



A Concept Analysis of Coping in Caregivers of Older People with Dementia

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ABSTRACT

Various terms have been used to define coping in caregivers of older people with dementia with varied abstract concepts that are widely used in nursing and other disciplines, such as psychology, medicine, and education. A strong understanding of the concept of caregiver coping is essential as a basis for providing appropriate nursing care. This concept analysis aims to clarify the concept of coping in caregivers of older people with dementia and develop the operational definition, attributes, antecedents, and consequences of this concept. This study utilizes Walker and Avant's concept analysis method. The analysis shows that coping attributes of caregivers of older people with dementia include cognitive and behavioral efforts in providing care, stress adaptation, and use of resources on oneself and the environment. Antecedents of coping include characteristics of caregivers, stressors, and caregivers' assessment of an event. Meanwhile, the consequences include positive impacts and negative impacts. This analysis can help nurses understand the concept and determine appropriate assessments and interventions for caregivers of older people with dementia. It is suggested that nurses be aware of caregivers' characteristics, stressors, and assessment of an event. Further research is needed to investigate the need for intervention on the consequences of coping in caregivers of older people with dementia.

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Kata kunci:

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Demensia

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ABSTRAK

Berbagai istilah digunakan untuk mendefinisikan koping caregiver lansia dengan demensia dengan konsep abstrak yang bervariasi luas yang digunakan di semua bidang keperawatan, serta dalam disiplin ilmu lain seperti psikologi, kedokteran, dan pendidikan. Pemahaman yang kuat tentang konsep koping *caregiver* lansia dengan demensia penting dalam keperawatan untuk dapat menjadi dasar dalam melakukan asuhan keperawatan yang tepat. Tujuan dari analisa konsep ini adalah untuk memperjelas konsep Koping *caregiver* dan mengembangkan definisi operasional dari konsep koping *caregiver* lansia dengan demensia, atribut, Anteseden dan konsekuensi dari konsep koping caregiver lansia dengan demensia. Metode yang digunakan adalah dengan Pendekatan analisis konsep Walker dan Avant. Hasil analisis menunjukkan bahwa atribut koping caregiver lansia dengan demensia meliputi Upaya kognitif dan perilaku, selama melakukan perawatan, Adaptasi terhadap stress, dan Penggunaan sumber pada diri dan lingkungan. . Anteseden untuk koping caregiver lansia meliputi karakteristik *caregiver*, stresor dan penilaian *caregiver* terhadap suatu peristiwa. Konsekuensinya meliputi dampak positif dan dampak negative. Analisis ini membantu perawat untuk memahami konsep dan menentukan pengkajian dan intervensi yang tepat

bagi caregiver lansia dengan demensia. Disarankan bahwa perawat harus menyadari karakteristik *caregiver*, stresor dan penilaian *caregiver* terhadap suatu peristiwa. Penelitian lebih lanjut diperlukan untuk menganalisis kebutuhan intervensi terhadap konsekuensi dari koping caregiver lansia dengan demensia.

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INTRODUCTION

Caregiver coping is a key concept in providing care. Caregiver coping affects the quality of care and the quality of life of the caregivers and patients that receive the care (Monteiro et al., 2018). Caregiver coping is a dynamic process in which caregivers make behavioral or psychological efforts to manage stress appraised as exceeding their resources (Kneebone & Martin, 2003). Caregiver coping, especially in caring for older people with chronic diseases, is essential since it is positively related to the caregivers' quality of life (Aren et al., 2017).

Dementia is a chronic disease in older people. Dementia is a syndrome of neurodegenerative diseases that affects memory, thinking, behavior, and the ability to perform daily activities. Dementia is one of the leading causes of disability and dependence among older adults; therefore, people with dementia often require long-term or permanent care (Sousa et al., 2009). Caring for older people with dementia could create burdens on the family, which include physical, psychological, economic, and psychosocial burdens (Widyastuti et al., 2011). Psychological burden is mostly experienced by the families of older people with dementia, followed by psychosocial, physical, and economic burdens (Krutter et al., 2020). The burden of caring for older people with dementia can cause health problems and increase the risk of death for caregivers, as well as reduce the quality of care provided (Contador et al., 2012). Dementia care also causes global economic losses estimated at \$818 billion annually. The cost of dementia care in upper-middle-income countries, such as Indonesia, is estimated at \$2.2 billion annually (Prince, 2015). This condition can lead to conflicts and dynamic changes in the families and other related crises (Werner et al., 2012). The burden of family caregivers in caring for people with dementia also increases the inappropriate treatment of older adults (Kishimoto et al., 2013). In caring for older people with dementia, caregivers can minimize the impact of the care if they have effective ways to adapt to stress and effective coping strategies (Mausbach et al., 2012). Caregiver coping can affect how caregivers respond to stressors; this coping also affects the quality of life of caregivers and older people with dementia (Kristofferzon et al., 2011).

