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The Experience of Husband Caring for Wife with Early-Onset DEMENTIA

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Abstract

Purpose: *Recently, Korea's rapid increase in the elderly population and the prevalence of dementia have emerged as a serious social problem due to the world's fastest aging population. Moreover, as the number of dementia patients is increasing rapidly among people in their 30s and 50s, interest in early onset dementia and the burden of caregivers for dementia patients are increasing.*

Method: *Participants in this study were 7 spouses who have been taking care of early onset dementia wives who was diagnosed with dementia before the age of 65 for more than one year. Data were collected through in-depth interviews and analyzed using the grounded theory method suggested by Strauss and Corbin(1998).*

Results: *The experience of going through process of husbands caring for early-onset dementia wives proceeds through four stages of 'recognizing the change', 'denying', 'trying', and 'accepting', and the core category is 'accepting the wife's dementia. Types of accepting dementia were classified into three types: 'active coping type', 'accommodative type', and 'helpless type'.*

Conclusion: *Through this research, the characteristics of early-onset dementia patients were understood, the theoretical basis for the caring process was established, and the importance of professional education and active promotion on early dementia was suggested for early detection and accurate diagnosis of diseases. Also, this study is expected to be a good foundation for the development of specialized programs that consider the characteristics of early onset dementia, establishment of nursing strategies and national support system.*

[Keywords] ***Dementia, Early-Onset Dementia, Experience, Husband, Grounded Theory***

1. Necessity and Purpose of Research

In Korea, where the elderly population is rapidly increasing, elderly diseases are becoming a social issue. Moreover, as news reports that the number of dementia patients among people in their 30s and 50s is increasing rapidly, interest in early onset dementia[1] is increasing.
Dementia is a syndrome that impairs overall brain functions such as memory, mental ability, thinking ability, learning ability, and judgment[2]. Although age is not an important criterion for diagnosing dementia, dementia has been generally considered to be predominantly occurring in the age group over 65.

Early-onset dementia is occurs before the onset age of 65 years and it is not easy to obtain an accurate diagnosis and implies the possibility of receiving several different diagnoses[3]. Misdiagnosis is also common, and 30% to 50% of early onset dementia patients are reported as misdiagnosis[4]. Also, it is common to apply the same diagnostic criteria for senile dementia and early-onset dementia even though differences in clinical symptoms have been identified [5].

Moreover, the diagnosis of early onset dementia is much more diverse than that of senile dementia and the symptoms of remarkable cognitive dysfunction except memory deterioration, convulsive major failure paralysis, convulsions, and myoclonic muscle spasms appear, along with neuropsychiatric features beyond cognitive impairment[6]. Therefore, since accurate diagnosis is very important in the management of not only the patient's plan but also the family's caring for the patient, an accurate diagnosis of early onset dementia is necessary.

Dementia is a representative chronic progressive disease that causes a severe psychological, physical, and economic burden on the patient as well as his family[7]. Just as the caregivers of elderly dementia patients, it is reported that even the caregivers of early-onset dementia patients, it is a difficult task that gives physical and emotional burden. In a study comparing the caregivers of patients with early-onset dementia and elderly dementia[8], caregivers of early-onset dementia patients had a higher burden.

A large number of studies on the experience of taking care of dementia patient have mainly been conducted on female caregivers such as daughter-in-law and daughter[9][10][11][12], recently, a study on the husband's caring experience of dementia in elderly couples[13], a phenomenological study on the caring experience of husbands caring for a spouses with presenile dementia[13][14] and other research on husband's caregivers are also being conducted. However, these are studies that suggest approaches and policy alternatives in the aspect of social welfare, and to provide effective nursing intervention for them, an approach is needed in the nursing aspect.

There have been many studies related to dementia in Korea, but most of them focused on the age group of 65 or older, and it is no exaggeration to say that there has been little research done on early onset dementia.

Therefore, in order to inductively derive the nature and variables of the care experience of early-onset dementia patients based on the experiences of the subjects, this study intends to develop a substantive theory by conducting the grounded theory research method, one of the qualitative research methods, the research question for this is 'What is the empirical structure of the caring process of a husband with an early onset dementia?'

