

REVIEW ARTICLE

THE RELATIONSHIP BETWEEN SOCIAL SUPPORT, SPIRITUALITY WITH STRESS TOWARDS THE BURDEN OF FAMILY CAREGIVERS OF CANCER PATIENTS: A LITERATURE REVIEW

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ABSTRACT

Cancer is a non-communicable disease that causes the second-highest death in the world. The study aimed to examine the relationship between social supports, spirituality with stress towards the burden of family caregivers of cancer patients. We searched literature from various relevant sources such as Ebsco, Science Direct, PubMed, and BMC Medicine, which published from 2012 to 2018. The results showed that social support reduced the stress of family caregivers. Spirituality could be as the coping for the family caregivers in dealing with stress. The factors associated with the high burden of family caregivers of cancer patients included age, cognitive as well as the family caregivers characteristics'. Further studies need to conduct spiritual and social support intervention to examine the effect of the intervention on health outcomes.

Keyword: social support, spirituality, stress, caregiving burden, family caregivers of cancer patients.

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1. Introduction

Family caregivers carried out the roles of providing care with little or no preparation and limited resources (1). The family caregiver was required to give a series of support in daily living included managing diet, self-care regimen, physical symptoms management, emotional and psychological support, financial management, and domestic work (2). Thus, family members who are taking care of cancer patients have high of burden.

The caregiving burden defined as the distress felt by caregivers (3). The caregiving burden will affect caregivers and patients well-being (2). The results of the study showed that the caregiving burden would negatively affect the quality of life of caregivers (3). Caregivers who regularly exposed to the caregiving burden will experience poor physical health and concentration, as well as increased mortality (4). On the other hand, the

increase in the difficulty of caregivers will also reduce the quality of care given to patients and disrupt the psychological well-being of patients (5).

Characteristics of the patients and their families have remained a factor associated with the burden of family caregivers of cancer (2). Social support is one source to reduce the caregivers' burden (2). The difficulty faced by caregivers every day encourages the need for support and assistance where if not fulfilled, it will cause an increase in stress (6). Spiritual well-being can be used as a coping for the family caregivers to the stressors, for example, at the time of diagnosis or throughout the cancer patients trajectory (7). Social support, spirituality, and stress are essential variables that are possible to influence the caregiving burden felt by the family caregivers of cancer patients. Their needs to be research that looks at the relationship between social support, spirituality, and stress toward the burden of family caregivers of cancer patients. In the next stage, these variables can be intervened to reduce the caregiving burden so that the quality of life of the family caregivers and cancer patients can be increased.

2. Objective

The study aimed to examine the relationship between social support, spirituality, and stress towards the burden of family caregivers of cancer patients.

3. Method

We conducted a literature review. We searched relevant from 2013 to 2015 from several databases, including Ebsco, Science Direct, PubMed, and BMC Medicine. Search keywords used were social support, spirituality, stress, caregiving burden, family caregivers, and cancer patients. Articles were collected and selected based on keywords, without limiting the article research method. The reviews included titles, abstracts, research objectives, research methods, instruments used, and research results.

The inclusion criteria of articles selection such as original articles, the articles focused on social support, spirituality, and stress about the burden of family caregiver of cancer patients. The study was conducted in both hospital and home care setting, with the study design such as cross-sectional, longitudinal studies, cohort studies, quasi-experimental, and interviews.

4. Results

A total of 45 articles obtained from search results, 21 articles were excluded because unmeet with the criteria inclusion. Finally, only 24 relevant articles reviewed, including 20 cross-sectional studies, one cohort study, and one studies used quasi-experimental design, longitudinal study, and systematic review.

The quantitative research samples of the articles we reviewed were mostly family caregivers of cancer patients. However, we also conducted reviews on the family caregivers of the chronic patient such as Alzheimer's, stroke, dementia, rheumatoid, and autism. The following are the review result of articles that match the search keywords.

4.1 Caregiving Burden

The caregiving burden was distress felt caused by difficulties in providing caring (3). This term is used to describe the physical, emotional, social, and financial impacts of the

caregiving to the ill family members, felt by family caregivers. This burden will affect the well-being of patients and caregivers (2).

The caregiving burden includes physical, emotional, social, and financial consequences (8). The examples of physical burden are disorders of sleep, fatigue, and pain that are often experienced by the caregivers (3). Helping cancer patients to overcome their feelings about cancer and provide emotional support to cancer patients is a complicated psychological task (3). The example situation that is a social burden is unable to work due to the responsibility of caring for cancer patients (3). Also, another condition which is a social burden is the obligation to care for others besides cancer patients (3). On the other hand, the financial burden included paying high medical costs and loss of income and savings (3).

