pointed out that caregivers who are inexperienced and taking care of people with various

behavioral problems due to dementia tend to emotionally deal with the circumstances. It is suggested that family members show emotional attitudes during care-giving when their thoughts are not understood by care-receivers and their stress levels due to when the care-giving burden reaches capacity limits.

Data in this study reflected that family members resided with caregivers and care-receivers saw caring daily and had opportunities to engage in self-care related supports. Thus, it was suggested that they tended to help caregivers not to collapse family life due to their burnout. Family members' engagements in self-care will contribute to a decrease in main caregivers' caring burdens. Family members will understand objectively the care-receivers circumstances through direct contact with care-receivers. However, other family members not living with caregivers and care-receives, especially care-receivers' children, showed merely sympathy and negative emotions. The results from this study corresponded with Watanabe's conclusions⁹⁾ pointed that guilty feelings of unable to offer caring among family members not resided with care-receives drove them to intervene in things which the care-receivers were able to do.

It is important that family relationships be supportive as Niina *et al.*¹⁰⁾ pointed out that positive emotional supports such as consultation and encouragements from family members eased relationship burden. There is a necessity that family relationships be supportive to make caring experiences fruitful for family members.

Family relationship changes through care-giving

This study brought both positive and negative aspects concerning family relationship changes through care-giving. Positive aspects reflected chances which enhanced deepening family ties and positive emotional changes towards others through caring. It is said that originally Japanese families increased their sense of belonging and dealt with problems together against disruptions and obstacles. Thus, it is suggested that participants deepen their family ties by dealing with the issues.

Three men among the four of the participants in this study experienced gender-related role changes when their wives became ill. It meant obtaining new roles

for them by engaging in housekeeping and caring for family members instead of their wives. Their new experiences sometimes increased the care burden, however, they rediscovered the meaning of life through caring and had achievements. Moreover, their new experiences guided them to an integrative phase which is the developmental task for aged people.

Participants experienced establishing new relationships with others, especially; meeting people under the same circumstances who encouraged them. It is suggested that gathering information concerning caring and discussing solutions enhanced communication between family members and deepened their family ties.

Meanwhile, negative aspects were revealed in this study. It was clarified that participants sacrificed their free time and 24 hours caring, so they were unable to enjoy life and complained about changes of sleep pattern and quality. Those changes of life style differ from families based on the care-receivers' dependant status, however, most families experienced those changes. Continuation of poor sleep caused dysfunction of thinking and depression. It was also clarified that participants experienced unexpected life changes in old age due to caring and had anxiety for one's future because of unforeseen care burden.

Conclusion

Five major categories were extracted concerning engagements in caring among family members: Emotional Involvements, ADL Support, Alternation of Caregivers, Supports for Specific Circumstances and Supportive Circumstance. Five major categories were extracted concerning family relationship changes. They were divided into positive aspects (Finding New Family Ties, Reconstruction of Life and Meeting New People) and negative aspects (Changes of Life-Style, Change of Life Designs).

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要 旨

この研究は、家族の強みを活かした心理・社会的サポートを行うために認知症の人との家族の関わりと家族の変化について明らかにした。対象者は在宅で認知症高齢者を介護している介護者 10 名にフォーカスグループインタビューを行った。データは家族の関わりと家族の変化に関するものを抽出した。

結果、情緒的関わり、日常生活の支援、介護の交替、療養支援、支えとしての存在の 5 つのカテゴリが抽出された。家族の変化では、5 つのカテゴリが抽出され、肯定的なカテゴリ（新しい家族の発見、生活リズムの変化、新しい人との出会い）、否定的なカテゴリ（生活の再構成、人生設計の変更）に分類された。