**Review Article**

**Caregiver Burden: A Concept Analysis**

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**Abstract**

Caregiver burden is not a new phenomenon. Its existence dates back to the 1960s when Grad and Sainsbury [1] in their study of community care for the mentally ill, measured burden as any cost to the family. Since then, the concept of caregiver burden has become one of the most commonly investigated caregiving outcomes in the literature. The numerous definitions of the term have rendered it vague and elusive and, as a result, have limited its relevance in clinical practice and policy-making. Often used interchangeably with terms such as caregiver strain and caregiver stress/syndrome, caregiver burden remains to be clarified. Utilizing the concept analysis method advocated by Walker and Avant [2] the meaning of caregiver burden will be explicated and its assumptions and characteristics examined.

**Keywords:** Burden; Care; Caregiver; Strain; Stress

**Introduction**

Caregivers and caregiving has become a major public concern and priority due to their related psychological and physical problems [3,4]. The National Alliance for Caregiving [5] reported that approximately 53 million Americans have been identified as caregivers. It is estimated that by the year 2050, the number of family caregivers will have increased by 85% [6]. This dramatic prediction is directly linked to the increasing population of older adults. The CDC’s report on aging and health [6] stated that the growth in the number and proportion of older adults is unprecedented in the history of the United States. This growth has been attributed to longer life spans due to significant medical advances and to the aging baby boomers. It is estimated that by the year 2030, the older adult population will double to approximately 70-76 million as baby boomers begin to reach the age of 65, thus comprising 20% of the U.S. population [6].

The rise in the number of older adults directly mirrors the number of chronic illnesses. More than 70 million Americans ages 50 and older suffer from at least one chronic condition, with two out of every three having multiple chronic conditions [6,7]. As aging trends continue to change, the need for caregivers for older adults and for those with chronic illness continues to grow exponentially. These changes directly impact the immediate family as well as family caregiving, thus giving rise to the term ‘family caregivers’.

Family caregivers have assumed many tasks that were once provided by health care personnel with formal and specialized education [8]. The provision of these tasks can take a tremendous toll on caregivers’ well being and health as well as cause significant costs to families and society [9]. The physical and emotional strain that accompanies caregiving has given birth to a concept referred to as ‘caregiver burden’. Caregiver burden is not a new phenomenon. Its existence dates back to the 1960s when Grad and Sainsbury [1], in their study of community care for the mentally ill, measured burden as any cost to the family. Since then, the concept of caregiver burden has become one of the most commonly investigated caregiving outcomes in the literature. The numerous definitions of the term have rendered it vague and elusive and, as a result, have limited its relevance in clinical practice and policy-making [10]. Often used interchangeably with terms such as caregiver strain and caregiver stress/syndrome, caregiver burden remains to be clarified.

Utilizing the concept analysis method advocated by Walker and Avant [2], the meaning of caregiver burden will be explicated and its assumptions and characteristics examined. In order to define the concept of caregiver burden, the two words will be examined both separately and as a term.

**Assumptions**

The assumptions that underlie the concept of caregiver burden include the following: caregivers are primarily women; male caregivers experience lower caregiver burden than do women; caregivers are young in age; caregiver burden increases the vulnerability of disabled elders to nursing home placement; and burden is strongly related to the severity of the patient’s disabilities [11].

**Definition and Uses of the Concept**

The term burden was first defined clinically as any negative consequence that occurs to the family of which the patient is a member [1]. In 1966, Hoening and Hamilton [12] were the first to examine burden as a concept and divided it into its subjective and objective dimensions. Events and activities associated with negative caregiving experiences were termed an objective burden, while the feelings that were awakened in caregivers as they undertook their caregiving tasks were referred to as a subjective burden [13], further explored the two terms. They defined objective burden as a negative psychological state that results from the perception that caregiving activities and responsibilities are infringing on other aspects of the caregiver’s life; these include time and energy to address other family obligations, leisure activities, and personal needs. They defined subjective burden as the caregivers’ attitude toward or emotional reactions to the caregiving experience. Similar definitions were reported by Fekete, et al. [14], where subjective burden was associated with poor health outcomes [15]. argued that a caregiver’s perception of burden is believed to change as the demands and the extent of caregiving involvement change, noting that what a caregiver considers burdensome at one time might change with the development of new coping mechanisms to deal with the patient’s impairment or be replaced with new problems or crisis situations.