The caregiving burden remained as a predictor and outcome. One example of the caregiving burden as an outcome is the increase of need to help carry out daily activities of patients will increase the burden of caregiver (9). On the other hand, one example of the burden of caregivers as a predictor is the caregiving burden is negatively related to the quality of life of caregivers (3). The increasing of caregiving burden will reduce the quality of life of caregivers. The high spirituality can reduce the level of stress and the caregiving burden felt by the family caregivers of cancer patients (7).

The concept of caregiving burden includes two dimensions, namely the objective burden that refers to concrete problems as a result of daily care (e.g., time per day) to the recipient of care or the impossibility of the caregivers to use more time for himself; and subjective burdens that refer to the caregiver's perception of caregiving, attitudes, and feelings (e.g., depression, anxiety, feeling guilty) (10). Objective burden describes family life disruption and can be measured through observation on specific care tasks; on the other hand, the subjective burden relates to the caregiver's experience regarding physical, emotional, social, and economic difficulties (4). The caregiving burden felt by family caregivers is influenced by several factors. Also, the caregiving burden is influenced by several characteristics inherent in the caregiver and patient.

The research results conducted showed that one of the factors associated with the caregiving burden is the emotional status of the caregiver (11). One of the factors that influence the caregiving burden is stress (12). Another factor associated with the caregiving burden was the quality of social support (13). The higher quality of social support received the result in the lower caregiving burden (13). Another factor associated with the caregiving burden is the spirituality of caregivers. Spirituality will improve the quality of life of caregivers (14). In addition, the caregiving burden was negatively effect on quality of life among caregivers (3).

4.2 Factors associated with Caregiver Burden

1. Social Support

The concept of social support is interpersonal interactions with others that can lead the positive feelings such as feeling loved, close, safe, belonging to a group, and providing emotional, physical, and information assistance (15). Social support covering three elements, namely, emotional, instrumental, and information (16).

Elements of social support in chronic diseases include emotional, information, and instrumental support (15). Gesture provides comfort, for example, always ready when needed, including emotional support. The older adults get emotional support from people

they love and feel useful if they are involved in their lives (17). Giving advice, instructions, orders, and information is a form of information support. On the other hand, instrumental support is provided through financial support and assisting in the implementation of tasks.

Sources of social support can come from friends, children, family members, and partners (17). The sources of social support can come from partners, children, family, friends, neighbors, and community members (16). Social support plays a vital role throughout a person's life.

A large family is one of the primary sources of social support. Adult individuals in the 55–85 years age range experience a shift in social networking with a decrease in the number of friends and an increase in the number of close relatives (16). On the other hand, older adults tend to be more dependent on friends as social support than family members or children due to an obligation in the family (16).

The next source of social support is friends. Friends are a crucial source of support for young adults. Friends tend to be more important in early and late adults than in middle adults (16). The role of this group of friends increases in adolescence to adulthood (16). Adolescents and young adults are more likely to friends than parents, related to self-disclosure and conversation about important topics (16).

Another source of social support is children. The relationship between parents and children is the most lasting in all life. Children have responsibilities as the primary caregivers to their parents (16). A study conducted by Gurung et al. showed that men most often get support from partners, while women also get assistance from children, friends, and relatives (16).

The next source of social support is a community. Increasing social relations within the city increased social support (16). However, interactions within this community will decrease with age and individual disability conditions.

Individual social networking is a powerful thing so that the chosen source of support varies throughout life. Individuals in the same age range tend to find the same source of social support. Adult individuals (28–60 years old) seek social support from their partners and influence mental health better. Another case is with individuals who are elderly (60–92 years) who choose social help from other children, friends, or relatives (16).

Social support gives benefits to individuals throughout their lives. The relationship of social support can influence the outcome of better physical and mental health (16). The results of the study stated that social support received by the family caregiver harms the caregiving burden (18). It was consistent with the study results, which said that if the social support received increases, the caregiving burden would decrease (19).

2. Spirituality

Spirituality is a broader search for the meaning of life, which involves universal power as a guide (7). Spirituality is a quality inherent in humans that refers to search, expressions of meaning and purpose and how to experience the connection to events, oneself, others, nature, something essential or sacred (20). Spirituality involves the recognition of the quality of attachment to God in every human activity (14). Spirituality and religion are interconnected domains. Religion is practiced inside or outside organized places of worship, and implies belief in God; God can be achieved through various processes including prayer, ritual, and community service. Religion is a manifestation of spirituality (14).

The spirituality was multidimensional connectedness such as interpersonal, intrapersonal, and transpersonal connectedness. Interpersonal connectedness refers to relationships with individuals, nature, and surroundings; intrapersonal connectedness refers to personal relationships with oneself that focus on self-strength, and transpersonal connectedness refers to a relationship with God or a higher power (21).