2. Research Method

This study is a qualitative study to derive substance theory from data obtained through in-depth interviews with husbands caring for early-onset dementia wives with dementia before age 65 by applying Strauss & Corbin's(1998) grounded theory method.

2.1. Research design

This study is a descriptive survey research in order to analyze the perception on dementia, the use of care services, and the demand & satisfaction for the dementia works.

2.2. Data collection

2.2.1. Selection of research participants

Participants in this study are those who have been introduced and accessible by the researcher as the subjects of the study, but among spouses who have been caring for early onset dementia wives diagnosed with dementia before the age of 65 for more than one year, those who could communicate and have in-depth interviews were selected as participants in this study. Most of the participants' spouses were being treated at the hospital's mental health or neurology department, and only one of them was using the dementia support center.

2.2.2. Method and period of data collection

The data collection period of this study was conducted for a total of 6 months from November

2012 to May 2013, and interviews were conducted over 1~2 rounds. Prior to the interview, after calling in advance and confirming the availability of the interview, the one-on-one personal interview method was implemented for the person who agreed to the interview on the possible date. An interview took about 2 to 2 hours and 30 minutes, and with the consent of the patient, the contents of the interview were recorded, using a portable recorder. The contents of the interviews with 7 participants were directly transcribed on a computer after the researcher listened. The part that was not clear or considered insufficient at the time of the interview was confirmed through supplementary questions at the time of the additional interview, and analyzed together with the on-site note, and the interview was conducted until the saturation was reached where new contents were no longer coming out from the participants.

2.2.3. Research questions

Specific research questions were different depending on the communication method with the participants, but examples of semi-structured questions are as follows.

'How long has your wife been diagnosed with dementia?'
'How did you find out that your wife had dementia?'
'How did you feel when you heard the story of dementia?'
'What are the symptoms of dementia that your wife shows?'
'How do you cope with your wife's behavior?'
'What has changed from taking care of your wife?'
'What are the challenges of taking care of your wife?'
'What do you think is necessary to take care of your wife?'
'What are your plans for the future?'

2.3. Ethical consideration of research

In order to protect the subjects, this study was conducted after deliberation and approval by the research subject protection review committee of the university to which the researcher belongs(IRB approval number: HYI-12-040-Supplementary3). The purpose of the study, the method of proceeding, and the method of use were explained to all participants in the study, and consent was asked to record the interview contents. Since this study guarantees anonymity and confidentiality, it was explained that the interviewed data should be discarded after the study is completed.

Consent was obtained in writing, including that it is also possible to withdraw participation during the study if not desired.

2.4. Data analysis

The collected data was analyzed by continuously and systematically conducting comparisons and questions. The analysis was conducted cyclically with data collection, and the procedure followed the methods of open coding, axis coding, and selective coding suggested by Strauss and Corbin(1998).

3. Results

3.1. General characteristics of participants

The general characteristics of the subjects participating in this study are as follows <Table 1>. Participants' age ranged from 59 to 64, and the period of support was from 1 to 7 years. Participants' wives' onset of dementia ranged from 54 to 61 years, diagnosed in 5 patients with Alzheimer's Disease(AD) and 2 patients with Frontotemporal Dementia(FTD). As for the family living together, two people lived only with their spouses, and five also lived with their children.

Before being diagnosed with dementia, participants' wives ran a restaurant, represented a clothing company, worked as a cook at a school, worked as an office worker, and operated a beauty salon and shop and most of the participants' wives had jobs and were active in social activities.

Table 1. General characteristics of research participants.

Participants	Age	Education level	Period of support	The age at which dementia occurred	Diagnosis	Status of cohabitation with family	Previous job	Economic level
1	59	College graduate	5 years	54	Alzheimer's disease	With wife and one daughter	Clothing company representative	Upper-intermediate
2	61	High school graduate	3years	55	Frontotemporal dementia	With wife and one son	a cook at a school	Intermediate
3	64	College graduate	1years	61	Frontotemporal dementia	With wife and one daughter and one son	Restaurant operation	Upper-intermediate
4	64	Middle school graduate	4years	60	Alzheimer's disease	With wife	Beauty salon operation	Low
5	60	High school graduate	6years	60	Alzheimer's disease	With wife and two daughters	Store operation	Low-intermediate
6	61	High school graduate	3years	57	Alzheimer's disease	With wife and one daughter and two sons	Housewife	Low
7	64	High school graduate	7years	57	Alzheimer's disease	With wife	Office worker	Low-intermediate

