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Article Review

The Burden of Care of People with Schizophrenia: a concept analysis

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Abstract

The term burden of care has been widely used in current nursing reference sources, but the definition of the concept of the burden of caring for caregivers of people with Schizophrenia has never been studied. Therefore, this article aims to analyze and provide relevant information related to the caregiver burden of people with Schizophrenia. This literature study uses an electronic article search tool from several online database sources such as (CINAHL (Cumulative Index for Nursing and Allied Health), PubMed, Google Scholar, Cochrane Library), health official websites (both non-government or government), and dictionaries. This analytical study adopts the principles of Walker and Avant to identify the attributes, antecedents, and consequents of this concept. This study has identified the attributes, antecedents, and consequences of the concept of caregiver burden of people with Schizophrenia. The attributes include Unequal distribution of responsibilities, persistent fatigue, and perception. Meanwhile, the antecedents are a lack of formal and informal social support, the conflict of various duties, and limited social activities. The last, in this study, has revealed the concept's negative consequences, including decreased quality of care, poor quality of life, and physical and psychological problems. A clear understanding of the caregiver burden of people with Schizophrenia has been defined. The results of this study can be used as a knowledge base for scientific development to improve the quality of nursing interventions, especially for caregivers of people with Schizophrenia.

INTRODUCTION

Schizophrenia is defined as a chronic and serious mental illness characterized by disturbances in thinking, perception, emotion, language, sense of self, and behaviour and is often accompanied by experiences of hallucinations and delusions.[1] More than 20 million people worldwide have been affected by Schizophrenia.[2] In the past, schizophrenic patients were only treated in hospitals, while today, caring for patients will be carried out by their families at home.[3] The shift from hospital-based to community-based care has identified the family as caregivers.[3] In Indonesia, almost all discharged schizophrenic patients will return to their own homes in the community.[4] The shift from hospital-based care to community-based care requires the joint role of health care providers, patient

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families, the wider community, and the function of policy markers.[4] Schizophrenia is a severe mental illness that affects the functions of thinking, perception, cognition, emotion, and motivation and can cause stress and burden on families, especially caregivers.[5]

In Indonesia, most of the caregivers of schizophrenic patients are their own families.[6] Previous studies conducted in Indonesia showed that caring for schizophrenic patients burdens caregivers.[7] The family's caregivers also suffer from financial problems and a lack of knowledge, especially information about Schizophrenia.[8] To help family caregivers care for patients at home, nurses must understand the burden of managing them.[6] Because better care prolongs the life of most people with schizophrenia, caregiver involvement is frequently required for long periods of time.[9] However, most studies on caregivers have focused on gathering information about the emotional experiences of caring for people with schizophrenia. Whereas information about the ability and knowledge of caregivers in providing care or about how they provide care to clients is minimal.[10]

Most of the findings from previous studies did not explain in detail related to the interventions needed by caregivers in accordance with the duties of the caring role, including knowledge or skills in carrying out the caregiving process. The concepts of competency, mastery, and preparedness have been considered as necessary components for effective decision-making and problem-solving by family caregivers. However, the formal care institution does not concern with these elements even though this knowledge is essential for designing and developing nursing interventions according to their needs.[11]

The caregiver burden is unique to informal or family caregivers. This term describes the cumulative physical, emotional, social, and financial impact of providing care. The lack of understanding of the burden of care can profoundly impact healthcare in the global system. This concept was chosen for analysis because the literature still debates the concept of caregiver burden, especially among the caregiver of people with schizophrenia. Therefore, this analytical study aims to define the concept of the caregiver burden of people with schizophrenia by investigating the latest and relevant resources and conducting a concept analysis. This analysis will establish a clearer understanding of the concept and motivate interprofessional communication related to the burden on caregivers as they are discussed.

METHODS

Concept Analysis Framework

To show how the burden of caring for people with schizophrenia is explained in scientific sources, this study adopted an eight-step concept analysis from Walker and Avant un.[12] 1) selection of concepts to be analyzed; 2) Determine research objectives; 3) identification of the usefulness of the concept; 4) identify the attributes contained in the concept; 5) Build a model case; 6) Identify bordering, related, and conflicting case models; 7) Identifying antecedents and consequences; 8) Defining empirical references.

