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## Research Article

## Experience of Dementia-related Anxiety in Middle-aged Female Caregivers for Family Members with Dementia: A Phenomenological Study

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## SUMMARY

**Purpose:** In Korea, most elderly with dementia receive care from family members, yet little research is available on the experience of dementia-related anxiety in middle-aged female caregivers for a family member with dementia. The purpose of this study was to describe the lived experience of dementia-related anxiety in middle-aged female caregivers for family members with dementia.

**Methods:** A descriptive phenomenological study was conducted. A purposive sampling strategy was used to recruit participants. Twelve middle-aged women (40–59 years, mean age = 51.90 years) who were family caregivers were interviewed from February 2014 to August 2014. Data were collected through semistructured interviews and analyzed using Giorgi's method.

**Results:** The essential structure of the phenomenon was a fear of losing self-identity. The main essence was represented by six components: keenly feeling the effects of aging because of memory deficit, continuous comparison of the family member's behavior with that of the participant's, *Finding it painful to see a family member with dementia as he/she does not know how this will end*, not knowing the conclusion of the disease process, reducing the risk of dementia, and trying to change one's lifestyle from what it used to be in the past.

**Conclusions:** The study provides the essential structure of the experience on dementia-related anxiety that caregivers of a family member with dementia have. The findings could help healthcare providers and researchers have better understanding of dementia-related anxiety and give more attention to the caregivers to relieve their anxiety.

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## Introduction

Dementia is a progressive brain disorder leading to a loss of memory, judgment, and the ability to perform activities of daily living [1]. According to a nationwide study on the prevalence of dementia in Korea [2], the risk of dementia increases with age; it reached 9.18% in those 65 years and older in 2012. Interestingly, the majority of the older adults with dementia (97.1%) were receiving care from a family member (e.g., a daughter or a daughter-in-law), rather than from nursing institutions. Of those who were caring for older adults with dementia in community settings, most were middle-aged women (67.2%) with an average age of 57.3 years [2]. The fundamental cause of the brain cell destruction in dementia is

still uncertain. However, considering the risk factors of dementia, such as aging and female gender [3], awareness of dementia is very important, especially in middle-aged female caregivers. To increase the early detection and public awareness of dementia, the World Health Organization recommends implementing intervention programs, not only reducing dementia-related stigma and providing better nursing care for patients with dementia, but also providing more information and support to their caregivers [4].

Caregivers for a family member with dementia (FMWD) experience emotional strain, including anxiety from the negative effects of caregiving [5]. According to the findings of a review of 33 published articles [6], caregivers of a dementia patient have high levels of anxiety and depression. In general, anxiety about dementia development has been reported in 50.0% of middle-aged adults [7], and concern about dementia development was more prevalent in adults with a family history of dementia compared to those without such a history [8]. Of adults aged 40 years and older, 51.0%

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recognized a family history of dementia as a risk factor [9]. Significantly, dementia-related anxiety (DRA) is associated with being a family caregiver for an elderly person with dementia; thus, caregivers for an individual with dementia may have additional strain [10].

According to a poll in the United Kingdom regarding their fear of various medical conditions [11], of those aged 50 years and over, two-thirds (68.0%) of the participants reported that dementia was their most feared disease, while only 9.4% mentioned cancer as the most feared. In another study conducted with adults ( $N = 1,007$ ) that examined the fear of Alzheimer's disease, the percentage of people who feared dementia increased 1.5 times, from 20.0% in 2006 to 31.0% in 2010; 66.0% of those surveyed were concerned (from "a bit" to "very") about providing care for a family member suffering from dementia [12]. From a survey of awareness of dementia risk and prevention in healthy adults (over 50 years), researchers reported that women were more worried compared to men about developing dementia, and persons with families affected by dementia were more concerned compared to those unaffected by dementia [9]. Another research finding about the fear of dementia showed that 60.0% of the study participants aged 18 years and older had dementia-related fear, and the fear of dementia in middle-aged women was experienced most often in those who had cared for someone with dementia [13]. Participants whose parents were diagnosed with dementia indicated that they were more concerned about their own risk factors for dementia compared to those who had no family history of dementia [14]. Researchers compared families with a dementia patient to those without a dementia patient and found that 92.0% of the participants with an FMWD worried about the onset of dementia at a level from "somewhat" to "very" [15]. This indicates that a family history of dementia is a major predictor of dementia worry and fear of dementia, and middle-aged women with a family history of dementia have the highest level of fear of dementia.