3.2. Open coding

In the open coding process, concept extraction and categorization were performed through analysis of the original data. In this process, 102 concepts were created, and 36 subcategories were created by grouping each concept into the same context, and then reorganized into 15 categories <Table 2>. The categories created through open coding are ‘Unaware', ‘Deny’, 'State before the onset', 'Social perception', 'couple relationships', 'Disappearance of hope', 'Support system', 'clearing the mind', 'adapting to the reality',' barely holding on','going through the situation', 'Trying to find hope', 'becoming a meaning of life', 'Becoming exhausted', and 'feeling sad'.

Table 2. Categorization of base data.

Paradigm element	Category	Subcategory	Concept
Causal condition	Unaware	Cannot recognize	There was no problem
			People around the subject noticed first

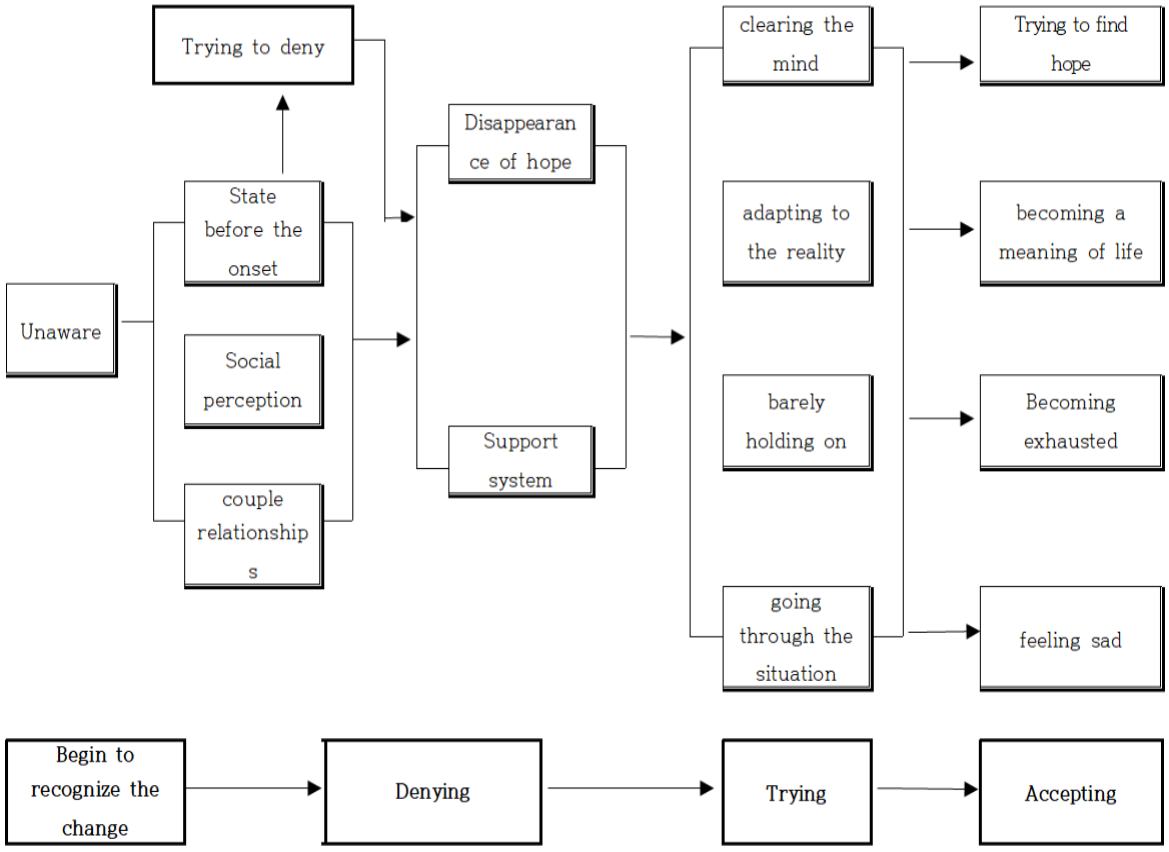
		Not considering it serious	Blamed the regular medicine
			Considering changes in wife as no big deal
		Experience of sudden change	Occurrence of problems with wife's work life
			Experience the sudden abnormal behavior of wife
			Noticing the difference in wife's behavior
Actual state	Rying to deny	Difficulty in diagnosis	Gotten a contradictory diagnosis
			Diagnosed with depression
			Late visit to hospital
			Diagnosis of dementia given late after highly proceeded
		The situation that makes no sense	Unthinkable wife's illness
			Collapsed in shock
			No reason to get sick
		Shopping of hospital services	Moving around hospitals
			Visiting famous hospitals
		Denial of reality	Regarded as just sick
			Considered just temporary problem
			Blaming the God
			Feeling lost
Context	State before the onset	Degree of social activity	The wife who used to be smart
			The wife whose social position used to be high
		Usual personality	Bright and cheerful personality
			Quiet and introverted personality
	Social perception	Geriatric disease	The disease for the elderly
		Negative perception	The disease worse than cancer
			Psychosis
			Incurable disease without cure
	couple relationships	The degree of attachment between couples	Wife is mine
			The affection of a couple
Intervention	Disappearance of hope	Finding other treatment options	Receiving oriental medicine treatment
			Receiving the laying on hands
			Doing an exorcism
			Praying at a temple
			Moving parents grave
			Doing every good thing
		Rapid progression of the disease	Sudden decline in memory
			Decreased concentration
			Disorientation
			Getting worse every year
		No more solution	Effort has been in vain
			No more way to do
	Support system	Lack of information	The only information was from doctors
		Social isolation	No one to open up
			The relationships around become estranged

