Caregiver Burden and Coping Strategies in Caregivers of Elderly Patients with Stroke

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Abstract

Background

Coping strategies play a key role in modulating the caregiving burden. The present study was aimed to determine the severity of the burden of care and its relationship with coping strategies among caregivers of post-stroke elderly patients in Zanjan City, Iran.

Methods

A total of 110 caregivers of elderly patients who had previously had a stroke participated in this descriptive and cross-sectional study. A demographic checklist, Zarit Burden Interview, and Lazarus and Folkman questionnaires were used for data collection. Questionnaires were completed by the caregivers, who were selected using convenience sampling. The collected data were analyzed using Pearson's correlations and independent t-tests.

Results

The mean age of 110 caregivers participated in the study was 32.09 ± 8.70 years. The most commonly used coping strategies were reappraisal and seeking social support. Results of the independent t-test showed that male caregivers used the reappraisal strategy (t(110) = 2.76; p = 0.007) and responsibility (t(110) = 2.26; p = 0.026) significantly more than female caregivers. Pearson's correlation showed a significant positive correlation between caregiver burden and emotional-focused strategies including escaping (r = 0.245, P = 0.010) and distancing (r = 0.204, P = 0.032).

Conclusions

Based on the results, caregivers with higher burden care used more negative coping strategies, such as escape and distancing. In order to encourage caregivers to utilize effective coping skills, appropriate programs should be designed and implemented to support caregivers. Use of effective coping skills to reduce the level of personal burden can improve caregiver physical health and psychological well-being.

Background

The world's elderly population is projected to continue to grow at an unprecedented rate due to improvement in life expectancy and health care techniques (1). Aging is a period of life in which the elderly are exposed to potential threats such as chronic conditions, loneliness and isolation, lack of social support, and a decline in independence (2). Chronic diseases tend to become more common with age (3). Aging is a well-known risk factor for the increase of multiple chronic diseases, including cardiovascular disease, stroke, cancer, osteoarthritis, and dementia (3). Approximately 80% of older adults have at least one chronic disease; the cost and duration of treatment for these diseases is 20 to 30 times higher than acute illnesses (2).

One of the major health problems among the elderly is stroke. It is the third leading cause of death in the world after cardiovascular diseases and cancer (4, 5). Stroke is a major cause of disability and disease burden worldwide (6). A stroke is one of the most severe neurological disorders and results from a decrease in cerebral blood flow in certain parts of the brain due to vascular injuries (7). Given that patients often need long-term care, the role of home caregivers is critically important (8).

Caregivers are divided into two types, formal and informal. Formal caregivers are paid, professionally trained caregivers for all types of care (9). Only one-third of older adults in need of professional care receive support from formal caregivers (10). Informal caregivers are defined as individuals who provide some type of unpaid, ongoing assistance with activities of daily living or instrumental activities of daily living for individuals with a chronic illness or disability (11). Informal, or home, caregivers are the backbone of the long-term care system, and are often composed of family members, friends, and relatives (12). Oftentimes, one individual serves as the primary caregiver and is assigned to be primarily responsible for most of the physical care and supervision (13). Caregiving is a difficult task, particularly for untrained primary caregivers who are taking care of an individual with serious, chronic health problems (14). Unsurprisingly, caregiver stress is common and is caused by the ongoing emotional and physical strain of caregiving (15).

The caregiver burden can be defined as the strain that is experienced by a person who cares for a chronically ill, disabled, or elderly family member (9). The burden of care is used to describe the side effects of care that are extremely problematic for the patients and their families (16). It is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience (17, 18). Caregiving often results in chronic stress, which compromises a caregiver's physical and mental health. Caregivers are
hidden patients who, as a result of their involvement with caregiving responsibilities, may not be able or eager to seek care for their own health needs (19). Caregiver burden and strain have been associated with increased health-risk behaviors (such as smoking), and higher rates of drug use (20). Caregiver mental health can be even more at risk when caregivers perceive the patient's care needs exceeds their caregiving capabilities (21). Most studies of family caregivers of stroke survivors have reported that caregiving had negative impacts on the caregivers’ health and well-being (22, 23).