High perceptions of spirituality are associated with low depressive symptoms, deep distress, and increased the quality of life for individuals diagnosed with life-threatening diseases (21). Spirituality also affects family caregivers. Spirituality can improve quality of life and reduce the risk of illness and death of the caregivers (14). The caregiving burden influences the quality of life of caregivers. Thus, a high level of spirituality can reduce the caregiving burden. It was following the study result added that high spirituality could alleviate stress levels, and the caregiving burden felt by family caregivers of cancer patients (7).

3. Stress

Caregivers often experience stress during the treatment of cancer patients. In the case of external stressors, people define stress in different ways because this is the perception of an event, not just the event itself, which stimulates the response.

When the demand for care exceeds the resources that are owned, the family caregivers will feel overwhelmed and report high levels of stress (22). At first, fear will have an impact on the individual's psychological well being, but when the pressure continues, physical well-being will also be disrupted. The effect of stress on psychological domain quality of life is emotional distress, anxiety, and or depression, feelings of needing help, loss of control, and coping difficulties related to the role of care delivery (1,22).

For some substantial reasons, the high level of stress of family caregivers is an important subject that needs to be observed more in order to be appropriately handled in the future. First, the results of longitudinal studies indicated that when the family caregiver experiences a high level of stress, it would negatively affect the patient's long-term adjustment. The high degree of anxiety of caregivers will enhance the patient's anxiety experience. Second, caregivers who experience stress will be more difficult in providing optimal patient care to patients. Third, caregivers with the high level of stress will experience changes in the immune system that can lead to autoimmune diseases, poor glucose control in the body, and more ranges from cardiovascular disease (22). The stress felt by caregivers is related to the stress felt by patients throughout the trajectory of the disease. When the caregiver experiences stress, the patient will also feel the same, and vice versa.

Approximately 50% of family caregivers experience increased stress. Caregivers of the cancer patient are one of the caregivers with the highest level of psychological stress among other diseases (23). Caregivers of cancer patients also reported experiencing high anxiety and symptoms of depression. The results showed that the higher emotional stress levels associated with a higher burden in providing long-term care (23). Caregivers who report high-stress levels also report other problems such as fatigue, sleep disorders, and unhealthy behavior (24). Thus, the high level of stress can increase the caregiving burden that is felt by the family caregivers.

5. Discussion

A cancer diagnosis affects patients and their families. The process of caregiving can cause a burden that is felt by the family caregiver. Cancer is the second disease after Alzheimer's, which is a family's reason for providing care with a high burden. Family caregivers are required to offer a range of assistance, which includes the patient's daily activities, diet preparation, self-care regimens, management of physical symptoms, administration, administration of drugs, emotional and psychological support, financial management, and housework. On the other hand, the family caregiver carries out the responsibility of providing this care with little or no preparation and limited resources. This gap is one of the factors that cause the high burden felt by family caregivers of cancer patients.

Social support spirituality and stress are the main variables that influence the burden of family caregivers of cancer patients. Also, the burden felt by the family caregivers of cancer patients is influenced by patient characteristics, namely age and cognitive level, as well as the aspects of caregivers, namely age and gender. The caregiving burden will be felt higher by female and older age caregiver. On the other hand, the caregiving burden is also perceived to be higher by families caring for younger patients and low cognitive levels. In the next stage, these variables, especially the primary variables, can be intervened to reduce the caregiving burden so that the quality of life of the family caregivers and patients can be increased.

6. Limitation

In this study, we conducted a review of many studies related to social support, spirituality, and stress about the burden felt by family caregivers of cancer patients. However, we also conducted several reviews regarding the research variables in family caregiver caring for other chronic patients such as Alzheimer's, stroke, dementia, rheumatoid, and autism. Thus, this study does not fully represent the relationship between social support, spirituality, and stress towards the burden of family caregivers of cancer patients.

7. Conclusion

This study reviewed the relationship between social support, spirituality, and stress to the burden felt by family caregivers of cancer patients. Based on the review result, it can be seen that social support can reduce the burden of family caregivers of cancer patients. The stress felt by family caregivers can increase the burden. On the other hand, spirituality can be used as coping for family caregivers in dealing with stress so that it can reduce the caregiving burden.

The burden felt by the family caregivers of cancer patients is also influenced by the characteristics of caregivers (age and gender) and patient characteristics (age and cognitive level). The caregiving burden will be felt higher by female and older age caregiver. On the other hand, the caregiving burden is also perceived to be higher by families caring for younger patients and low cognitive levels.

Based on the results of this study, it is necessary to conduct further research related to interventions to reduce the burden of family caregivers of cancer patients. This intervention can be carried out on the domain of social support, spirituality, and stress that have been known to affect the burden of family caregivers of cancer patients. Besides,

interventions can also be carried out on family caregivers who are at risk of experiencing a more significant burden, namely to caregivers who are female and older.

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