A process analysis concept must be observant and careful because this process concept of analysis will produce products that will continue to be developed because what is considered accurate now is unlikely to be disproved in the future. Therefore, the process of this analysis concept must be careful, focused and detailed. Besides that, this concept analysis limits one's idea of a concept. This illustrates that the more the process of analysis of a concept, it is possible to replace one's initial idea or core idea of the concept.[12]

Selecting the concept

The concept of caregiver burden has been widely used in nursing scientific resources. However, this concept has not been interpreted in detail because there is still debate among experts regarding opinions regarding this concept.[13] Limited attention related to the issue of caregiver burden is likely to have a significant impact on the healthcare system. Due to the ambiguity and urgency of the need to define this concept, seen from the fact that there is currently a prominent and essential form of contribution to understanding the practical application of the concept of caregiver burden, this concept was chosen for analysis.

Data sources

Some related information on the caregiver burden of people with Schizophrenia was explored using an electronic article search tool from several online database sources such as (CINAHL, PubMed, Google Scholar, and Cochrane Library), health official websites (non-government or government), and dictionaries. Keywords for searching the database were "caregiver burden," which was linked with "Schizophrenia," "mental disorder," and "mental illness."

RESULTS

Related Concept

Related concepts are usually terms used interchangeably with ideas and have similar meanings, as distinguished from conceptual analysis.[12] Carer burden is a term used to refer to the combined stress (economic, psychological, and physical) felt by those providing care to others who are sick/disabled or need care because of a minor status.[13] Other terms used interchangeably include caregiver stress, strain stress, and burnout. Caregiver stress is the most common synonym researchers use to represent caregiver burden in the literature. In this conceptual analysis, I use caregiver stress as a related concept. Caregiver stress is considered both subjective and objective. Personal stress refers to the caregiver's emotional or cognitive response, such as burnout, inequality, or perceptions of the current state of parenting. Objective stress primarily reflects the caregiver's responsibilities for the care, a measure based on the care recipient's needs.[14]

Attributes

A concept has its attributes as their characteristic. Walker and Avant (2008) stated that the critical attributes of the concept being analyzed are the characteristics of the concept that repeatedly emerge throughout the literature. After the literature review, the essential attributes of the caregiver burden of people with Schizophrenia are unequal distribution of responsibilities, persistent fatigue, and perception.

1. Unequal Distribution of Responsibilities

Unequal distribution of responsibilities among caregivers due to caring for someone with a prolonged disability.[15] Due to the decline in the care recipient's cognition level, the care recipient, the problem behavior of the care recipient, the lack of support for the caregiver, and the daily needs of the care recipient, over time the caregiver can experience a burden over time. The unequal division of care responsibilities is related to the gender gap between female and male caregivers. The caregiver literature consistently shows that female caregivers are more burdened than male caregivers.[16-18] Male caregivers started seeking help earlier and realized the importance of having time for themselves. They are more willing to share some of the demands of parenting and engage in personal activities that provide respite from parenting.[17] These findings provide insight into the gendered nature of caregiving and its relationship to observed differences in care burden between male and female caregivers.

2. Persistent Fatigue

Caregivers can experience fatigue and decreased immune system function, which can affect caregivers' physical and emotional health. Caregivers experience poor emotional and physical health due to continuing to care for someone with a chronic illness.[19] In addition, caregivers may experience mental health problems, such as anxiety, depression, delusional thinking, and irritability.[20-21]

3. Perception

Caregivers' perceptions are about caregivers reflecting on personal experiences during the parenting process. According to Bhattacharjee et al.[22], caregiver burden refers to "positive or negative feelings and perceptions of caregivers related to providing care functions. Logically, caregivers feel varying degrees of burden. Another study reported that more than half of family caregivers experienced high levels of burden, but only a quarter of caregivers revealed that their burden negatively impacted their daily life.[23]

Caregiver Expense Case Model

The case model is a case from real life where all the concept's attributes are contained. This case model is the best-case example in applying this concept because all the attributes that have been defined are described in real situations.[12]

> *Mrs. Rahimah was diagnosed with Schizophrenia after her husband passed away. She has three children, of which two sons live in different cities. Fitri is her youngest daughter and is her primary caregiver. Fitri is responsible for her daily life, such as washing clothes, cooking, and preparing food for Mrs. Rahimah. In addition, Fitri is also responsible for her mother's treatment process, such as accompanying her mother to visit the hospital to check on her mother's condition. Therefore, Fitri quit her job to take total care of her mother because it was not safe for her to be left alone.*
>
> *Meanwhile, her two brothers could only come to visit her mother occasionally and mostly only called to ask how her mother was* ***(Unequal distribution of responsibilities)****. Recently, her mother's condition has gotten worse. Sometimes she doesn't even recognize Fitri, and Mrs. Rahimah often forgets to take her medicine. This condition made Fitri feel that her task was more difficult than before* ***(Perception).*** *The many care tasks that Fitri had to perform caused her to experience insomnia, become irritable, and lose her appetite, resulting in her losing weight. Apart from that, Fitri's fatigue makes her stressed and causes other health problems* ***(Persistent Fatigue).***

The case above has illustrated the use of all the attributes contained in the concept of caregiver burden of people with Schizophrenia.