Support is needed to enable informal caregivers to continue in their role as long as possible, without compromising their personal physical or mental health. Effective and adaptive coping strategies may play a protective role in reducing the caregiver's distress (24). Coping strategies are the cognitive and behavioral efforts of individuals to interpret and overcome problems that generally include three types of problem-focused, emotion-focused, and avoidant coping (25). In the problem-focused coping strategy, individuals attempt to define and accurately assess the problem and try to catch the possibility of changing or dominating it to reduce the adverse effects of mental stress (26). Problem-solving skills help to determine the source of a problem and find an effective solution (27). The emotion-focused coping strategy entails the skill of forgetting the problem or enlisting emotional support from others (28). Escape coping has been recognized as an effective short-term strategy, but in the long term, it prevents psychological adjustment and increases symptoms of helplessness such as depression (29). Exposure to stressors without overwhelming the caregiver can help facilitate the process of learning appropriate coping skills, resulting in greater adaptation (30).

Considering the negative impacts of caregiving on caregiver health status, psychological conditions, and quality of life of caregivers of stroke patients, a great deal of attention has been given to the study of coping strategies adopted by the caregivers when facing stressful situations. Therefore, the present study was aimed to determine the relationships between caregiving burden and coping strategies used by a group of caregivers of elderly patients with a history of having a stroke.

**Methods**

This cross-sectional and correlational study was conducted on 110 caregivers of elderly patients with a history of stroke. The convenience sampling method was used for selecting the representative sample. To identify the caregivers, medical files of stroke patients hospitalized in the Valiasr hospital in the six-month period before the start of the study were extracted and reviewed. Contact information for the stroke patients was extracted from the files, and they were then called for the initial screening. Valiasr hospital is the only hospital that admits stroke patients in Zanjan, Iran.

Inclusion criteria for family caregivers included a willingness to participate, aged 18 years old or over, having at least a primary level education, being the principal caregiver for a minimum of 1 month, not being paid for the care provided, and having a family relationship with the elderly patient. Conversely, caregivers not fulfilling such criteria, namely not able to communicate or caring for another patient, were not considered for inclusion in this study. Inclusion criteria for elderly patients included being aged 60 years old or over, having a diagnosis of a stroke, and having a family caregiver. Those who appeared to meet the inclusion criteria were invited to come to the rehabilitation centers or clinic of neurology, depending on the region where they resided. At the time of the phone call, an explanation about the study purpose and procedures were provided to the potential participants.

To determine the sample size, the correlation coefficient between caregiver burden and coping strategies was extracted from the results of Aboozadeh Gotabi et al. (31). Considering the correlation coefficient ($r = 0.25$) at an alpha level of 0.05, confidence level of 0.95, and power of 90 percent, the necessary sample size was calculated to be 100 participants. By considering a 10% nonresponsive rate, a sample size of 110 caregivers was finalized for this study.

The sampling was carried out from December 2017 to May 2018. The questionnaires were completed by the primary caregivers of the elderly patients.

**Instruments**

Demographic checklists, Zarit Burden Interview (ZBI), and Lazarus coping strategies questionnaires were used for gathering the data.

Demographic characteristics for caregivers included age, gender, marital status, educational level, financial status, job, and history of chronic illnesses. Demographic characteristics for the elderly patients included age, gender, marital status, and level of education.

The ZBI questionnaire was used for measuring caregiving burden. It is the most widely used instrument to assess the perceived caregiving burden in clinical and research settings. It is a multidimensional questionnaire (physical, emotional-psychological, social, and economic) consisting of 22 items and scored on a five-point Likert scale where 0 = “never” and 4 = “nearly always.” The score ranges from 0 to 88 points.
(32). The ZBI is a validated instrument for Iranian populations. It has good internal consistency (α = 0.82) (33), and a high correlation coefficient with the Hamilton anxiety questionnaire (r = 0.89) and Beck depression scale (r = 0.67) (34).

The Lazarus and Folkman Coping Strategies questionnaire consists of 66 questions about coping with a stressful situation. Responses are given on a 4-point Likert scale, ranging from 0 = “does not apply and/or not used” to 3 = “used a great deal.” It measures 8 subscales consisting of confronting coping, distancing, self-controlling, seeking social support, accepting responsibility, escape avoidance, problem-solving, and positive reappraisal. Higher scores in each subscale indicate greater use of that particular coping strategy (35). Internal consistency of this questionnaire is high (Cronbach’s alpha = 0.85) as confirmed by Ramzi et al. (2010)(36).