Burden is also frequently referenced in the Bible. From a Christian perspective, burden is viewed as a severe task (Exodus 2:11). Those who are strong have an obligation to care for the weak and to carry each other’s burdens, as this will fulfill the law of Christ: Love one another as Christ loved you (Romans 15:1-2; Galatians 6:2). In addition, 1 Timothy 5:8 states that, “if anyone doesn’t take care of his own relatives, especially his immediate family, he has denied the Christian faith and is worse than a non-believer.” For Christian believers, caregiving becomes an obligation that has been bestowed upon them. When the burden becomes too heavy, Christians are urged to cast their problems over to the Lord and He will take care them (Psalms 55:22) [16], in their study on caregivers of dementia patients who attended church on a regular basis, found that church attendance was associated with lower depression, lower self-rated health, and greater life satisfaction.

In 1958, sociologist George Homans [17] introduced the social exchange theory, which posits that people consciously or unconsciously account for the exchange of costs and benefits in relationships and favor relationships with the greatest benefits. From a social exchange perspective, caregiver burden is theoretically defined as an evaluative outcome of an ongoing relationship between caregiver and care-receiver. This theoretical model suggests that the caregiver might enter a relationship with an expectation of obtaining personal or interpersonal rewards in exchange for providing care. When these expectations are not met, the act of caregiving becomes burdensome. The demands and needs of the care-receiver may become more than the caregiver had initially anticipated, thus leading to a negative evaluation of the relationship [18].

The caregiver identity theory views caregiving as a journey that includes a series of transitions that normally results from changes in the caregiving context and in personal norms that are grounded in familial role and culture [13].

The theory suggests that the caregiving role emerges out of a prior familial role, most often the role of child or spouse [13]. further state that in time, the changes that occur in a caregiving context, such as the declining health and increased dependency of the care-receiver, is what leads to changes in the caregiver’s behavior and creates an identity discrepancy. Identity discrepancy is defined as a disparity between the care activities in which a caregiver is engaging and his or her identity standard, or personal norms. The identity discrepancy is what is manifested as burden or stress [13].

Merriam-Webster (2014) defines ‘care’ as suffering of mind, a disquieted state of mixed uncertainty, apprehension, and responsibility, while the Oxford English Dictionary (OED) defines it as a “Burdened state of mind arising from fear, doubt, or concern about anything; solicitude, anxiety, mental perturbation.” ‘Give’ has been defined as “to bestow gratuitously; to render (a benefit or service) without payment.

**Related Terms**

Two related terms are sometimes used interchangeably in relation to caregiver burden: caregiver strain and caregiver stress/syndrome [19]. defined caregiver strain as the difficulties encountered while performing the caregiver role and is characterized by providing direct care and by tension, worry, economic burden, communication problems, and lack of support or resources, while Piesyk [20] defined caregiver stress/syndrome as a condition of exhaustion, anger, rage, or guilt resulting from unrelieved caring for a chronically ill dependent.

**Defining Attributes**

According to Walker and Avant [2], defining attributes are the characteristics of a concept that appear over and over and that provide a deeper insight into the concept being analyzed. The defining attributes of caregiver burden that seem to reoccur in the literature include entrapment, resentment, guilt, ambiguous loss, and overload, and the phenomenon is an ongoing process (Figure 1).



**Figure 1**: Caregiver Burden Model.

Entrapment is defined as an experience associated with a high degree of desire to escape, sometimes with fantasies of escaping but feeling blocked or unable to do so. Caregivers may develop a sense of being trapped due to the increasing demands of caring for their family members [21].

Harboring feelings of resentment is another attribute of caregiver burden. According to Williamson, et al. [22] caregivers may resent care-recipient dependency and the caregiving process. Resentment includes harboring ill feelings toward the care-receiver, which ultimately leads to tension in the relationship, feelings of burden, and intense feelings of anger.