Related Case

The related case is a case similar to the case model in that there are several attributes of the caregiver burden concept. However, in the related case, not all the attributes that have been interpreted are included in this case model.[12]

> *Mrs. Rahimah was diagnosed with Schizophrenia after her husband passed away. He has three children, of which two sons live in different cities. Fitri is his youngest daughter and is his primary caregiver. Fitri is responsible for her*

> *daily life, such as washing clothes, cooking, and preparing food for Mrs. Rahimah. In addition, Fitri is also responsible for her mother's treatment process, such as accompanying her mother to visit the hospital to check on her mother's condition. Therefore, Fitri quit her job to take total care of her mother because it was not safe for her to be left alone.*
>
> *Meanwhile, his two brothers could only come to visit his mother occasionally and mostly only called to ask how his mother was* ***(Unequal distribution of responsibilities)****. Fitri loves her mother very much and accepts her current situation where she is the primary caregiver for her mother while her two brothers only occasionally come to help because these are all Fitri's responsibilities as a child to serve her mother. In addition, the health workers around her house always support Fitri when she needs help. This is a source of Fitri's coping in dealing with problems from caring for her mother. This made Fitri accept her role as the primary caregiver for her schizophrenic mother.*
>
> The case above has illustrated the innate condition that feels that it has unequal responsibilities. With the help of medical personnel as a source of coping, Ftri can accept the responsibility for this treatment.

Borderline case

The borderline case is the case that contains the definition of the most dominant attribute of the concept of the burden of caring for people with Schizophrenia. However, the borderline case only has a few attributes, and not all interpreted attributes are included in this case model.[12] The borderline case helps to reflect on the defining attributes of this concept. The following is an illustration of the borderline case as shown below:

> *Mrs. Rahimah was diagnosed with Schizophrenia after her husband passed away. She has three children, of which two sons live in different cities. Fitri is her youngest daughter and is her primary caregiver. Fitri is responsible for her mom's daily life, such as washing clothes, cooking, and preparing food for Mrs. Rahimah. In addition, Fitri is also responsible for her mother's treatment process, such as accompanying her mother to visit the hospital to check on her mother's condition.*
>
> *This care task makes Fitri not have much free time to socialize with her friends and people around her house, which causes Lilis to feel isolated* ***(perception),*** *which causes her stress. Therefore, Fitri told the health workers at the hospital about her condition. Her two brothers did not provide full support in caring for her mother. They could only come to visit her mother occasionally. At the same time, Fitri has to care for her mother* ***(an unequal responsibility).***

The case above has illustrated the use of dominant attributes in the caregiver burden of people with Schizophrenia.

Contrary case

> *Mrs. Rahimah was diagnosed with Schizophrenia after her husband passed away. She has three children, of which two sons live in different cities. Fitri is his youngest daughter and is his primary caregiver. Fitri is responsible for her daily life, such as washing clothes, cooking, and preparing food for Mrs. Rahimah. In addition, Fitri is also responsible for her mother's treatment process, such as accompanying her mother to visit the hospital to check on her mother's condition. However, Fitri does not do it alone in caring for her mother. Her two older siblings visited alternately daily to give Fitri time to rest. Fitri usually cycles using her favorite bicycle in spending her spare time with*

her friends.

The example above is a good example that describes the condition of a primary caregiver who does not experience the burden of care. In the case above, Fitri did not show any defining attributes of the caregiver burden of people with Schizophrenia.

Antecedents

Antecedents are events that occur before the occurrence of the concept.[12] The reviewed studies show that the antecedents of caregiver burden are a lack of formal and informal social support, the conflict between multiple tasks, and limited social activities.