**Ethical Considerations**

All stages of the study were based on the Provisions of the Declaration of Helsinki of 1975. The written informed consent form was signed by all the caregivers before completing the questionnaires and after giving information about the purpose and procedure of the study. The written informed consent was obtained from all the participants before completing the questionnaires. The study was approved by the Ethics Committee of Qazvin University of Medical Sciences, Qazvin, Iran (IR.QUMS.REC. 1396.371).

**Statistical Analysis**

All statistical analyses were conducted using the Statistical Package for Social Science version 19 (SPSS IBM V.19, New York). Demographic variables were described using frequencies and percentages for categorical variables and mean and standard deviations for continuous variables. Pearson's correlation was used to examine the association between caregiver burden and coping strategies. Differences in the mean scores of coping strategies scales for gender were analyzed using independent t-tests. The statistical significance level was set at p < 0.05.

**Results**

A total of 110 caregivers with mean age of 32.09 ± 8.80 years participated in this descriptive and cross-sectional study. Caregivers were predominately women (n = 77, 70.0%), married (n = 75, 68.2%), housewife (n = 55, 50.0%), and had children (n = 67, 60.9%). Nearly half of the sample had a diploma or academic education (n = 56, 50.9%) and were located in the middle-range income bracket (n = 60, 54.5%). Nearly 90% of the caregivers reported not having any chronic diseases.

The mean age of care recipients was 69.91 ± 10.50 years old. More than half were female (n = 57, 51.8%), the majority were married (n = 82, 74.5%), and illiterate (n = 82, 74.5%; see Table 1).

**Insert Table 1 here**

The mean of caregiving burden was 32.80 ± 11.97. There was no significant differences for caregiving burden between female (32.44 ± 11.40) and male (33.64 ± 13.34) caregivers (t(108) = .478; p = 0.633). The results also showed that the most common coping strategies used were reappraisal and seeking social support, and the least were confronting, escape, distancing, and direct confronting.

Figure 1 shows the average range of coping strategies used amongst caregivers of elderly patients with a history of stroke based on gender. Results of the independent t-test showed that male caregivers used the reappraisal strategy (t(108) = 2.76; p = 0.007) and responsibility (t(108) = 2.26; p = 0.026) significantly more than female caregivers.

**Insert Table 2 here**

The information displayed in Table 2 shows that the total burden of care was significantly correlated with escape (r = 0.245, p = 0.010) and distancing (r = 0.204, p = 0.032). As caregivers more likely used of escaping and distancing by increasing their care burden.

**Discussion**

Coping strategies are common ways for dealing with demands, in situations that are perceived as threats (14). Therefore, the present study was aimed to determine the association between caregiving burden and coping strategies among caregivers of elderly patients with a history of stroke.
Based on the results of this study, women compromised a large majority of caregivers. This is consistent with national (37, 38) and international (39-41) studies which have found that most caregivers are women. A possible explanation for this might be that women believe that caregiving is their role and responsibility, as caregiving of children and other family members is often undertaken by women. Furthermore, women are more emotional than men and sacrifice their social life for their family (38), and they request little assistance from others, even if social support is available (42). Additionally, the results of the present study did not find any differences between men and women in the burden of caregiving. Although other studies have not detected any significant relationship between gender and caregiver burden even across different types of burden (43, 44), some previous studies have reported that female caregivers experience more caregiver burden than their male counterparts (40, 45). This discrepancy may be related to the Iranian culture, where women believe that caregiving is their duty and is expected of them from family members and society.