The coping in caregivers of older people with dementia is an abstract concept that varies widely. However, the term is commonly used in all areas of nursing and other disciplines such as psychology, medicine, and education. A strong understanding of the concept of coping in caregivers of older people with dementia is essential as a basis for providing appropriate nursing care. Therefore, further analysis of the concept of coping in caregivers of older people with dementia is required. This concept analysis aims to clarify the concept of coping in caregivers of older people with dementia and develop the operational definition, attributes, antecedents, and consequences of this concept.

METHODS

A concept analysis is a strategy to identify the attributes or characteristics of a concept (Walker & Avant, 2014). The purpose of a concept analysis is to clarify the use and definition of a concept to help identify a phenomenon and the things that underlie the phenomenon. According to Walker and Avant (2014), the concept analysis approach includes: 1) choosing a concept, 2) determining the purpose of the analysis, 3) identifying the use of the concept, 4) determining the characteristics of the definition, 5) identifying model cases, 6) identifying borderline and contrary cases, 7) identifying antecedents and consequences, and 8) defining empirical referents (Walker & Avant, 2014).

The purpose of this concept analysis is to clarify the concept of caregiver coping and develop the operational definition of the concept, as well as identify the use of the concept in all disciplines and provide clarity of the concept to be a guideline in conducting research.

To obtain a comprehensive understanding of the concept of coping in caregivers of older people with dementia, a literature review was conducted using some electronic databases, including PubMed, EBSCOhost, Science Direct, and Google Scholar. From the literature review, eight relevant articles were obtained and analyzed to determine the attributes of the concept of coping in caregivers of older people with dementia. The literature sources in this study included journal articles published from 2000 to 2020. The search keywords were coping, caregivers, and older people with dementia.

RESULTS AND DISCUSSION

Definition and Use of Coping in Caregivers of Older People with Dementia

The literature review found eight relevant articles that provide the definition of coping in caregivers of older people with dementia from various disciplines. An analysis was carried out to determine the attributes of the concept of coping in caregivers of older people with dementia (Table 1).

Definition of Attributes of Coping in Caregivers of Elderly People with dementia

Attributes are the characteristics of a concept that are written repeatedly in the literature (Walker & Avant, 2014). This study shows that the attributes of the concept of coping in caregivers of older people with dementia include: (1) cognitive and behavioral efforts: cognitive processes that are constantly changing and behavioral efforts, intentional actions of cognitive and behavioral, processes that involve cognitive and behavioral approaches, cognitive and behavioral steps, and making behavioral or psychological

efforts; (2) during care/treatment: during care/treatment, the impact of care; (3) adaptation to stress: coping with difficult problems or situations, handling, overcoming, and controlling negative impacts of stressful events or situations, facing stressful conditions, dealing with problems, managing stress, adapting to care responsibilities, actively making an adaptation, and improving abilities to control; and (4) use of resources from oneself and the environment: the best way to do according to the individual abilities. In addition, there is reciprocal interaction in which individuals and the environment interact and influence each other; variations in

coping depend on the individuals, and ways of solving problems are adapted to individual circumstances and stress.

Based on the analysis of the four attributes above, an operational definition of caregiver coping is made. Coping in caregivers of older people with dementia is a cognitive and behavioral effort made by caregivers consciously to adapt by facing, controlling, and managing stressful events or situations with responsibility in providing care of older people with dementia using the available resources from oneself or the surrounding environment.

Table 1. Definition of Coping in Caregivers of Older People with Dementia and its Use in Various Disciplines

No	Definition	Discipline	Author/Year
1.	Coping is a dynamic process consisting of a series of reciprocal responses in which the individual and the environment interact and influence each other; coping includes a series of intentional, cognitive, and behavioral actions intended to control the negative impact of a stressful event or situation.	Medicine	(Monteiro et al., 2018)
2.	Coping is a process that involves cognitive and behavioral approaches to dealing with stressful conditions.	Nursing	(Sun, 2014)
3.	Coping during treatment; variation of coping depends on the individuals; individuals actively adopt and seek information to be able to deal with problems and improve control skills, but use avoidance techniques when considering future conditions and feel helpless with the burden they have.	Psychology and Social Science	(Williams et al., 2014)
4.	Coping during treatment; caregivers can adapt to the responsibility of caring.	Nursing	(Robinson-Lane et al., 2020)
5.	Caregivers understand the role in providing care and how to solve problems based on individual circumstances and stress.	Psychology	(Gottlieb & Wolfe, 2002)
6.	Coping is a dynamic process in which caregivers make behavioral or psychological efforts to manage stress appraised as exceeding their resources.	Psychology	(Kneebone & Martin, 2003)
7.	Caregivers perform different activities to reduce the impact of care.	Nursing	(Faronbi, 2018)
8.	Cognitive and behavioral efforts of caregivers to deal with stressful situations.	Nursing	(Ducharme et al., 2011)