Regarding dementia caregivers, researchers have conducted studies on psychological issues, such as caregiving burden [5,16], distress, and depression [17–19]. However, few studies have focused on DRA experienced by caregivers directly or indirectly while taking care of an FMWD [6] or had not addressed the significant DRA phenomenon experienced by middle-aged women with a family history of dementia. Therefore, the study purpose was to describe the lived experience of DRA in middle-aged caregivers who have taken care of an FMWD.

## Methods

### Study design

A descriptive phenomenological study was conducted to explore the lived experience and essential structure of the experience of DRA in family caregivers. Giorgi's [20] phenomenological method was used.

### Participants

Participants were recruited from a specialty clinic for dementia disorders in Korea. The snowball sampling method was used for convenience and accessibility of data collection on this special phenomenon. Regarding adequacy and sufficiency as based on Giorgi's method [20], a caregiver was considered eligible for participation in this study if she was aged middle-aged (40–59 years), was taking care of a family member with dementia, and could read, write, speak, and understand Korean. Women 60 years and older were excluded from the study because of the

chances that the respondents could already be in the early stages of either age-related anxiety or dementia.

The sample consisted of 12 family caregivers. The participants' mean age was 51.90 years (4 in their 40s, 8 in their 50s). All participants were married and nine had completed college or a higher degree (75.0%). Two participants had both parents with dementia, and 10 participants had one parent with dementia (6 with a father, 4 with a mother). Six patients were diagnosed more than 5 years before this study. All participants' parents had either Alzheimer's disease or a vascular type of dementia. Three participants were giving direct care at home; the others ( $n = 9$ , 75.0%) were giving indirect support, which meant that they had placed their parents in a nursing home and made regular visits to those family members. No eligible caregiver refused to participate in this study, and no participant dropped out.

### Data collection and procedure

After institutional review board (IRB) approval, data were collected through face-to-face in-depth interviews by the researchers from February to August 2014. Interviews were conducted in each participant's home or office, or at their parent's nursing home, depending on the participant's preference. Participants were allowed to bring other family members or their friends to the interviews, but no one did. Initially, interviews began with semistructured open-ended questions to provide various possibilities for the participants' answers. These questions were as follows: "Can you please tell me about what you have felt when you first found out that your family member had dementia?" and "Please tell me your thoughts or experiences while taking care of and watching the patient." As the interviews progressed, the researchers used the following prompts:

- What do you think about the relationship between dementia and you?
- How did you feel when you realized that your parent had dementia?
- Considering your experience as a caregiver for an FMWD, how do you want to spend your old age?

The interviews were audio taped and lasted for approximately 60–90 minutes. The researchers met with each interviewer at least twice, depending on the circumstances. While interviewing, the researchers carefully observed the participant's physical or psychological discomfort. A short break was given to the participant if the interview lasted for 60 minutes or longer, and whenever the participant wanted it. Theoretical sampling lasted until consistent components emerged from the participants' responses.

### Data analysis

Recorded interview contents were transcribed verbatim by two independent researchers. Thoughts or feelings (e.g., desperation and doubts) that surfaced during the discussion were written on the field notes. Transcribing the recordings took three or four times longer compared to the time taken for the interviews. The emerging components and related quotations were returned to the participants for correction and feedback in the subsequent interviews.

Data were analyzed in three steps according to Giorgi's phenomenological analysis method [20]. In the first step, the entire descriptions were read independently several times by two researchers to obtain awareness of DRA from the caregivers, and then they summarized the descriptions. In the second step, meaning units of the middle-aged women's DRA were identified and

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