

# A Concept Analysis: Caregivers' burden of Elderly Adults with Alzheimer's Disease

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## Abstract

The purpose of a concept analysis of caregivers' burden is to identify this in formal and informal caregivers to provide improved care to elderly adults with Alzheimer's disease (AD) and to reduce the burden of caregiving. The concept analysis proposed was conducted by Walker and Avant's eight-step method. The search was performed in December 2016. Four databases were included: CINAHL, EBSCO Host, Google Scholar, and Science Direct. The outcome of the search was five areas found overall: nursing, gerontology, medical, public health, and psychological. Exclusion criteria included editorials, and duplication in each database. Finally, 24 papers were used for analysis in the concept of "caregiver burden in caregivers of elderly adults with AD". The result of the concept analysis has three attributes including: physical and psychological problems, family function, and social support.

**Keywords :** a concept analysis, caregivers' burden, elderly adult, Alzheimer's disease.

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Advanced medical technology is causing longevity; the ageing population will increase. So, will the number of new and existing cases of Alzheimer's disease (AD), as age is one risk factor for developing AD.<sup>1</sup> Aging people with AD in Thailand could increase to 74.7 million by 2030, and a projected 131.5 million by 2050.<sup>2</sup> The chronic or long-term disease influences the patient's family and society as a whole. Consequently, caring or caregiving is important for long-term care and is a challenging issue because of the high demand and overload of elderly caregivers. "**Caregiver burden**" is the term that describes this situation. According to Zarit et al.,<sup>3</sup> the meaning of caregiver burden is the degree to which a carer's emotional or physical health, social life or financial status has suffered as a result of caring for their relative. The idea of caregiver burden is not new; although older people have good physical, psychological or emotional health, they may still need caregivers to take care of them.<sup>4,5</sup>

Most caregivers come from family members who care for elderly parents or someone who cares for elderly people with AD. Indeed, most informal caregivers experience significant levels of fatigue, depression, isolation, functional decline, and even increased mortality. Consequently, exploring the concept of caregiver burden in caregivers of elderly adult with AD is important to ensure a better quality of care in elderly with AD. Burden as a concept was first explicated by Hoenig and Hamilton.<sup>6</sup> Literature suggests that caregiver burden and depressive symptoms are interrelated in caregivers of persons with cancer and AD, with the burden being a precursor to depressive symptoms.<sup>7</sup> However, the burden is normally found in caregivers especially of elderly adults with AD. It is very important to consider caregiver burden and give a definition for caregiver burden. Given that concept analysis is not a standard method to generate or clarify the characteristics or concepts of caregiver burden in AD, it has not only been defined from the literature review but also from relevant attributes and irrelevant attributes. Concept analysis is thus beneficial in refining ambiguous concepts, which can become a precursor of theory, enhance knowledge development for research, and help to improve practice.<sup>8</sup>

Received: March 12, 2021

Revision received: June 1, 2021

Accepted after revision: July 14, 2021

BKK Med J 2021 ; 17(2): 155-159.

DOI: 10.31524/bkkmedj.2021.23.001

www.bangkokmedjournal.com

Caregiver burden is a phrase that is normally used in nursing and it is not an umbrella term. Interestingly, it was related with health care providers or family members that take care of Alzheimer patients. Indeed, we have to explore the burden of caregivers because it is so important in the caregiving process. However, after working on the literature review, it showed that the caregiver burden in elderly adults with AD is still unclear. As a consequence, developing nursing knowledge for reducing the burden in caregivers of elderly adults with AD has benefits to nursing education, practice and also research.

The purpose of this study was to examine and clarify the attributes or characteristics of caregiver burden in caregivers of elderly adults with AD and to clarify the meaning, define the attributes, explain the term, and scope of the concept. The method used in the analysis was based on Walker and Avant's concept analysis<sup>8</sup> by clarify all of the attributes of caregiver burden in caregivers for aging adults with Alzheimer's disease.