The results showed that caregivers used more problem-focused coping strategies consisting of reappraisal and social support, and less emotion-focused coping strategies such as escape and direct confrontation. Likewise, Rajesh Kumar et al. (2015) (14) found that the least used coping strategies by caregivers of stroke patients were denial, self-blame, and alcohol consumption and smoking. Alnazly (2016) (46) also showed that caregivers of dialysis patients used more self-control, reappraisal, and problem-solving strategies. Furthermore, Kadivar et al. (2015) (47) reported that most neonatal caregivers in the intensive care unit most often used social support coping strategies and least often used the strategy of avoidance. However, Ayuarno et al. (2014) (24) found that the caregivers of patients with Alzheimer's disease were more likely to use emotion-focused strategies. In another study by Mathew (2013) (48), avoidance was the most common coping strategy used by primary caregivers of AIDS patients. These results may be due to the differences in the level of burden perceived by the caregivers. Cultural and religious differences are also influential factors in the type of coping strategy used by caregivers.

The results of this study showed that male caregivers were more likely to use reappraisal than female caregivers. Consistent with the results of this study, Hassan et al. (2011) (49) reported that male caregivers of patients with schizophrenia were more likely to use reappraisal coping strategies than their female counterparts. However, Alnazly (2016) (46) found that male caregivers of patients undergoing hemodialysis used distancing more than women caregivers. In addition, Suriyamoorthi et al. (2018) (50) showed that male caregivers of patients with bipolar disorder used self-distraction and substance use as coping strategies while females used religion and denial. These different results may be related to the type of care recipients' illnesses.

Based on the results of the present study, caregivers with higher care burden used more emotion-focused strategies such as escape and distancing. The results of many previous studies are in line with this result. Kumar et al. (2015) (14) reported that caregivers of stroke patients used emotion-focused coping strategies of denial with increasing caregiving burden. Abbasi et al. (2013) (51) also showed that there was a direct and significant relationship between the use of emotion-focused coping skills and increasing care burden of the caregivers of cancer patients. Furthermore, the results of a study conducted by Papastavrou et al. (2012) (52) indicated that by increasing caregiving burden, caregivers of cancer patients did not adopt appropriate coping strategies. Jaracz et al. (2014) (53) also found that increased caregiving burden was associated with greater use of negative coping strategies. In other words, increasing the burden of care beyond the caregiver's ability can result in reliance on less effective emotion-based strategies rather than more effective problem-focused coping strategies and consulting with others (54).

Limitations

The present study only focused on caregivers of elderly patients with a history of stroke. As the literature shows a variety of other coping strategies are used depending on the type of illness present, the findings cannot be extended to caregivers of all elderly patients. Furthermore, since this study was conducted on Iranian caregivers, it may be difficult to extend the findings to other countries or cultures.

Conclusion

From the results of the present study, the adoption of coping strategies depends on the severity of the burden in caregivers of stroke patients. To cope with these stressors, informal caregivers often use emotion-focused strategies of escape and distancing which often do not help with developing in-depth reduction of the problem. It is recommended to plan and implement training programs teach caregivers for using efficient coping strategies and increase in their coping abilities.

Declarations

- Ethics approval and consent to participate

The study was approved by the by the Ethics Committee of Qazvin University of Medical Sciences, Qazvin, Iran (IR.QUMS.REC. 1396.371).

- Consent to publish
Not applicable

- **Availability of data and materials**

All data generated or analyzed during this study are included in this published article [supplementary file: SPSS file].

- **Competing interests**

The authors declare that they have no competing interests.

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This article was extracted from a self-financial master thesis in geriatric nursing.

- **Authors' Contributions**

AK and SAM and JA conceived and designed the research method and helped to draft the manuscript. AK collected the data. MM performed the statistical analysis. AK, SAM, KAA revised the manuscript. All authors read and approved the final manuscript.

- **Acknowledgements**

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**Disclosure**

The authors report no conflicts of interest in this work.

**References**


Table 1. Demographic characteristics of caregivers of elderly patients with stroke

<table>
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Table 2: Associations between caregiving burden and its subscales and coping strategies and its subscales

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<th>Coping strategy (Total)</th>
<th>Confronting</th>
<th>Distancing</th>
<th>Self-controlling</th>
<th>Social support</th>
<th>Responsibility</th>
<th>Escape</th>
<th>Problem solving</th>
<th>Reappraisal</th>
<th>Caregiving Burden</th>
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<td>0.291</td>
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</table>

*p ≤ 0.05
p ≤ 0.001

Figures
Figure 1

Weighted average of subscales of coping strategies among caregivers of elderly patients with stroke

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Kazemietal.xls