

## Review

## Caregiver Burden of Palliative Cancer Patients: A Cross-Cultural Perspective

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## Abstract

Although the burden of caregiving is universal among people caring for advanced cancer patients, the perception of burden and the impact on individuals vary according to the society in which patients and caregivers are located. The characteristics of caregivers and the dimensions of burden they experience are influenced by the structure of each society. Therefore, the burden of caregivers is shaped by the situation in each country and its cultural perspective. Reducing the burden on caregivers and supporting individuals can make the patients they care for feel better. For this reason, caregivers should receive social, psychological, and economic support from society, the government, and their families, and efforts should be made to reduce the burden of caregiver assistance. To protect and improve the health of caregivers, health personnel should provide training on effective caregiving methods based on the needs of caregivers. It is especially important to support the patient's family members when the patient is in the terminal phase and to prepare them for the grieving process. The aim of this study is to better understand the level of caregiver burden and to guide researchers by providing a cross-cultural perspective.

## Introduction

Cancer is a group of diseases caused by the uncontrolled proliferation of cells in different parts of the body and is a global problem that is associated with the thought of death worldwide. Cancer consists of several stages. It is a known fact that in advanced stages of the cancer, disease spreads to organs and tissues different rates depending on the type and characteristics of the respective cancer, therefore different treatment methods are required for different type of cancer. In addition, the advanced stage of cancer is a time when patients spend their last time in bed, patients experience physical depression, symptoms are more severe and frequent, and patients are more dependent on activities of daily living. It is known that the advanced stage of cancer is more likely to bring physical, psychological, spiritual, social, and economic disadvantages to both the patient and family members (Kyu et al., 2018). Especially for caregivers, these negative situations are a great burden. This situation is defined as caregiver burden. Caregiver burden is a term used to describe the burden that the caregiver perceives when caring for a patient. Caring for cancer patients is a known condition that causes physical, emotional, social, and economic stress which results in caregiver burden (Cuiet al., 2014). The stress experienced by the caregiver also affects the family. The increase in severity and frequency of symptoms in individuals diagnosed with cancer causes physical and psychosocial problems for caregivers. These symptoms

decrease the quality of life for both patients and caregivers and cause individuals and their families to have difficulty adjusting to treatment. In addition to symptoms, the financial burden of cancer increases the burden on caregivers through various factors such as the inability of individuals to carry out their daily activities, the deterioration of individuals' social relationships, and poor emotional status (Yoon et al., 2016).

The perception and content of caregiver burden in cancer patients may vary from country to country according to their culture. Culture can be described as different social groups with unique ways of thinking, communicating, acting, customs, habits, values, and beliefs. The sociocultural structure of countries, government type, religious beliefs, level of education, the value placed on health, and the level of development of the country can influence the burden of care for cancer patients in different dimensions (Figure 1). Culture is recognized as an important element of effective health care. Culturally appropriate health care should be planned and delivered according to the needs of the individual and family. To provide culturally specific, high-quality, skilled care, nurses must be culturally sensitive and culturally informed.

Differences between cultures can be observed in advanced stage cancer patients due to the nature of the caregiver burden of the disease (Morgan et al., 2022). Many studies have been

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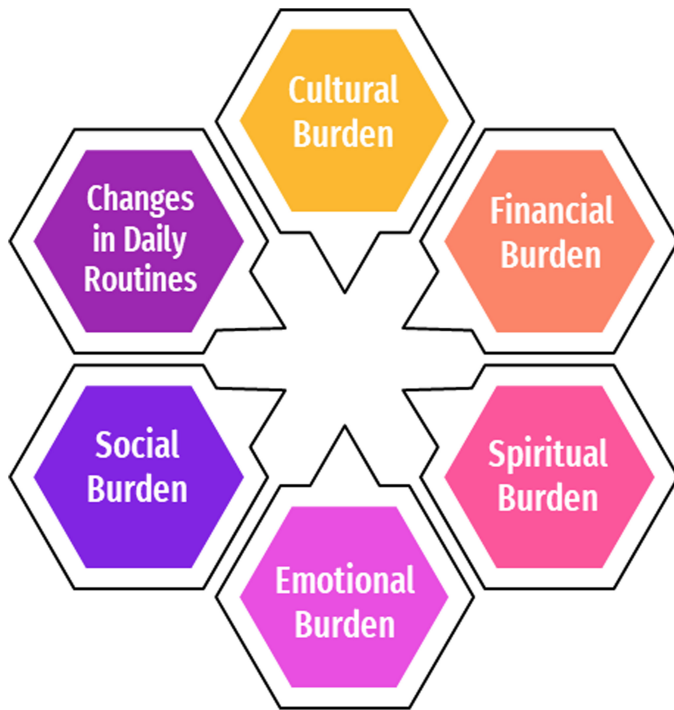
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**Figure 1.**  
*Dimensions of Caregiver Burden.*

