International Journal of Science and Engineering Applications
Volume 14-Issue 04, 01 – 04, 2025, ISSN:- 2319 - 7560
DOI: 10.7753/IJSEA1404.1001

Construction of a Support System for Caregiving Burnout of Family Caregivers for Elderly Patients with Chronic Diseases

Li Huijie
School of Social Undertakings

Henan Normal University
Xinxiang, China

Abstract: The issue of care for the elderly after they fall ill has become an unavoidable topic for family members, and the phenomenon of care burnout is widespread among their family caregivers. This paper conducts research on the current situation and causes of care burnout among family caregivers of elderly patients with Alzheimer's disease. From the perspectives of home-community linkage and professional intervention, it proposes the development and improvement of community care, support services provided by social workers, and the coordination of family members' participation as relief paths, with the aim of improving the situation of care burnout among family caregivers of elderly patients with Alzheimer's disease.

Keywords: Family caregivers; Caregiver burnout; Hydropower scheduling; Alzheimer's disease

1. INTRODUCTION

With the deepening of the aging process of the population, the proportion of the elderly population is constantly increasing. Alzheimer's disease has become one of the reasons for the elderly to lose their ability to take care of themselves, and patients often need to rely on the care of others to complete their basic daily life. Therefore, family caregivers are required to spend a lot of time and energy taking care of the daily life of elderly patients with Alzheimer's disease. In such a situation, the problem of caregiving burnout is extremely likely to occur. To this end, social workers provide nursing support to the family caregivers of elderly patients with Alzheimer's disease, helping caregivers improve their caregiving abilities, change their bad cognitions and negative psychological emotions. This will be conducive to alleviating the caregiving burnout of family caregivers.

2. The Current Situation of Caregiving Burnout among Family Caregivers

2.1 Torment at the physical level

Individuals experiencing caregiving burnout are prone to physical exhaustion. In particular, family caregivers under empathic stress are likely to develop caregiving burnout when taking care of Alzheimer's disease patients over a long period. The most common symptoms of caregiving burnout include: feelings of loneliness, a sense of uselessness, a feeling of being ununderstood, as well as physical symptoms such as headaches and chest tightness.[1]Sometimes, family caregivers may also be unable to distinguish the meanings conveyed by their body signals and lose sensitivity to their physical sensations. This phenomenon is known as "alexithymia". It can be seen that individuals with caregiving burnout will experience a decrease in relevant intuition and physical awareness abilities.

Currently, most family caregivers of Alzheimer's disease patients have various forms of sleep quality problems, which are closely related to the special nature of their caregiving work. For example, family caregivers often need to deal with sudden incidents, especially more prominently at night, which can prevent them from falling asleep or lead to sleep interruptions. After a sudden incident occurs, as the people who have the closest contact with Alzheimer's disease patients, family caregivers will inevitably be involved in the entire process of handling the incident and thus become involved in the event. Due to the severity of some incidents, most family caregivers will experience acute traumatic reactions such as being unable to fall asleep, having repeated nightmares, and being flooded with distressing memories after the fact. If family caregivers often experience the phenomenon of traumatic events repeatedly and uncontrollably appearing in their minds, it indicates that they have already developed symptoms of caregiving burnout.

If family caregivers can adapt to and reasonably cope with relevant stimuli, these physical reactions may gradually fade over time. However, if they are exposed to a tense traumatic situation for a long time, coupled with inappropriate adaptation and handling methods, the excessive physical reactions of the body will deteriorate.

2.2 Psychological Suppression

The psychological symptoms of family caregivers for patients are mainly manifested in two aspects: emotions and cognition. In terms of emotions, they mainly experience low mood, depression, numbness, emptiness, a sense of meaninglessness, and even despair. Family caregivers may exhibit emotional indifference due to excessive emotional consumption. Especially, some family caregivers are full of enthusiasm when they first come into contact with the patients, motivated by the traditional concept of filial piety and a sense of responsibility and obligation. However, after a few years, even when the patients encounter acute situations, family caregivers may lose their ability to express emotions and so on. When patients show agitation and aggressive behaviors, sleep problems, and abnormal motor behaviors, it will increase the physical and mental stress of family caregivers and make negative feelings more prominent.[2]Although the phenomena discussed in most cases of job burnout are similar to this, many studies have found that there are many similarities between the symptoms of caregiving burnout and job burnout. In terms of psychological emotions, caregiving burnout may also involve situations such as irritability, avoidance, anxiety, etc., and even many family caregivers develop a sense of avoidance towards the patients and relevant situations.

The changes in cognition are mainly manifested as changes in concepts. Family caregivers who experience caregiving burnout will separate themselves from the caregiving situation and lack care for the patients during the caregiving process, and deal with the interpersonal relationships with the patients in a mechanical and indifferent manner. For example, they get used to negative crisis events, feel a sense of powerlessness after a crisis event occurs, shift from being family caregivers to bystanders, or exaggerate their own responsibilities and obligations excessively, and thus get involved in the crisis events.