### Concept analysis of caregiver burden in caregivers of elderly adult with Alzheimer's disease

#### Method

The concept analysis proposed by Walker and Avant's<sup>8</sup> eight-step method. Data were collected from multiple bases, this decreased the bias of the study. The literature search used combinations of the following key terms: **caregiver, adult caregiver, caregiver burden, combined with elderly adult**, and AD. The inclusion criteria included publication in English language, full text of academic journals and/or dissertations, and the year of publication from 2008 to 2016. The search was performed in December 2016. Four databases were interrogated; CINAHL, EBSCO Host, Google Scholar, and Science Direct. The outcome of the search was five areas found overall: nursing, gerontology, medical, public health, and psychological. Exclusion criteria included editorials, and duplication in each database. Finally, 24 papers were used for analysis in the concept of "caregiver burden in caregivers of elderly adults with AD".

#### Step 1: Select the concept

The phenomena of caregivers' burden of elderly adults with AD are important. Besides, it is very important to consider caregiver burden and give a definition for caregiver burden. The caregiver burden in elderly adults with AD is still unclear. As a consequence, developing nursing knowledge for reducing the burden in caregivers of elderly adults with AD has benefits to nursing practice.

#### Step 2: Purposes of analysis

The purpose of a concept analysis of caregiver burden in terms of nursing to identify this in formal and informal caregivers to provide care to elderly adults with AD and to reduce the burden of caregiving.

#### Step 3: The identification of all possible uses of the concept

##### • Caregiver

The definition of a caregiver in a psychological and medical context is that a caregiver means someone who takes care of a person who is young, old, or sick and has a minimum amount of care to be provided by a family member of around 4 hours per day or help with at least one activity of daily living (ADL).<sup>9,10</sup> Caregiver means both a formal and informal caregiver, this concept focuses on informal caregivers or family caregivers in AD.

##### • Caregiver burden

Caregiver burden in terms of nursing, medical health is defined as fatigue and in psychological terms as depression, which is defined as overload in caregiving, therefore, it is important to identify this in formal and informal caregivers, who provide care to elderly adults with AD and to reduce the burden of caregiving. There are many types of caregivers, for example, formal caregivers are direct caregivers including care workers, whereas informal caregivers are non-paid and provide care to family members.<sup>11</sup> The primary caregivers are wives, but secondary caregivers are daughters.<sup>12</sup> Most caregivers are women because they have more internal motivation and emotional attachment to care and to become caregivers.<sup>13</sup> As a result, caregivers prepare themselves for caring, which differs from the physical, psychological, and environmental factors that are facing them.

In the perspective of family members caring for aged who have AD, it increases the family caregiver's load as they also have to fulfill their role in the family membership and try to function well in both roles.

##### • Elderly Adult

Elderly people are defined as a section of the population who have reached the age of 60 years.<sup>14</sup> This can be an important issue because studies that include caregivers who have minimal caregiving responsibilities may show less impact on family caregivers, ageing results from the impact of the accumulation of a wide variety of molecular and cellular damage over time. This leads to a gradual decrease in physical and mental capacity, a growing risk of disease, and ultimately, death.<sup>15</sup>

From the point of view of the health care provider, elderly adults have regression in biological and cognitive functions so they need care from another person.

##### • Combine the word "Caregiver burden" with "elderly adult" with "Alzheimer's disease"

This means caregivers who give help and protection to elderly adults with AD. Its synonym is a person who provides direct care to Alzheimer's aging patients. *In terms of health care providers*, it means the number of hours of caregiving or

workload to care for elderly adults with AD.<sup>16</sup> However, based on the aspect of *family caregiver defines* caregiver burden of an elderly adult with AD is generally a family member, such as a spouse, adult child or close friend of the care recipient.<sup>1</sup>

#### Step 4: The creation of the defining attributes

- The step to determine the defining attributes of a concept is at the heart of concept analysis. The three characteristics that seem to be most observable among all those divergent uses of the term coping were
  1. The attribute of covering something
  2. The attribute of protection
  3. The attribute of adjusting or rebalancing<sup>8</sup>
- Based on the literature review and definition, the concept of caregiver burden of elderly adults with AD has three attributes:
  1. Physical and psychological problems
  2. Family function
  3. Social support, which are described below

**-First attribute:** physical and psychological problems.

Physical and Mental capacity are the most common to clarify the concept.