1. Lack of formal and informal social support

Informal social support is support from family caregivers who live together, children who live separately, relatives, friends, neighbors, and other non-professionals.[24] Formal social support is support from caregivers, family doctors, care managers (registered professionals who plan and manage LTC schedules for older people with disabilities), domestic helpers, visiting nurses, community health nurses, social workers, public institutions officers, etc. professionals.[25]

One study found that having informal social support was associated with a lower caregiver burden, whereas formal social support was not. A significantly lower caregiver burden was observed among caregivers with informal social support from family caregivers living with them and relatives. In contrast, among legal sources of social support, only help from family doctors was significantly associated with a lower caregiver burden.[26] In particular, perceptions of social support from caregiver families living together and children living separately were significantly associated with lower burdens. Previous studies also argue that social support from caregivers' informal interpersonal relationships can reduce caregiver burden.[27-28] Apart from receiving informal social support, legal and social help from family doctors was associated with lower burdens. This may imply that family doctors play an essential role in reducing the burden on caregivers when they are without informal social support.[26]

2. The conflict of various duties

The majority of caregiver is a spouse, mother, child, or relative who performs multiple roles. They often have difficulty balancing roles and fulfilling care responsibilities. Parenting involves physical, psychological, and spiritual support and assumptions in many other forms.[29]

Parenting includes a variety of responsibilities, such as direct care, assistance in daily activities, emotional encouragement, and medication monitoring.[30] More specifically, medication intake, follow-up visits, bathing, toilet use, changing clothes, transportation, and shopping are all included in providing care.[29]

3. Limited Social Activities

The caring process that consumes time and energy in parenting can result in loss of social networks, loss of or less time spent on paid work, changes in family roles, and less time spent on self-care and recreational activities.[31] Social participation involves social activities within the family, community, or society.[32] Decreased social participation is a relevant and modifiable risk factor for social isolation. In caregivers, social isolation implies additional problems such as depression, withdrawal, low self-esteem, self-confidence, increased perceived burden, and potential for abuse and neglect of care recipients.[33] Being socially isolated is seen as one of the most relevant consequences of providing care to others, primarily as it has been associated with reduced health and mortality in caregivers.[34] Poor social participation was associated with lower levels of life satisfaction, health problems, and death in this group.[35]

Consequence

Consequences are factors derived from the literature resulting from the concept.[12] Consequences of caregiver burden include decreased quality of care, poor quality of life, and physical and psychological health problems.

1. Decreased quality of care

Caregivers who experience a burden without adequate support or resources cause a decrease in the quality of care provided.[36] Another study stated that the quality of service decreases when the service provider experiences a burden. This may be due to decreased coping skills and a lack of emotional support for care recipients. In addition, many family caregivers report lacking the necessary skills and knowledge to provide ongoing care for people with mental illness, leaving them lacking self-confidence and feeling unprepared. Caregivers say they receive little guidance from health professionals (Nurses). They don't know how to play a caregiver.[37]

2. Poor quality of life

Findings from several studies investigating caregiver quality of life reveal that burden among family caregivers significantly affects caregiver quality of life.[38] Because caregivers spend time caring for patients every day, their daily activities are limited, and they have limited time to provide for themselves. Overall, caregivers experience a burden and share a decrease in quality of life.[39] Additionally, other studies have found that reducing the burden on caregivers can improve their quality of life. Furthermore, the effect of caregiver burden on quality of life differs according to the phase of the disease experienced by the recipient at a particular time.[40]

3. Physical and psychological problems

Caring for patients with chronic illnesses takes much time and effort, although they rarely care about themselves. Maybe it's the lack of rest time; caregivers often neglect caring for themselves, even when sick and rarely seek medical help.[41] Some studies have found that more than 50% of family caregivers report chronic health problems such as heart problems and hypertension. In addition, caregivers experiencing varying degrees of physical exhaustion and deterioration in health after long-term care are well documented in the literature.[42] On the other hand, many researchers have explained that caregivers experience psychological problems and especially feel depressed, angry, worried, guilty, and anxious.[43]