Case identification of coping in caregivers of older people with dementia

Model Case

A child takes care of his 80-year-old mother, who was diagnosed with Alzheimer’s dementia six months ago. The mother experiences a cognitive decline and behavioral and emotional changes and requires 24-hour care from her child. Their child learns and seeks information regarding how to care for dementia (cognitive and behavioral efforts that individuals consciously carry out). The mother has been walking around all night for two days, not sleeping, not taking a shower, getting angry, and throwing things when asked to take a shower. The child takes a deep breath to control his anger and communicates calmly (adapting to face, control, and manage a stressful event or situation) as he should provide the best care for his mother (responsibility during care/treatment) because, from the knowledge he has obtained, behavioral changes in his mother occur due to the impact of dementia (using available resources from the individual or surrounding environment).

In the case above, the caregiver has a positive coping with the stressor he is facing. His actions in caring for an older person with dementia illustrate the attributes of the concept of coping in caregivers of older people with dementia. The caregiver makes cognitive and behavioral efforts by learning and seeking information related to the care, and adapting to face, control, and manage a stressful event or situation by controlling anger and communicating calmly with the patient. In addition, the caregiver adapts positively to improve health status and responsibility by

providing the best care and using the available resources from oneself or the surrounding environment with the knowledge that he has obtained.

Borderline Case

A wife takes care of her husband, who has Alzheimer’s dementia. The husband has a cognitive decline, so he forgets his wife. The wife diligently follows the instructions of the health workers in caring for her husband (cognitive and behavioral efforts that the individual consciously carries out). The wife realizes that her husband no longer remembers her due to the disease, as explained by the health workers (adaptation to face, control, and manage stressful events or situations). The wife cares for her husband with love though the husband does not recognize her (responsibility during the treatment).

The case above is an example of a borderline case for the concept of coping in caregivers. The caregiver makes cognitive and behavioral efforts to overcome stressors and is responsible during the care. Therefore, several attributes related to the concept of caregiver coping are found in this case. However, one attribute does not appear, namely the resources used in dealing with stress.

Contrary case

A grandson takes care of his 70-year-old grandmother diagnosed with Alzheimer’s dementia. The grandmother is wandering and requires 24-hour supervision. This condition makes the grandson tired and often angry as he is confused by his grandmother’s behavior (no cognitive or behavioral

effort). The grandson sometimes yells at his grandmother because she often goes into other people's homes. This condition makes him feel embarrassed (not adapting to stress), so the grandmother is placed in a locked room (no responsibility during the treatment as this is the best way to do, according to the grandson, to prevent the wandering behavior of his grandmother (do not use the resources that exist in the individual or the surrounding environment)).

The case above illustrates an example of the absence of caregiver coping. Caregivers experience negative impacts in caring for an older person with dementia and perform acts of violence against this individual. Caregivers can minimize the impact of treatment if they have effective ways to adapt to stress and effective coping strategies (Mausbach et al., 2012).

Antecedents and consequences of the concept of coping in caregivers of older people with dementia

Antecedents

Antecedents are the elements or events that should exist before a concept can occur (Walker & Avant, 2014). The antecedents of caregiver coping are the characteristics of caregivers, including age and education; stressors that include the functional status of people with dementia, behavioral and memory problems in people with dementia, and length of care for people with dementia (Pearlin et al.,

1990); and caregivers' assessment of an event (Haley et al., 1987).

Consequences

Consequences are the events resulting from the concept (Walker & Avant, 2014). Caregiver coping has positive and negative impacts. The positive impact of caregiver coping is manifested in problem-focused coping that can increase the caregiver's resilience (Wilks et al., 2011). Other studies have shown that caregivers' problem-focused coping can increase the ability to control problems (Williams et al., 2014) and is associated with positive acceptance (Hawken et al., 2018). Coping also positively correlates with quality of life (Rodríguez-Pérez et al., 2017). On the other hand, the negative impact of caregiver coping is shown by avoidance coping which will increase the burden on caregivers, increase depression, and decrease life satisfaction (Mausbach et al., 2006). Another study showed that caregivers' dysfunctional coping is associated with anxiety and depression (Maria Garcia-Alberca et al., 2013).