Guilt is experienced and expressed through a concern for ‘the other’ and requires empathy. The feeling of guilt is accompanied by a concern and fear of having caused harm to the care-receiver [23].

Ambiguous loss, also referred to as “chronic sorrow,” is a loss that remains unclear and thus has no closure. This loss cannot be clarified, cured, or fixed; the grieving process has no end. Ambiguous loss has been categorized into two types: physical absence with psychological presence and psychological absence with physical presence. Caregivers normally experience the psychological absence of the family members and may describe the care-receiver as being “Here but not here” [24].

Overload is a situation whereby the perceived demands exceed the resources available to the caregiver. The demands may arise from the care-receiver, work, society, and family members, while the resources may develop from the caregiver or other support systems. The caregiver might feel burdened with the increasing demands of the care-receiver when these exceed the resources available [25].

Caregiver burden is an ongoing process. According to Perlick, et al [15], burden changes over time as the demands and involvement of caregiving increases. As caregivers develop coping skills to tackle old problems or obstacles, new problems might arise. Therefore, tasks that were once considered burdensome might be replaced by new tasks that are perceived to be even more taxing.

**Antecedents and Consequences**

According to Walker and Avant [2], antecedents are the events or incidents that must happen before the occurrence of a concept. For the concept of caregiver burden to occur, an individual must have a pre-existing relationship with the care-receiver. Savundranayagam, et al. [26] state that the pre-existing interpersonal relationship between the caregiver and care-receiver is what facilitates the existence of a burden due to the caregiving responsibilities that the caregiver assumes. Chronic illness is another antecedent that must occur for a caregiver to feel burdened with caregiver tasks. The burden of care emerges due to the never-ending nature of chronic or progressive illness [27].

Disruption of a caregiver way of life is another antecedent that can bring about burden due to a longing by caregivers for their previous life prior to the illness of a family member. According to Pehler, et al. [28], longing appears as an interruption within a person’s relationships, health, and/or purpose in life due to illness, injury, disability or death. Financial difficulties are brought about by the increasing needs of the care-receiver requiring the caregiver to be more present. Caregivers have had to quit their jobs, retire early, reduce their hours, or take a leave of absence in order to take care of family members [29-31]. found that family caregivers with the lowest income reported the highest burden in terms of both the number of hours they spend helping their family member and in their actual proportion of income spent on care. For caregivers with a low education level, the concept of caregiver burden stemmed from the inadequate amount of information and the inability to access information.

Rammohan, et al. [32]. stated that caregivers with a low education level predominantly come from a lower socioeconomic background and are also afflicted with financial difficulties, thus contributing largely to the perception of burden.

Poor social support is one of the highest indicators of caregiver burden [33]. Social support refers to the availability of people that individuals feel they can access and rely on for tangible and intangible assistance as well as emotional support [34]. Support refers to a generalized appraisal that individuals develop in the various role domains of their lives in which they believe that they are cared for and valued, and that significant others are available to them in times of need [35].

**Consequences**

Consequences are those events or incidents that arise as a result of the occurrence of the concept, thus providing ideas and thoughts that can steer research into new directions [2]. Social Isolation is one of the consequences of caregiver burden [36]. defined social isolation as the distancing of an individual, psychologically and physically, from his or her network of desired or needed relationships. They further defined isolation as a loss of place within one’s group, which can be voluntary or involuntary. Social isolation is usually accompanied by feelings of aloneness, loss, and solitude.

Most caregivers also experience psychological problems during the caregiving process, such as depression and anxiety. Seligman [37] states that depression occurs when individuals have no control over their environment. Depression as a state of mind and body characterized by a change in mood toward being miserable, worried, discouraged, irritable, unable to feel emotion, fearful, despondent, hopeless, or ‘down in the dumps’. Several studies have reported that increased caregiver burden is associated with higher depression [33,38]. In a study of 180 family members [38], found that higher depressive scores were significantly associated with higher caregiver burden. Almost half of the family members in this study had clinically significant levels of depression, a finding consistent with research by Doyle, et al. [33].