2.3 Pressure at the Social Level

For family caregivers, they must arrange their personal time according to the various needs of the patients in order to better serve them. While family caregivers spend a great deal of time and energy taking care of the patients, their own discretionary free time is significantly reduced. Interpersonal interactions are restricted to a certain extent. Their relationships with friends become alienated, and the number of times they participate in community activities is basically zero. Caregivers may feel that their personal life values and pursuits seem to be confined to the patients and their homes. After feeling restricted, they don't have enough energy to display their social talents. Since there are usually no other available substitutes, they generally feel that they don't have spare time to engage in recreational activities or develop their hobbies. Therefore, caregivers have a certain need to improve their interpersonal communication. Only when there are other family members who can replace them as caregivers will their personal time be relatively more flexible.

From another perspective, it can be seen that under the pressure of long-term patient care, what lies behind the caregivers' social pressure and interpersonal needs is the demand for time, manpower, and respite care services. Over time, it will exacerbate the caregiving burnout of the caregivers.

3. Direct Stimuli and Long-term Pressure: An Attribution Analysis of the Generation of Caregiving Burnout

3.1 The Degree of Exposure to Traumatic Events

As the patient's condition worsens, the levels of anxiety and depression exhibited by the cared-for individuals reach as high as 76% and 42% respectively.[3]This may have an impact on the psychological state of family caregivers. As the informal core resource for the patients, they are an important force for the quality of life of the patients in their later years. Objectively speaking, the intensity of the stimuli from the patients to the family caregivers is relatively high, and it is extremely likely to cause psychological trauma to them. Family caregivers often need to personally provide daily care and psychological support for the patients, making them prone to being exposed to traumatic situations.

The duration of contact between family caregivers and patients is related to the occurrence of caregiving burnout. At the same time, the condition, behavior, needs, and personal problems of the cared-for individuals can also trigger caregiving burnout. Different from the cared-for individuals, in addition to witnessing the stress caused by the crisis event after the patient's condition flares up, caregivers may not be able to avoid the special information related to the event like the patients do because they need to spend a great deal of energy dealing with subsequent tasks. As a result, family caregivers are continuously exposed to relevant traumatic situations, which leads to chronic trauma and then gives rise to caregiving burnout.

3.2 Overload in Long-term Caregiving

As the patient's condition deteriorates, the physical condition of the cared-for person will worsen. At this time, family caregivers are required to provide more care. However, when the needs of the cared-for person exceed the scope of what the caregiver can provide, the caregiver will experience a caregiving burden. Research has found that nearly 48% of family caregivers bear a relatively heavy caregiving burden, and the length of caregiving time is one of the main factors affecting the physical and mental health of caregivers.

In Taiwan region, more than 91.5% of the caregivers for Alzheimer's disease patients are family members. On average, they spend 2,166, 4,299, and 5,871 hours respectively on the full-time care of patients with mild, moderate, and severe Alzheimer's disease.[4]For family caregivers who need to provide long-term care, the heavy caregiving load and pressure are self-evident.

This not only significantly shortens the rest time of family caregivers. Over time, it is extremely likely to have an impact on their physical health. Moreover, most patients have symptoms of depression and anxiety, which have a serious impact on the psychological state of family caregivers. Negative emotions still exist even in the years after they stop providing care.

As a mental health problem related to work pressure, caregiving burnout is more prominent among family caregivers of patients. Currently, relevant research focuses on the needs of patients but ignores the needs of family caregivers. Under the reality of no compensation and the caregiving work that requires high emotional investment, the pressure on family caregivers gradually increases. Therefore, appropriate rest and temporary disengagement can help family caregivers relieve stress from the high-pressure environment and thus take better care of the patients.

3.3 Diversity of Roles and Role Engulfment

The most remarkable characteristic of family caregivers is the diversity of their roles. As the main force in taking care of patients, they also have to balance multiple roles such as spouse, parent, and employee. For example, many family caregivers not only need to handle their work well, but also have to take care of the patients after getting home, and at the same time, they need to deal with the relationships between husband and wife and with their children. Influenced by traditional Chinese concepts, transferring the elderly to a nursing institution is regarded as unfilial. Therefore, family caregivers must take on the task of caring for the patients.

Multiple roles will generate competitive demands for the caregivers' time and energy, which will in turn lead to mental depression. However, multiple roles can also enhance the caregivers' self-esteem and sense of identity, increase their material and social resources, enable them to establish connections with other networks, and improve the effectiveness of problem-solving.

However, in the context of taking care of patients, the lack of compensation and low emotional support make it easy for them to lose the positive support brought by multiple roles. At the same time, the diversity of roles will make the roles assumed by family caregivers compete with each other. If family caregivers fail to handle this properly, the phenomenon of role engulfment will occur.