			Avoiding friends meeting
		Nowhere to go	No facilities to go
Action/ interaction	Clearing the mind	Emptying the mind	Abandoning pride and face
			Changing the mind
			Shifting the ground
			Accepting as the destiny given to me
			Thinking that it came a little faster than others
		Guilty conscience	All this is my responsibility
			Punishment for my sins
			Sorry for not being good to wife
	Adapting to the reality	Wife-centered life	Determination to do my best
			Focusing on wife's health
			Daily life that everything is tailored to wife
		Adding roles	Learning to housekeeping
			Dedicated to what wife was doing
			Taking the place of mother
		Undertaking	Quitting work
			Taking care of wife alone
	Barely holding on	wanting to hide	Feeling like falling to the floor in one moment
			Fear to be honest to tell
		worry about children	Worry about the possibility of passing on to the children
			Worry about the possibility of being an obstacle to children's marriage
		Hardship	No control of behavior
			Difficulty in communication
			Feeling like he will have dementia too
			Repression of emotions dozens and hundreds of times a day
			Economic difficulty
		Fear	The speed of the disease too fast
			Fear that the wife forgets one by one
			Fear to be left alone
			Start of writing a diary
			Remingding children to do well when they can
	Going through the situation	Finding a way	Sending to a nursing hospital
			Request for a care worker
			kindness to those around
			Getting help from a friend or neighbors
		Encouraging my energy	Paying attention to health management
			Taking time for me
Result	Finding hope	Expectation	really want to heal
			Looking forward to the development of new drugs
			Comforting not being alone
	Becoming a meaning of life	Being the reason I live	A life that wife became everything
			wanting to let go but not being able to let go
			wanting to go back to those difficult times
		Gratitude	Satisfied with current status

		Rather feeling grateful that I can take care of wife
	Hoping it goes slowly	Hope it goes slowly
		Hope to keep this state as it is
Becoming exhausted	Reaching the limit	Body is destroyed
		Death impulse
		barely endured while doing just this much
	Inability to control himself	Just living without a plan
		The vague future make him feel more and more difficult
		Not lingering in life
Feeling sad	Pognant sadness	Heartbroken for being still young
		Tears pouring out just by thinking
		Sorry for not being able to heal it

3.1.3. Conceptual framework

Figure 1. Conceptual framework of a husband's "accepting to the wife's dementia" who cares for a wife with early onset dementia.



3.1.4. Analysis of the type of 'accepting wife's dementia'

In this study, the types of "accepting the wife's dementia" of husbands caring for early-onset dementia wives were identified in three types: active coping type, accommodative type, and helpless type <Table 3>.