The American Association of Psychiatry (2010) defined anxiety as an emotion characterized by feelings of tension, worried thoughts, and physical changes such as increased blood pressure. People with anxiety disorders usually have recurring intrusive thoughts or concerns. Caregivers with the highest burden have been reported as also experiencing higher levels of anxiety and anger, and physical health problems [39].

Family conflict is another consequence of caregiver burden. Conflicts among family members may arise due to the primary caregiver’s dissatisfaction with the amount of support received from the rest of the family members, thus arousing anger, negative self-evaluations, and depression [40,41] also confirm that conflicted families ultimately interfere with the caregivers’ ability to cope with the emotional distress that frequently accompanies a caregiving situation.

**Cases**

**Model Case**

Mrs. Bennett prided herself on being an accomplished mother of four children, ages 16 to 22, and a loving wife. She was also able to maintain a fulltime job and once a week would take some ‘me time’ to attend ballet classes for adults. Mrs. Bennett loved to talk about her children, especially John, her oldest son, who was in the military and stationed in Iraq. Life was blissful until John returned from war at the age of 22 and was not the same John: he was diagnosed with Mild Traumatic Brain Injury (mTBI), the result of an indirect blast to his head. In addition, John was also diagnosed with schizophrenia. “I don’t know what I did wrong,” said Mrs. Bennett. “I don’t understand my son any more. He’s anxious, depressed, and sometimes he tells me that he sees things on the walls, and he talks to himself. Where did I go wrong? No one seems to understand what I’m going through. I feel alone even while taking care of my son. He’s here with me, but he’s not my John.” Mrs. Bennett stopped attending ballet classes and focused all her attention on John. Most of her friends from ballet class stopped communicating with her because they now had nothing in common. Most of her nights were spent worrying and checking on her son. John’s hospital visits became so numerous that his mother had to get a part-time job. On one occasion, John attempted to kill himself after being fired from a recently acquired job because of his lack of concentration brought about by his mTBI. Mrs. Bennett was beyond herself with grief. “I can’t take it anymore,” she told the ER nurses as she took a 0.25 mg Xanax pill. “I watch him every single day and night. I want the best for him. But what about me? This is not life. And because I’m no longer present, my husband has started cheating on me - and just look at me: I’m not desirable anymore. My other children want nothing to do with us. They’re embarrassed of us. If my own family is disowning us, who will accept us?” Unfortunately, John overheard his mother’s lamentation. A few days later, he went missing. He was found in the woods, hanging on a tree - dead. Mrs. Bennett was overwhelmed with guilt. On the day of John’s burial, she ended her own life.

**Borderline Case**

Borderline cases are those examples or instances that contain most of the defining attributes of the concept being examined, but not all of them [2].

Mia has been taking care of her husband Jose for the last five years, ever since he incurred moderate traumatic brain injury as a result of a motor vehicle accident. Both Mia and Jose are immigrants from Guatemala and speak primarily Spanish. As all their relatives are back in Guatemala, Mia is the only one who can take care of Jose. However, the two had formed close relationships with other immigrants from their country, and Mia finds comfort in speaking with them about her husband’s endless needs. These friends also assist the couple in various ways, including taking Jose to medical and psychiatric appointments. Mia has had to take on an additional part-time job at the nearest Dollar Store to supplement their household income, as Jose has not been able to get a job since the accident. Even two jobs, however, the family continues to suffer financial hardships and has had to rely on donated food and clothing to survive. This has caused a lot of distress to Mia, who always considered herself an independent, self-sufficient woman. In addition, Mia’s nights are spent calming Jose during his bouts of irritability and aggression. Mia was recently diagnosed with depression and was placed on anti-depressant medication. Jose’s constant shifts in behavior have caused a rift in their once-close marriage. Mia has often thought of divorcing her husband but usually becomes engulfed in feelings of guilt for wanting to leave him in his time of need. She has recently found a church that she now attends. Once in a while, Jose will join her in worship. Mia says that church-going has helped her find a little peace and solace in God.

