I. Introduction
A. Challenges in Caregiving People Living with Dementia
The percentage of the population with dementia in South Korea is projected to expand from 10.2% to 15.1% by 2050, increasing the annual costs of dementia care with over $1 billion (Korean Central Dementia Center, 2018). Caring for a person with dementia has a number of challenges. In addition to assisting a clinical evaluation of the disease and care planning, people living with dementia (PLWD) need assistance with instrumental and basic activities of daily living (ADLs and IADLs, Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015), meaningful activities, and management of dementia-related symptoms (Black et al., 2013). Most importantly, caregivers need to be knowledgeable about the disease and the effective caregiving skills to pursue their caregiving role. Due to the lack of healthcare professionals to cope with this increasing caregiving demand, informal caregivers of PLWD have become a major resources. In Korean culture, it is expected that a family caregiver will provide informal care for their parent and spouse who has dementia (Kim, Hong, Lee, Kim, Kang, & Lee, 2009). This is expected in the context of family obligation. This cultural norm and the lack of available social service to support caregivers lead them to keep their loved ones at home for as long as possible. However, previous studies found that unmet needs were related to nursing home placement and death, caregiver stress, social isolation, depression, insomnia, and lower quality of life (Black et al., 2013; Jennings et al., 2015; Park et al., 2018; Richardson et al., 2013). Therefore, enhancing in-home care by providing social supports to the family caregivers is essential to reduce or prevent these results and enhance their ability to carry out their role.

B. Gaps in Current Research
However, relatively lower attention to what Korean family caregivers have difficulties in caregiving and what strategies they used to resolve the difficulties. The majority of the studies focused on the Western population and paid caregivers.

C. Purpose of the Study
The study explored Korean informal caregivers’ lived experiences when they provided care for people living with dementia.

II. Methods
A. Design
Qualitative description was used to describe caregivers’ experience on the difficulties and strategies they used.

B. Participants/Sampling
This study included nine Korean informal caregivers who currently provide their family or relative living with dementia. The inclusion criteria were: 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) has place their family or relative who has disease or other dementia in a long term care facility within one year. The participants were recruited from churches, adult daycare center, and senior home care center from May to July 2018.

C. Data Collection
The PI conducted nine in-depth interviews with family caregivers of PLWD. Interviews was held at home, cafe, or adult daycare center with the participants’ preference. The participants was asked to focus on their experience about caregiving difficulties and strategies they used. All the data collection process followed by IRB recommendation.

D. Data analysis
After the interview, recorded caregiver interviews were transcribed verbatim and analyzed line-by-line using inductive approaches. The PI created and read each transcript, highlighted significant data, and coded manually. After the coding was completed, the codes were added, revised, or deleted to fully explain different domains. The final codes were clustered into themes and summarized.

III. Results
Interviews of nine caregiver were included in the analysis. Among the 9 caregivers, over half of them (n = 5) were male and had less than a bachelor’s degree. The mean age was 64.7 years (SD = 13.4) with an average of 33 months (SD = 22.9) as a caregiver. The relationship with PLWD was varied, from spouse (n = 3), son (n = 2), and others.

A. Caregiving Difficulties
Participants identified 31 type of difficulties for dementia care within six domains.

1. Behavioral and psychological symptoms
Behavioral and psychological symptoms in dementia were defined as agitation, aggression, apathy, anxiety, delusions, depression, disinhibition, hallucinations, irritability, motor disturbances, or nighttime wakefulness exhibited by the PLWD.

2. Lack of knowledge about disease symptoms
Caregivers often expressed uncertainty over the PLWD changing behavior and memory, and care planning for the future.

3. Performance of activities of daily living and instrumental activities of daily living
Caregivers frequently described caregiving burden related to ADL and IADL care for the PLWD. This domain included a variety challenges related to mealtimes, medication administration, bathing, toileting, and housekeeping.

4. Respite care
Caregivers often stated that they wanted to use more formal respite services including home care assistant, but also expressed the limited range of these services available.

5. Frustration from other family member
Caregivers expressed frustration from other family member, including spouse or siblings. Caregivers felt they wanted to share their physical, emotional, and financial support from other family member, but caregivers expressed they were often frustrated from them when they did not get much support.

6. Financial difficulties
This domain included financial difficulties that resulted from the loss of caregiver’s previous job due to the caregiving role and use of respite services.

B. Frequently Used Strategies
Participants identified six strategies they frequently used to resolve the PLWD’s symptoms related to disease, although they stated the uncertainty about the effectiveness of the strategies.

1. **Correction of mistakes**
   Caregivers described they often correct PLWD’s mistakes in verbal and non-verbal way such as telling the truth or saying don’t do the specific behavior directly to PLWD.

2. **Immediate response to their loved one**
   Caregivers identify they often showed immediate response to PLWD in verbal and non-verbal way, such as following every routine of PLWD, looking for solution to the PLWD’s behavioral symptoms.

3. **Being neutral**
   On the other hand, caregivers stated that they sometimes did not react to the PLWD’s verbal or non-verbal behavior when the behavior was not correct with other strategies.

4. **Scolding**
   Although caregivers recognized its negative effect on PLWD, some caregivers described that they react to the PLWD with anger, threat, or scolding.

5. **Asking a favor**
   Caregivers stated that they frequently used this strategy when they wanted to complete the caregiving tasks, although the ways of asking favor were varied.

6. **Providing activities**
   Caregivers described their some meaningful activities with PLWD to reduce their memory and behavioral symptoms, including conversation, reading a bible, singing, and walking.

**IV. Conclusion**
Caregivers appealed to have insufficient knowledge or appropriate strategies for caregiving. This can result in a lack of confidence and feeling unprepared that contribute to their caregiving burden. It is important to know about specific caregiver needs for better decision-making and to provide appropriate social support for them.

---

**Title:**
Korean Informal Caregivers’ Experience for Family With Dementia: Difficulties and Strategies

**Keywords:**
Caregivers, Dementia and Qualitative Research

**References:**


**Abstract Summary:**
The study explored nine Korean informal caregiver’s experiences for people living with dementia. The qualitative description was used to analyze in-depth interviews. Participants identified six caregiving difficulties and six strategies they used. The results indicates focus areas for interventions to help informal caregivers manage their distress and caregiving skills.

**Content Outline:**
I. Introduction
   1. Challenges in Caregiving People Living with Dementia
   2. Gaps in Current Research
   3. Purpose of the Study
   II. Methods
      1. Design
      2. Participants/Sampling
      3. Data Collection
      4. Data Analysis
   III. Results
      A. Caregiving Difficulties
         1. Behavioral and psychological symptoms
         2. Lack of knowledge about disease symptoms
         3. Performance of activities of daily living and instrumental activities of daily living
         4. Respite care
         5. Frustration from other family member
         6. Financial difficulties
      B. Frequently Used Strategies
         1. Correction of mistakes
         2. Immediate response to their loved one
         3. Being neutral
         4. Scolding
5. Asking a favor
6. Providing activities

IV. Conclusion

First Primary Presenting Author
Primary Presenting Author
Sohyun Kim, MSN, RN
University of Iowa
College of Nursing
Iowa City IA
USA

Author Summary: I worked as a clinical nurse for five years with masters’ degree in nursing in South Korea, I am a Ph.D candidate at University of Iowa currently. I have a certificate in gerontological nursing and research experience with caregivers and the patients with chronic disease including dementia. My research interest area is communication patterns of informal caregivers of people living with dementia and interventions for improving the interaction between people living dementia and their caregivers.