Figure 1 shows that the antecedents of coping in elderly caregivers include the characteristics of caregivers, stressors, and caregivers' assessment of an event. In addition, the attributes of coping include cognitive and behavioral efforts during the care/treatment, adaptation to stress, and use of resources from oneself and the environment. Meanwhile, the consequences include positive impacts and negative impacts.

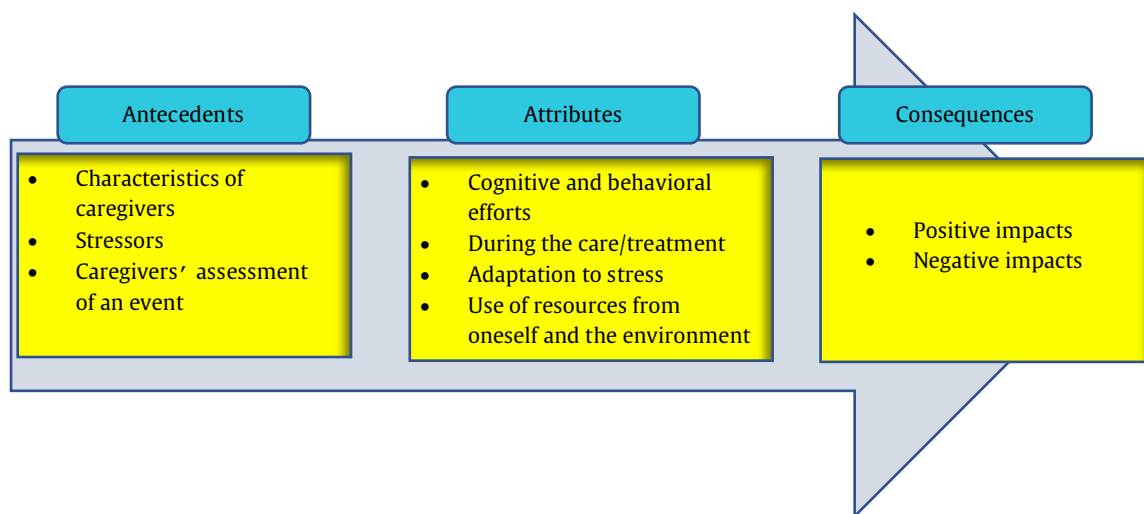


Figure 1. Antecedents, attributes, and consequences of coping in caregivers of older people with dementia

Empirical Referent

An empirical referent is a validated technique to measure a concept and is often used for research purposes (Walker & Avant, 2014). Empirical referents are classes or categories of actual phenomena which, due to their existence, demonstrate the occurrence of the concept itself (Walker & Avant, 2014). Empirical referents of caregiver coping are adaptation and adjustment. Adaptation is a process of psychological adjustment due to existing stressors by providing a self-defense mechanism with the hope of being able to protect or survive from attacks or unpleasant things. Adjustment is the ability to cope with pressure from the needs, frustrations and the ability to develop appropriate psychological mechanisms.

Coping is a broad concept with numerous techniques of measurement. Lazarus and Folkman developed a questionnaire to measure coping, i.e., *Ways of Coping*. This questionnaire consists of 50 questions and has two main aspects: problem-focused solving and emotional-focused coping. Meanwhile, a questionnaire that specifically measures coping for caregivers was developed by Magliano et al., i.e., the *Family Coping Questionnaire (FCQ)*. This questionnaire explores caregiver coping, which includes information, positive communication, social interest, coercion, avoidance, resignation, and patient social involvement (Magliano et al., 2000). Furthermore, since FCQ does not contain the element of religion, Ibrahim et al. developed the *Caregiver Cope (CgCope™)* questionnaire, which includes distraction, caring, venting, religion,

recreation, emotional support, and instrumental support (Ibrahim et al., 2017).

CONCLUSIONS AND SUGGESTIONS

The concept of coping in caregivers of older people with dementia is complex, multi-dimensional, and dynamic. The analysis shows that coping attributes of caregivers of older people with dementia include cognitive and behavioral efforts in providing care, stress adaptation, and use of resources on oneself and the environment. Antecedents of coping include characteristics of caregivers, stressors, and caregivers' assessment of an event. Meanwhile, the consequences include positive impacts and negative impacts. Coping in caregivers of older people with dementia is a cognitive and behavioral effort made by caregivers consciously to adapt by facing, controlling, and managing stressful events or situations with responsibility in providing care of older people with dementia using the available resources from oneself or the surrounding environment. Therefore, this concept analysis is expected to increase the knowledge and motivation to conduct further theory development and research related to caregiver coping and the application of this concept.

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