

# **Korean Informal Caregivers' Experience for Family With Dementia: Difficulties and Strategies**



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- **Conflict of Interest**

No conflict of interest

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# INTRODUCTION

- South Korea (Korea) has experienced very rapid aging; second fastest aging country in the world between 2015 and 2030.
- The percentage of the population with dementia in Korea from 10.2% to 15.1% by 2050.
- Informal caregivers of person living with dementia (PLWD) provide care valued at \$10 billion.
- A sense of filial responsibility in Korean culture is prevalent.
- Understanding Korean caregiver experience regarding the difficulties to provide care and strategies they frequently use is critical.
- Little is known about the current experience of Korean informal caregivers of PLWD within changing socio-cultural contexts.

# PURPOSE

To explore the Korean informal caregivers' lived experience and frequently used strategies when providing in-home care for their family with dementia.

# METHODS

- ***Sample***

Nine Korean informal caregivers who currently or recently provided care to PLWD during June and July 2018.

Inclusion criteria : 1) a Korean informal caregiver who resides with a person with diagnosis of mild, moderate, and advanced stage of Alzheimer's disease or other dementia; or 2) placed their family member or relative who had disease or other dementia in a long-term care facility within one year at the time of recruitment.

- ***Data collection***

Caregiver experience focused on the difficulties and strategies they used to reduce the behavioral symptoms of PLWD.

The examples of the interview question: what was like when you experienced difficulties in caregiving?; How did you/your loved one react with those difficulties?

# METHODS

- ***Data Management***

The interviews were transcribed verbatim.

The transcriptions were verified with the audiotape.

Field notes and observations were incorporated into each uploaded comprehensive data document.

- ***Data Analysis***

Qualitative thematic analysis.

Create themes and subthemes on caregiver's experience based on Campbell's a model of consequences of dementia caregivers' stress process (Campbell, 2009).

The final codes were clustered into themes and summarized.

# RESULTS

# PARTICIPANT CHARACTERISTICS

- Over half of nine caregivers were male and had less than a bachelor's degree.
- The mean age was 64.7 years (SD = 13.4) and provided an average of 33 months (SD = 22.9) in caregiving.
- The relationship with PLWD was children (n = 5), spouse (n = 3), and siblings (n = 1).

## A. Caregiving Difficulties

### a. Behavioral and Psychological Symptoms

Agitation, aggression, verbal abuse, anxiety, delusions, hallucinations, irritability, resistiveness to care, or nighttime wakefulness exhibited by the PLWD

You cannot put anything around. He hits and destroys them all. He sometimes hit the wall, oh, it was really bad. Last year, he hit the wall in the middle of the night and screamed. See, my hands look old now, because taking care of him is too busy and tired.

## A. Caregiving Difficulties

### b. Lack of Knowledge about the Disease Symptoms

Uncertainty over the PLWD's changing behavior and memory, and care planning for the future

I was quite upset about how to deal with it (disease) first. I had no knowledge of dementia, but I believed my mother was sure to have dementia... I did not look for the resources to learn about the disease and how to care for her. I just heard that from somebody, that she is a patient, and that sentence came to my mind... I would have thought that as the same way as usual (that she is lying for all things) if I had not heard that (she is a patient).

## A. Caregiving Difficulties

### c. Performance of Activities of Daily Living (ADL)/ Instrumental Activities of Daily Living (IADL)

Caregiving burden related to ADL/IADL care for the PLWD during mealtimes, bathing, toileting, or housekeeping

(it is hard to) prepare for her meal, she needs even more assistance and I need to grind all food she eats. Then I need to wash our dishes when we finish our meal... I help her to take a shower. The most disappointing thing is that when I see my mother, because I am her son, the opposite sex, so I am a kind of reluctant to take care of her toileting.... If she ever makes a mistake...it was hard.

## A. Caregiving Difficulties

### d. Respite Care

Desire to more use of formal respite care, but feel distressed when these services did not meet the PLWD's medical/personal characteristics

I of course heard of the support group kind of thing, the people around me often recommend that but I didn't send her off there. First thing is that her personality, she doesn't like the crowded place, and second, she cannot walk herself well and has auditory problems. I thought it is not appropriate for us.

## A. Caregiving Difficulties

### e. Conflict with Other Family Members

Desire to share caregivers' physical, emotional, and financial stress with other family members, but feel frustrated when they did not get appropriate support from them

(My family) does not understand (my situation). Once I told my family what my mom said, and I was having a hard time, but they didn't understand me (and didn't help me to) take care of her. When I called them that (she had some behavioral problems)... and they called to her and say, "She is just fine, what's wrong with you?"

## A. Caregiving Difficulties

### f. Financial Difficulties

Due to the loss of caregiver's previous job for their caregiving role, and use of respite services

The financial part is huge. It is over out of our budget to place him at (nursing home) ... it is not really a great cost that I can pay it happily. It is expensive. No service or person that I can be supported for this. I already spent my retirement reimbursement to pay his healthcare costs.

## B. Frequently Used Strategies

### a. Asking a Favor

When the caregivers wanted to complete the caregiving tasks, but ways of asking for a favor were varied

After her diagnosis of dementia, it is impossible to persuade her to do something by logically. So I just ask for her to do this and that.

## B. Frequently Used Strategies

### b. Immediate Response

Immediate response to PLWD verbally and non-verbally, such as answering the PLWD's behavioral symptoms

When I hear his voice or any sounds, I wake up right away and go to his room.

I just follow her every routine every day. I am her primary caregiver, so, I just be with her unless I had something to do for my job.

## B. Frequently Used Strategies

### c. Providing Activities

Meaningful activities for PLWD to reduce the memory and behavioral problems, including conversation, reading a bible, singing, or walking

When she's acting out, I tell her. "Would you want to read bible and sing gospels together?" then, she looks getting calm and follow my word.

## B. Frequently Used Strategies

### d. Ignore the Problems

No response to the PLWD's verbal or non-verbal behavior problems when the behavior was not corrected with other strategies

Well, I should have shown my appropriate response to her in this situation (her acting out), but she has dementia, I just tell her, "Just forget about it, it is nothing."

## B. Frequently Used Strategies

### e. Correction of Mistakes

Correct PLWD's mistakes in verbal and non-verbal ways such as telling the truth or stop the PLWD's behavior directly

She put that (toilet paper) in her mouth. I said, "Give it to me," but she said "No, it is not, I am eating lettuce with wrapping a piece of grilled meat." So, I said, "This is not lettuce, this is toilet paper, mom." When she just keeps saying whatever she wants to talk, we say, "No mom, it is not. We don't think it is."

## B. Frequently Used Strategies

### f. Negative Reinforcement

Response to the PLWD with anger, threats, or scolding, although caregivers recognized its negative effect on PLWD

I sometimes just threaten her, like “If you keep doing like this, I won’t visit you anymore.”

# CONCLUSION

- Caregivers had insufficient knowledge or appropriate strategies for caregiving.
- A lack of confidence or feeling unprepared, which exacerbate their caregiving burden.
- Should aware of specific caregiver needs to help their better decision-making and to provide appropriate support for them.

# REFERENCE

Campbell, J. (2009). A model of consequences of dementia caregivers' stress process: Influence on behavioral symptoms of dementia and caregivers' behavior-related reactions. *Research and theory for nursing practice*, 23(3), 181-202.