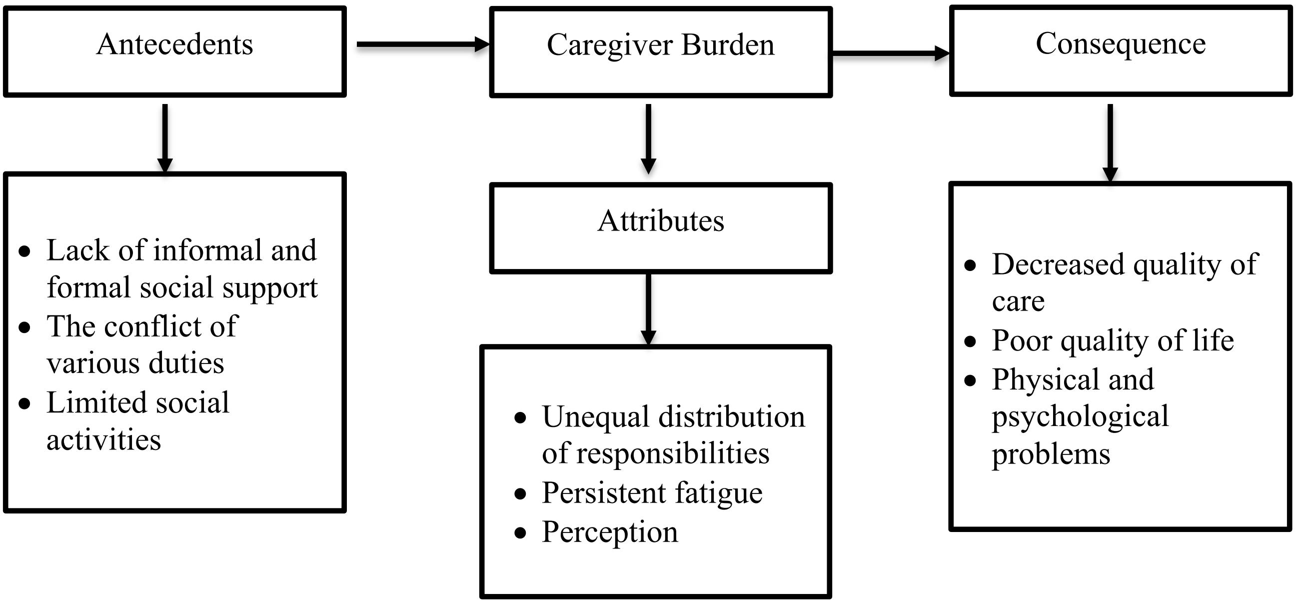

Figure 1
Conceptual Framework of Caregiver Burden of People with Schizophrenia

Empirical Reference

An essential step in the conceptual analysis used is identifying empirical sources. This step describes how a concept is evaluated or measured in reality. In the literature, several measuring instruments are used to measure this concept, but the most widely used are The Caregiver Reaction Assessment Scale (CRA) and The Zarit Burden Interview (ZBI).

1. Zarit Burden Interview (ZBI)

The first measuring tool to evaluate the effect of the care process on caregivers was developed by Zarit, Reever, and Bach-Peterson in 1980, which later, this tool was called the Zarit Caregiver Burden Interview (ZBI). Over the years, this measuring instrument has undergone many evaluations and improvements. Currently, there are several versions of the widely used measurement tool to evaluate caregiver burden, such as ZBI-7, ZBI-12, and ZBI-22.[44-45] Furthermore, this measurement tool has been available in several different language versions, such as Korean, Japanese and Indonesian. Besides that, this measuring instrument has received attention by adding a spiritual aspect to this measuring instrument.

2. Caregiver Reaction Rating Scale (CRA)

The Caregiver Reaction Rating Scale (CRA) evaluates the multidimensional feature of caregiver suffering. This is a self-declared questionnaire consisting of 24 items. The 24 items are included in 5 subscales.[39] The measure consists of subscales assessing feelings of role restraint, overload, relational deprivation, competence, personal gain, coping, trust and family conflict, work conflict, and financial disruptions. CRA, however, aimed to assess the caregiver's experience with respect to the caregiver's five life domains: daily schedule, financial situation, relationships with others, and caregiver's physical strength and self-esteem. These five domains represent a core set of caregiver experiences in informal settings.[46]

CONCLUSION

This analysis provides an in-depth understanding of the caregiver burden of people with schizophrenia by identifying the background, main characteristics, and case models that define the concept of caregiver burden in the context of advanced lung cancer. These factors include caregiver characteristics (age, gender, education, and ethics), health status, inadequate financial resources, and social support. Using these antecedents and predictors will lay the foundation for early identification of caregiver burden and help direct research around these potentially harmful events.

Three attributes are the attached caregiver burden of people with schizophrenia, unequal distribution of responsibilities, persistent fatigue, and perception. This concept must be adequately understood. A strategy for identifying caregivers of patients with schizophrenia and screening for antecedents and characteristics of caregiver burden is needed; it can prevent the negative consequences associated with caregiver burden.

A detailed explanation of the concept of caregiver burden is also essential to help health professionals and the general public better understand caregiver burden. This study defines the meaning of caregiver burden. Health professionals and caregivers need to understand the issue's significance from the caregiver's point of view.

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