
Caregiver Burden: A concept analysis

Mrs. Shweta Thorat* & Dr. Pratiksha Patrick**

**Ph.D Scholar, Malwanchal university Indore*

***Guide- Dr.Pratiksha Patrick (Professor)
S.S Institute of Nursing Sehore (M.P)*

I. INTRODUCTION

With an aging population that continues to grow and the number of people living with chronic disease increasing, health care is shifting from hospital to community and family[1,2]. Family members are key to the delivery of long-term care for patients and loved ones[3,4]. An abundance of research notes that family caregivers experience a significant burden in providing care to patients with specific illness such as mental health illness [5], parkinson disease [6], dementia [7] and terminal cancer [8]. Although the concept of caregiver burden is not uncommon in the field of nursing research, a clear definition of “caregiver burden” is lacking [6,7]. Tamizi et al. [9] undertook a systematic review on the concept of caregiver burden in relation to schizophrenia and Mulud [10] conducted a concept analysis on caregiver burden in mental illness. Little is known about caregiver burden when caring for an individual with Alzheimer’s disease. The concept caregiver is often used interchangeably with terms such as “stress, problem and negative effects” [7], leading to a clear lack of understanding of the concept. Therefore, the aim of this paper is to clarify the concept of caregiver burden by reviewing the most recent and relevant literature and undertaking a concept analysis. The paper will be guided by the Walker and Avant’s framework [11].

Caregiver stress: Caregiver stress is considered both subjective and objective. Subjective stress refers to the emotional or cognitive responses of the caregiver, such as fatigue, inequality, or the perception of the current state of caregiving. Objective stress mainly reflects the care responsibility assumed by the caregiver, which is a measurement based on the need of care-recipients [15,16].

II. THE DEFINING ATTRIBUTES OF CAREGIVER BURDEN

The key aspect of a concept analysis is to determine the defining attributes. Attributes are the features that appear repeatedly in the literature and are the critical attributes of the concept according to Walker and Avant [11]. The three key attributes of caregiver burden identified from the literature are self-perception, multifaceted strain, and over time.

Self-perception (perceived by an individual)

Self-perception is about the caregiver reflecting on personal experience during the caregiving process. Even though the literature alludes to subjective and objective perception, the author of this article believes that caregiver burden can be subsumed into self-perception. According to Bhattacharjee et al. [17], caregiver burden refers to “the positive or negative feelings and perceptions of the caregiver associated with providing caregiving functions”. It is logical that

among caregivers in the same nursing context, the level of perceived burden varies. A mixed approach study on caregiver burden conducted by De Korte-Verhoef et al. [18] reported that more than half of family carers experienced a high level of burden; however, only a quarter of the caregivers expressed that their burden negatively affected their daily life.

Multifaceted strain

The fact that caregiver burden is multidimensional has been extensively demonstrated in the literature. Due to the long-term care, the caregivers of patients with end-stage cancer pay limited attention to their own state of health [4] and often suffer from health problems, such as weight loss, fatigue and sleep disturbances [19]. Emotional distress and psychological stress [19] are also common among carers. In terms of family function, numerous studies [19] have illustrated that caregiver burden often causes alienation or deteriorates of family relationships. Furthermore, providing long-term care [21] can disrupt the caregiver's schedule and lifestyle [20], thereby limiting social activities [19] and, resulting in the feeling of being socially isolated. Varying degrees of economic problems faced by caregivers have also been frequently report.

Over time

Caregiver burden, in essence, is not always static [22,23]. Many published studies suggest that the longevity of caregiving, social/family support, and the trajectory of disease are all factors that significantly affect the level of burden on caregivers [21,22,23]. A longitudinal study conducted in Taiwan indicated that the overall burden levels perceived by caregivers changed dynamically over time and that having another family member in need of care or no one who could share the care task was significantly correlated with change in the caregiver burden. On the other hand, a cross-sectional investigation from Malaysia was conducted among family caregivers of chemotherapy patients, and a scaled assessment illustrated that the burden on caregivers decreased over time. According to the stress adaptation theory, caregivers master various nursing skills step by step over time and gradually adapt to the pressure brought by caring tasks [21]. The results of a quantitative study of the informal caregivers' burden of breast cancer patients showed that the external support can help caregivers adapt to changing roles, thereby reducing the burden [22].

III. ANTECEDENTS OF CAREGIVER BURDEN

Antecedents are events that take place before the occurrence of the concept [24]. The reviewed studies show that the antecedents of caregiver burden are insufficient financial resources, multiple responsibility conflict and lack of social activities.

Insufficient financial resources

The cost of care is one of the key indicators of caregiver burden [25]. Carers often leave full time employment in order to care for loved ones which in turn can have an effect on the financial resources of carers. It has been reported that eighteen percent of caregivers report financial stress due to the provision of care [26].