4. Family-Community Linkage and Professional Intervention: Relief Strategies for Caregiving Burnout

4.1 Develop and Improve Community Care to Help Caregivers Get Out of Traumatic Situations

Community care originated in the UK. In order to reduce government responsibilities, the UK handed over the daily care responsibilities of psychiatric patients and the elderly to the community.[5]Community care refers to the integration of social resources and the use of social support networks to enable those in need of care to lead a normal life. One of the important reasons for the occurrence of caregiving burnout is that family caregivers are continuously in a traumatic situation. Research has found that to alleviate the problem of caregiving burnout, it is necessary to first develop community care that combines home care and community institutions to provide professional support for the cared-for individuals.

The government should continue to further promote the integration of medical and elderly care services. Through practical incentive measures, high-quality medical staff should be truly retained at the grassroots level, and then medical staff should conduct regular home inspections.[6]At the same time, certain publicity methods should be adopted to let caregivers know about the relevant policies of community care so that they can have solutions when encountering problems. However, many family caregivers said that they still cannot completely entrust the care work to the community. On the one hand, they believe that family care is more comprehensive than community care. On the other hand, entrusting the care to institutions is regarded as an act of shirking responsibility. It can be seen that community care still needs to be recognized by family caregivers.

Therefore, the government plays a very important role in elderly care services, transforming from the direct provider of elderly care services in the past to a policy maker and service supervisor. A community support network should be constructed, with social organizations as the service carriers, communities as the support, and families as the foundation. It emphasizes the participation of family caregivers, community rehabilitation coordinators, community medical staff, local police officers, and other personnel. And it advocates the coordination, sharing, and integration of social rehabilitation resources through this network[7].Eventually, it enables caregivers to temporarily get out of the traumatic situation, thus restoring their energy and emotions, and truly improving the quality of life of the elderly.

4.2 Social Workers Provide Supportive Services to Alleviate the Overloaded State

Making appropriate use of the support resources of social workers to provide nursing support services for family caregivers can help them recover both physically and mentally, enabling them to provide better care. Supportive services refer to the use of material or spiritual means to provide encouragement, assistance, or support services for family caregivers.[8]Nursing interventions can implement alternative care services, professional skills training, music meditation, and other nursing methods according to the situation of the cared-for individuals, so as to relieve the negative emotions and bad cognitions of the patients and thus reduce the burden on family caregivers.

In addition to providing skills training and alternative care, the psychological support and cognitive changes provided by social workers for family caregivers also play a very important role. They help family caregivers master some positive psychological suggestions and self-care methods. For example, family caregivers can practice meditation during non-caregiving time, trace the past, feel the present, and look forward to positive psychological suggestions for the future. They can establish supportive and intimate relationships with family members and friends, improve their self-awareness ability, timely adjust their caregiving state for patients, reflect on their psychological emotions, and solve problems in a timely manner.

Facing the pressure and emotional investment in caregiving, family caregivers should start from their own situations. First of all, they should learn to regulate their emotions and stress, and engage in appropriate physical activities and exercises, such as badminton, table tennis, jogging, yoga, etc. Secondly, they should also enhance their self-efficacy, increase the input of positive emotions, scientifically understand the importance of their own emotions, and give themselves appropriate rest time. Thirdly, resilience has a positive effect on caregiving burnout. For family caregivers, emotional investment is a kind of resource, but excessive emotional investment is a loss of resources. This loss must be replenished in a timely manner; otherwise, they will be at risk of caregiving burnout. Individuals with a higher level of resilience can adapt to more complex traumatic situations, and it also gives family caregivers more confidence and a sense of competence when facing patients. Finally, they can enhance their psychological quality by reflecting on the setbacks encountered in caregiving. At the same time, they need to reduce self-blame, recognize the importance of their own caregiving, find reasonable ways to vent, give themselves material rewards, and encourage themselves positively.

4.3 Coordinate the Participation of Family Members to Resolve Conflicts Arising from Diverse Roles

Social workers can help family caregivers integrate and mobilize resources from multiple sources.[9]Family caregivers not only have to shoulder their family responsibilities, work, and the care of their children, etc. Moreover, as the patient's condition deteriorates, caregivers need to devote more energy and time to taking care of the patients. In such a high-pressure situation, the sense of responsibility stemming from blood relations often outweighs their own well-being. This leads caregivers to show excessive understanding and sympathy for the patients' situations, making it inevitable for them to fall into anxiety and depression. There is also a high probability that it will trigger caregiving burnout, resulting in a general decline in the desire, ability, and energy to care for others.

The relatives of family caregivers are also important informal resources, and attention should be paid to giving full play to the roles of these resources during the caregiving process. Therefore, social workers can convene the caregivers' relatives to discuss their participation in caring for the patients and the possible problems that may arise during the caregiving process. Then, they can negotiate solutions to these problems and arrange for appropriate rotational care, which has a positive impact on both the patients and their caregivers.

The care provided by other family members not only enables the patients to feel valued, thus regulating their negative emotions with the company and support, but also helps family caregivers better resolve the conflicts arising from diverse roles, balance their work and family life, and ultimately alleviate the problem of caregiving burnout.

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