Table 3. Types of 'accepting wife's dementia'.

	Active confrontation	Accommodative type	Helpless type
Causal condition	Not finding out(strong)	Not finding out(strong)	Not finding out(strong)
Core category	Receiving dementia (active, positive)	Receiving dementia (inactive, positive)	Receiving dementia (inactive, negative)
Contextual condition	State before onset(good) Social perception(negative) Couple relationships(strong)	State before onset(good) Social perception(negative) Couple relationships(strong)	State before onset(good) Social perception(negative) Couple relationships(weak)
Interventional condition	Disappearance of hope(weak) Support system(wide)	Disappearance of hope(strong) Support system(narrow)	Disappearance of hope(strong) Support system(narrow)
Action/ interaction strategy	Clearing the mind(active) Adapting to the reality(active) Barely holding on(weak) Going through the situation (active)	Clearing the mind(active) Adapting to the reality(active) Barely holding on(weak) Going through the situation (inactive)	Clearing the mind(inactive) Adapting to the reality(inactive) Barely holding on(strong) Going through the situation (inactive)
Result	Trying to find hope(strong) Becoming a meaning of life(strong) Becoming exhausted(weak) Feeling sad(strong)	Trying to find hope(weak) Becoming a meaning of life(strong) Becoming exhausted(weak) Feeling sad(strong)	Trying to find hope(weak) Becoming a meaning of life(weak) Becoming exhausted(strong) Feeling sad(strong)

4. Discussion

Participants of this study experienced changes in their wives due to dementia insignificantly or without notice. In the case of early-onset dementia, cognitive function, especially frontal lobe function, is reported to be significantly impaired compared to senile dementia[16][17], and the pre-temporal dementia, which is more common among younger patients shows BPSD(Behavioral and Psychological Symptoms of Dementia) remarkably, such as abnormal behavior or personality change from the beginning[18]. Therefore, participants in the study may experience changes in their wives' behavior unexpectedly. If the deterioration of memory, known as the initial symptom of dementia, was not noticeable and there was a lack of prior knowledge that dementia can develop at a young age regardless of age, the abnormal behavior of the wife would not have been considered dementia.

In a study by Werner and so on, the clinical difficulties encountered in early onset dementia are concentrated between the time from the initial signs of dementia to the diagnosis. This may be due to the fact that the patient is still young, and the participant does not think he or his family have dementia, and in general, dementia is related to age, so the primary specialist does not tend to diagnose young patients as dementia.

It is necessary to change the social awareness that dementia is a disease that occurs in the elderly, and for this, education should be conducted in various aspects along with active promotion, and to receive an appropriate diagnosis early, the professional knowledge and training

of medical personnel should be expanded.

To detect dementia early, local public health centers and dementia support centers in 25 autonomous districts in Seoul are conducting early dementia screening programs, but the target of the project is over 60 years of age, and management of patients with early-onset dementia that occurs before that time is insufficient. Therefore, it is necessary to expand the target of early dementia screening programs and services of management programs.

The state before the onset, social perception of the disease, and the couple relationship acted as contextual conditions for participants to recognize dementia. A study also reported that the main provider's marital relationship before and after support affects the support[19]. Most of the participants in this study showed being not able to let go of hope while looking forward to the development of new drugs rather than despair due to dementia is believed to be due to the love and affection between couples that have been accumulated over a long period of time and is considered a strength that only spouse care giver can have.

Participants do not want to admit their wives' dementia but have experienced progress of the disease such as acceleration of symptom onset that leads to difficulties in daily life, sudden decline in memory, loss of direction due to disorientation, aggressive behavior, difficulty in communication due to loss of words and their meanings. This is consistent with previous studies showing that early onset dementia occurs relatively quickly, and rapid progression of disease compared to senile dementia[20]. In a study comparing cognitive function and daily life performance ability of early onset Alzheimer's disease and delayed-onset Alzheimer's disease in homogeneous conditions such as gender, educational background, disease severity, depression level, and duration of disease(Sujin Kang, Sumi Choi, 2007), it was found to be more degraded than the delayed expression of Alzheimer's disease, indicating that early-onset dementia progressed more severely and rapidly than that of senile dementia.