For the caregiver aspect,

- 1) *Physical problem*, means many problems related to physical wellbeing such as fatigue. Some studies found that caregivers in poor health were consistently found to have significantly higher burden levels.<sup>4</sup>
- 2) *Psychological problems* are the burden of distress and related coping processes and also the severity of caregiver distress related with specific coping strategies.<sup>17</sup>

Burnout means “a syndrome of physical, intellectual and emotional exhaustion correlated to chronic strain”.<sup>18</sup> Appropriate therapeutic management of AD patients, particularly their behavioral symptoms, may reduce the burden placed on family and professional caregivers. Informal caregivers or family members showed higher levels of depression and anxiety.<sup>19</sup> Importantly, the amount of burden for caregivers of AD correlated in a positive way with the characteristics of AD patients, including cognitive function, mood, manner, and motor impairment of patients.

**-Second attribute:** Family Function

Family function is an important role in the care of the Alzheimer patient including providing care for personal

behaviors such as eating, bathing, and doing ADL. Caregivers also provide the daily care activities of the care receiver both basic ADLs, and instrumental activities of daily living.<sup>20</sup> These duties cause caregiver an increased burden.<sup>21</sup> Another study of Lou et al.,<sup>22</sup> found the levels of burden comes from a long duration of being a caregiver and being a spouse. Although many caregivers experience feelings of burden and stress associated with their role, some caregivers also derive feelings of satisfaction from their duties. It is thought that caregiver satisfaction is not the opposite of burden, but rather they are two separate entities that can occur simultaneously.<sup>21</sup> This study was concerned with the factors contributing to the feeling of burden and the consequent coping strategies adopted by family caregivers of patients with AD living in the community. Coping skills are an important factor allowing caregivers to focus on challenges with a problem-solving attitude.<sup>17</sup> Moreover, a systemic review by Stolz et al<sup>12</sup> found that caregivers need to desire to have respite, having experience with negative emotions, burden, stress and worry during times of caring for elderly people at home.

**-Third attribute:** Social Support

Social support is an important activity, caregivers who find social support can reduce their psychological problems in the caring role leading to caregivers having more time for socialization.<sup>4</sup> The study of caregiver burden in AD also found interventions in social support for caregivers such as self-help groups, family meetings, educational seminars, and telephone counselling. In cases of resistance to other psychoeducation approaches, counselors may propose structured cognitive-behavioral therapy, which has been found to be able to reduce diurnal cortisol levels in caregivers of patients with AD.<sup>17</sup> According to the burden of elderly caregivers, family members facing financial strain are likely to have decreased recreation and social isolation.<sup>23</sup> Moderate evidence is found that cares need networks in social support groups, having a fear of social isolation, fear of loss of control, relationship duty changes and loss of reciprocity. Moreover, education programs for carers are important and effective methods to support family caregivers and their elderly.<sup>12</sup>

#### Step 5: Definition the model case

- **Model case**

Identifying a model case of the concept is the sample of using the concept to present functional status based on the real life of patients in the community which the author used to assess Alzheimer care.

**Table 1:** Model of Caregivers' burden of elderly adults with Alzheimer's disease : Concept analysis.

Antecedents	Attributes	Consequences
Caregiver's characteristics	Physical and Psychological problems.	Quality of life
The demands of caregivers	Family function	Reduce stress
The involvement in caregiving	Social support	

#### • Model case

The following is a model case where all defining aspects (health care professional and family member) have been included. Mrs. A is a 42-year-old, single caregiver of a mother who is elderly having AD for 6 years. She has physical and psychological problems such as fatigue and anxiety. She also has limitations to care for her mother in ADL, especially eating. Her mother does not know she has eaten a meal already. She does not have enough money and has to borrow money or find someone to help her. However, the Model case includes all attributes.