In this case, Mia has obtained some social support from her fellow immigrants. She has also found additional support and some inner-peace by joining a church. Mia is lucky: most caregivers who report feeling burdened by their care-receivers usually have little-to-no social support.

**Contrary Case**

Contrary cases are clear examples of what is not the concept [2]. Bill and Mary have been married for 35 years. Both have well-paying jobs and together they enjoy a monthly getaway to the Poconos. One afternoon, while tending her flower garden, Mary fell and broke her hip. She requested time off from work for her surgery and additional physical therapy. Bill was saddened by his wife’s fall and wanted to spend as much time with her as possible during her recovery period. He was granted a month off from work and spent it taking Mary to her appointments and seeing to her needs. Prior to her discharge, Bill was taught how to assist Mary with position changes and was given additional information about hip surgery. During the last week of Mary’s recovery, Bill took her to a “Mind, Body, and Spirit” retreat for couples to help Mary get rid of any remaining stressors stemming from her acute injury. Bill says his wife’s hip injury has brought them closer as a couple and that their marriage has never been stronger.

In this case, there is an absence of caregiver burden. Although Bill was saddened by his wife’s injury, he was not consumed by it. Thanks to their well-paying jobs, both were able take time off without undue financial hardship. Bill also appears to have grasped the new knowledge and information given to him about hip surgery and position changes and was able to take Mary to her appointments. And as Mary’s injury was acute, it would eventually come to an end. Bill reported enjoying a closer relationship with his wife because of the injury.

**Empirical Referents**

The empirical referents associated with caregiver burden are measurable variables of caregiver strain/stress. Several authors have measured caregiver burden using different measurement tools. Caregiver burden was originally operationalized by Zarit, et al [42], authors of the Zarit Burden Interview (ZBI), a 22-item instrument that measures a caregiver’s perceived burden using a 5-point Likert scale. The interview questions focus primarily onthe caregiver’s overall health, psychological and financial well-being, social support,and the relationship between the caregiver and the care-recipient. Scoresrange from 0 to 88, with the highest score signifying a greater burden. Others have also developed reliable and valid measurement tools to operationalize burden. For example Lawton, et al. [43], developed the Caregiver Appraisal Scale based on Lazarus and Folkman’s [44] stress model. One of its subscales is an assessment of burden as a stressor perceived by caregivers.

The Modified Caregiver Strain Index (MCSI) was originally developed and modified by Thornton and Travis [45]. This 13-item instrument measures caregiving-related strain. There are five major domains represented in this tool: financial, physical, psychological, social, and personal. Thornton and Travis [45] collected data using the modified MCSI tool from a sample of 158 family caregivers providing assistance to older adults living in a community-based setting. Scoring is two points for each ‘yes’ and one point for each ‘sometimes’ response. The higher the score, the higher the level of caregiver strain.

**Summation and Conclusion**

This concept analysis examined the concept of caregiver burden within the broader concept of caregiving. The origin of the concept was provided, with definitions that were derived from the Bible, dictionaries, evidenced-based literature, and the theoretical approach delineated. Attributes, antecedents, and consequences were also thoroughly analyzed. Altogether, this concept analysis has provided a comprehensive appreciation of the impact of caregiving and information on the variables that can lead to caregiver burden. With this knowledge, health care providers can play an integral part in alleviating some of the burden by providing adequate information and training to anyone assuming a caregiver role. In addition, the analysis of caregiver burden has provided more explicit conceptual and operational definitions that could be effectively incorporated into future research studies.

The funnel-shaped diagram above is borrowed from a physics’ wormhole time-travel diagram. The cyclical nature of the diagram portrays how the concept of caregiver burden is an endless, on-going process that may be accompanied by guilt and feelings of resentment and loss. The narrow, redder neck of the diagram symbolizes how a caregiver might feel suffocated by caregiving tasks and thus begin to experience the consequences of caregiver burden: depression, anxiety, social isolation, low self-esteem, family conflicts, and finally death.

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