Participants endeavor to heal their wife's illness, but in a situation where there is no support system at all, they experience extreme pain while taking care of themselves and the heavy role of husband and parent. Isolation that comes from not being able to live in social life as a head of a family at the age where they have to play an active role in society, the financial difficulties and the burden of raising children are thought to be much more severe than supporters of elderly dementia patients.

Participants had negative perceptions of current nursing homes and welfare facilities operated for dementia patients and were also not active about the services available. In the absence of other services for patients with early-onset dementia, currently available services are inevitably insufficient to properly support early-onset dementia patients and their families. Participants had a critical mind about the quality aspects of current services, the possibility of patient abuse, and the lack of specialized programs for patients with early onset dementia. Therefore, the needs of patients with early onset dementia and their care givers are different from those with senile dementia, and a different approach is needed.

Therefore, crisis intervention of care givers for early-onset dementia, establishment of social resources, and support systems available to them are urgently needed. Providing effective interventions to reduce the care giver's burden of care is essential to providing high-quality care to both patients and care givers.

5. Conclusion and Suggestion

This study applies a grounded theory research method to develop a substantive theory about the husbands' experience of caring for wives with an early-onset dementia by exploring the experience of husbands' caring for wives with an early onset dementia and identifying the relationship between the nature and concept of caring experience, 36 subcategories and 15 categories were derived from the participants with 7 participants, and the results are as follows.

The causal condition leading to the phenomenon of ‘Deny' appeared as ‘Unaware’, and the phenomenon was confirmed that the context as 'State before the onset', 'Social perception',

'Couple relationships,' and the interventional condition as 'Disappearance of hope', 'Support system', and the action/interaction as 'clearing the mind', 'adapting to reality',' barely holding on‘, 'going through the situation'.

The 'accepting dementia', a core category of the experience of husbands' caring for wives with early onset dementia, was analyzed into three types, focusing on attributes and the dimensions. The first type is 'active coping type', which shows a active attitude rather than being inactive about the problem situation, the second type is the 'accommodative type', which accepts the current state as it is and adapts to the reality with the best possible effort, and the third type is the 'helpless type', which is exhausted by the limitations of care and passive coping.

As a result of this study, since husbands' caring for wives with early onset dementia spend a long time before being diagnosed with dementia in their wives without an accurate understanding of the disease and social awareness of dementia, it was shown that early recognition and active intervention of experts are very important for early detection of disease and delaying progression. Also, since husbands caring for wives with early onset dementia are inevitably more suffering such as feeling of bondage due to inability to work at the age of social activity, financial difficulties, and burden of raising children, so developing specialized nursing and specialized programs and support groups that fit the characteristics of early-onset dementia that reduces their burden of care, and the need to establish support systems and services designed for them are necessary.

Based on the above results, I would like to make the following proposals.

1. In this study, since the husbands of Alzheimer's disease patients, who have the highest proportion of senile dementia, were the majority of all subjects, a study to confirm the experiences of supporters according to each causative disease including more diverse causative diseases as subjects in the future.
2. The subjects of this study are husbands who cares for wives with Alzheimer's disease and anterior temporal dementia. As the clinical characteristics of Alzheimer's disease and anterior temporal dementia are different, there may be differences in the experiences of care givers. Therefore, I propose to conduct a follow-up study comparing the differences in experiences between these care givers.
3. This study was conducted on spouses of early onset dementia patients diagnosed with dementia before 65 years of age, but the average onset age was 57 years old, and I propose to conduct a study to compare and analyze the differences between care givers and young patients in their 30s and 40s.
4. Since the participants of this study have good marital relationships and are mainly interested in the treatment of their wives, I propose to conduct a study to check the experiences of husbands who do not, and what circumstances and conditions affect them.

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7. Appendix

7.1. Authors contribution

	Initial name	Contribution
Author	SYP	-Set of concepts ☑ -Design ☑ -Getting results ☑ -Analysis ☑ -Make a significant contribution to collection ☑ -Final approval of the paper ☑ -Corresponding ☑ -Play a decisive role in modification ☑ -Significant contributions to concepts, designs, practices, analysis and interpretation of data ☑ -Participants in Drafting and Revising Papers ☑ -Someone who can explain all aspects of the paper ☑

7.2. Funding agency

This Paper Summarizes Soyoung Park's Hanyang University Doctoral Thesis.