#### Step 6: The identification of borderline, related, contrary, invented and illegitimate cases

##### • Borderline case

According to Walker and Avant<sup>8</sup>, a borderline case contains almost all of the defining attributes of the concept being analyzed but includes an inconsistency in relation to the model case. A grandson, who is a caregiver, takes his grandfather, who has AD, to a plush resort. They spend a week relaxing. They receive full body massages at the spa, sunbathe, walk along the beach, and converse about their childhoods in the sea. All tensions felt are gone. Additionally, a nursemaid is hired at the end of the day to provide supervision and help the care receiver prepare for sleep. The grandson goes out to dinner to socialize with his girlfriend and friends. At the end of the day, both the caregiver and care receiver feel refreshed and relaxed. The caregiver says “good night” to the care receiver and mentions that he wishes his life could stay like this forever. The caregiver has physical and psychological problems such as muscle strain, and anxiety. Fortunately, he is involved in a social club sometimes for relaxing. He also has a limitation to care for his grandfather in ADL, especially walking, eating and bathing. He cannot find financial support. Therefore, he receives poor subsistence allowances from the government.

##### • Related case

A related case is very similar to the concept but does not contain all the defining attributes. Mrs. C is a 45-year-old single caregiver of her mother who is elderly having Alzheimer's disease for 5 years. Mrs. C has physical and psychological problems such as fatigue, low back pain and depression. She also has a limitation to care for her mother in ADL, especially walking, eating and bathing. She gets financial support from her relatives but not enough. Therefore, she works at home decorating toys to send to a store.

##### • Contrary case

Mrs. A is a 42-year-old single caregiver of his mother who is elderly having Alzheimer's disease for 6 years. She is a good caregiver neither having physical nor psychological problems. She works comfortably to care for her mother with

AD in ADL. She and her mother have a good relationship. She has enough money to survive and spend on relaxation. She goes to a dance club to relax. However, the Contrary case contrast of the Model case does not include all attributes.

#### Step 7: The identification of antecedents and consequences

##### • Antecedents

Antecedents occur before the application of the concept. The concept of caregiver burden in caregivers of elderly adults with Alzheimer's disease has three antecedents factors which are a caregiver's characteristics, the demands of caregivers, and the involvement in caregiving.<sup>4</sup> Especially in AD, the demands of the caregiver are to examine the limitation to care and the degree of disturbance to the caregiver in the family. The financial impact of caregiving for a person with AD and related dementias have a higher demand in caregiving.<sup>20</sup>

A caregiver's characteristics defines gender and socioeconomic status. According to *gender*, many studies found that woman were the most important in the care of the elderly who had chronic disease. Socioeconomic status, from the literature review financial expense of caregiving could predict caregiver burden. Most of the caregivers of AD had financial problems. The demands of the caregiver are to examine the limitation to care and the degree of disturbance to the caregiver in the family. The involvement in caregiving time or hours per day spent with an elderly adult with AD.

##### • Consequences

The consequences of burden generate problems for the caregiver, family, and the health care system. The quality of life of the caregiver is a positive outcome, the consequence from informal caregiving affects biological, emotional, financial, and social aspects of the patient and their family.<sup>24</sup> In case of a family member who cares for aged relatives with AD, they should decrease their stress.<sup>21</sup> The health care system should promote quality of life for the caregiver to ensure effective care in AD patients. Studies in Alzheimer's Patient Familial Caregivers show that the outcomes should focus on improving the health and quality of life concurrently in both the caregiver and the care recipient.

#### Step 8: The definition of empirical references

To measure the concept of caregiver burden in caregivers of elderly adults with Alzheimer's disease, the caregiver's quality of life (stress or measure depression) can be measured by using questionnaires.

#### Conclusion

This concept of caregiver burden in AD of aging is changing rapidly. In developing nursing knowledge, health care providers try to promote caregiver health to reduce burden. It is important to know the attributes, antecedents, and



consequences of caregiver burden concept analysis in caregivers of elderly adult with AD. The caregiver burden would support health care providers to explore their patient's unique ideas of caregiver burden in AD. Health care providers should be aware of these concepts. To use this knowledge, health care providers should focus on patient factors and promoting caregiver care

as this will be helpful in the perceived burden of caregiving. The enormous physical, emotional, psychological, social and financial impact of caring for an AD patient is captured by the term "caregiver burden".<sup>25</sup> This review presents current literature on caregiving burden, risk factors, and interventions, and proposes recommendations for future research.

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