Multiple responsibility conflict

The majority of caregivers are spouses, children, or relatives who perform multiple roles. They often struggle to balance these roles and fulfil caring responsibilities. Caregiving not only involves physical, psychological and spiritual support but also assumes many other forms. Caregiving covers a wide range of responsibilities, such as, direct care, assistance in daily activities, emotional encouragement and medication monitoring [3]. More specifically, medication intake, follow-up visits, taking a bath, using the toilet, changing clothing, transportation, shopping are all included in care delivery tasks [27]

Lack of social activities

Caregiver burden is usually experienced by those who provide long-term care to others. Goldstein et al. [32] described caregivers with restricted social networks are more prone to feeling burdened, which is consistent with the finding reported in previous studies [13,28].

Consequences of caregiver burden

Consequences are the factors derived from the literature that result from the concept [24]. The consequences of caregiver burden include negative consequences; decreased care provision, decrease in quality of life, physical and psychological health deterioration. The consequences of caregiver burden include consequences related to the caregiver and care recipient.

Decreased care provision

One of the consequences of caregiver burden is reduction in care provision. Caregivers experiencing caregiver burden without adequate support or resources, leads to a reduction in the quality of care provided. A study by Given et al. [29] claims that the quality of care is reduced when a care giver is experiencing burden. It may be manifested due to a decreased coping ability, and lack of emotional support for the care-recipient. Furthermore, a child's state of health (including physical and mental) is influenced by the physical and mental state of the parent (caregiver) and his/her perception of the child's condition.

Decrease in quality of life

Several studies investigating the quality of life of caregivers show that caregivers' quality of life is significantly related to caregiver burden [30], and that reducing caregivers' burden can improve their quality of life. As caregivers spend periods of time caring for patients every day, their daily activities are limited, and they have limited time to attend their own needs. Overall, caregivers experience caregiver burden and have a reduced quality of life. According to research of Weitzner et al. [33], the effect of caregiver burden on quality of life differs according to the phase of illness the recipient is experiencing at any given time.

Physical and psychological health deterioration

Caregivers devote a large amount of time and energy to caring for their loved ones while seldom caring about themselves. Because of the lack of rest time, caregivers often neglect to take care of themselves, even when sick, and rarely seek medical help [31]. More than 50% of family caregivers report chronic health issues such as heart problems and hypertension. Additionally, caregivers experienced varying degrees of physical fatigue and decreased health after long-term care are also well documented in the literature. On the other hand, researchers at home and abroad have described that caregivers experience' psychological

problems and primarily feel depressed, angry, worried, guilty, and anxious. Family caregivers helping during the late stage of cancer had significantly more anxiety/depression than the general population and were more susceptible to mental impairment [31].

- IV. **Objectives** of this study are the Caregiver burden is used frequently within the nursing literature. It has not yet been clearly defined as there are different opinions regarding this concept. The purpose of this paper is to provide clarity surrounding the concept caregiver burden.
- V. **Results** showed that At total of 33 articles were included. The three attributes of caregiver burden were identified as self-perception, multifaceted strain, and over time. The antecedents included insufficient financial resources, multiple responsibility conflict, lack of social activities. The consequences of caregiver burden resulted in negative change which included decreased care provision, decrease in quality of life, physical and psychological health deterioration.

Caregiver burden can be defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member [13]. Caregiver burden is related to the well-being of both the individual and caregiver; therefore, understanding the attributes associated with caregiver burden is important.

Hoening and Hamilton [12] first proposed the concept of burden and believed that burden could be divided into subjective and objective burden. Subjective burden primarily involves the personal feelings of carers generated while performing the caring function, while objective burden is defined as events or activities related to negative caring experiences [12]. Zarit, Reeve, and Bach-Peterson [13] delineated burden as “the extent to which caregivers perceived their emotional, physical health, social life, and financial status as a result of caring for their relative” (p. 261). In addition, these authors considered burden to arise from a particular, non-objective, explanatory procedure [13]. Collins et al. [14] proposed that caregiver burden refers to psychological pain, physical health issues, financial and social strains, impaired family relationships, a sense of hopelessness and other negative outcomes of care tasks.

Study concluded that it's a definition of caregiver burden was developed. Tools to measure caregiver burden were identified. The findings from this analysis can be used in nursing practice, nursing education, research and administration. Clarifying the concept of caregiver burden is essential for helping healthcare professionals and the general population to obtain a better understanding of caregiver burden. This paper clearly clarifies the meaning of caregiver burden. It is necessary for healthcare professionals and caregivers to clearly understand the meaning of caregiver burden from the perspective of the caregiver. Nurses can now assess caregiver burden by using measurement tools and thus develop interventions and support mechanisms to support caregivers. This concept analysis provides information which can be used in nursing practice, education, research and management.

FUTURE IMPLICATION IN NURSING

Having a deep understanding of the concept of caregiver burden is key to understanding caring from the perspective of the caregiver. Healthcare organizations need to implement support structures to alleviate caregiver burden on caregivers. Caregivers play a vital role in

reducing costs and resources on the healthcare system by caring for loved ones at home. Therefore, it is essential to take care of caregivers to reduce the long-term effects of caregiver burden.

Further studies are recommended to determine caregiver burden from the perspective of the care recipient. Additionally, developing new strategies for specific diseases and expanding the research scope of caregiver burden are also critical.

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