carried out in different cultures on the loads of caregivers. In these studies, Zarith Caregiver Burden Scale, The Caregiver Quality of Life Index—Cancer scale, Caregiver Burden Inventory, Index of Caregiver Burden—COPE, health-related quality of life, Comprehensive Needs Assessment Tool for Cancer Caregivers, and Preparedness for Caregiving Scale were the most used scales (Li et al., 2022). Patient's difference in cultures resulted in a variety of scales, which also evolved the modified versions of the same scales. In reviewing the studies and the scales that have been used, it was found that there are changes in their daily lives and that they have similarities as well as differences in emotional, spiritual, economic, cultural, and social burdens. The common point of these scales is that they have used these aspects as dimensions of their scales. The aim of this study is to better understand the level of caregiver burden by identifying which areas of advanced cancer patient care are provided by individuals and to guide researchers by providing a cross-cultural perspective.

### Cultural Burden

Cancer is a disease that is associated with death and disability throughout the world and is considered incurable by most communities, resulting in cancer patients being perceived as physically, emotionally, and socially inadequate, even when treated. These negative perceptions about cancer lead to voluntary or involuntary stigmatization of cancer patients. Stigmatization is defined as a situation in which patients and caregivers are labeled, deprived of their rights, and devalued (Yildiz & Caydam, 2020). In addition to the cancer itself, the type of cancer is another factor that increases stigma. Cancers such as testicular cancer, cervical cancer, ovarian cancer, breast cancer, and prostate cancer seem to be cancers that society is afraid

to talk about, while for cancers with visible lesions such as skin melanomas and head and neck cancer, the community tends to remove the person with cancer. However, especially in countries with low socioeconomic levels, stigma is more widespread (Solbraekke & Lorem, 2016).

In a study with 953 people in Iran, 17.4% of the participants reported that they were not comfortable being around a cancer patient, 26.9% avoided marrying an individual with cancer, and 48.4% were hesitant to share a cancer diagnosis with their coworkers and environment (Badihian et al., 2017). In a study by Pakseresht et al. of 140 Iranian women diagnosed with breast cancer in 2021, it was found that more than half of the individuals delayed diagnosis by 60–90 days because they feared that their colleagues and friends would move away from them if they were diagnosed with cancer (Pakseresht et al., 2021). The study of 158 breast cancer patients in Korea conducted by Kang et al. provides a different perspective on this issue. According to the research results, 44% of the women who participated in the study reported that they did not experience stigma unless there was a visible change in the treatment process (hair loss and breast surgery), but after the visible changes, people were afraid to be in the same environment with them (Kang et al., 2020). A study of 53 early-stage lung cancer patients in Canada found that stigma was predominantly associated with the poor prognosis of lung cancer and smoking (Bedard et al., 2022). Another study shows that people living in the United Kingdom have low cancer stigma overall (Vrinten et al., 2019).

In a study conducted in 2019 with 301 participants in Turkey, it was found that male participants were more prone to stigma than female participants, while individuals with a family history of cancer diagnosis had a more negative view of cancer and its treatability. The fact that males have a higher stigmatization tendency is explained by the fact that women are more compassionate and male roles and responsibilities in Turkish society are influencing males to be more judgmental about certain types of diseases (Ozturk et al., 2019). In another study conducted by Yilmaz et al. in Turkey in 2019, half of the 303 patients who participated said they could recognize cancer patients by their appearance, and 1 in 10 participants said they were excluded by their family and friends because of a cancer diagnosis (Yilmaz et al., 2017).

Stigma is an important social problem faced by people with a cancer diagnosis and their caregivers. The cancer itself, its treatment, the course of the disease, and the society to which the individual and his or her family belong are cited as factors that influence stigma. Stigma is affected by the cultural differences between countries, especially perception of health in different societies. The stigmatization of those affected also affects their families and indirectly leads to stigma, which results in various psychosocial symptoms and a reduction in the quality of life. Although stigma is more prevalent in countries with low and middle socioeconomic levels, it can also occur to varying degrees in countries with high socioeconomic levels. For this reason, societies or communities with low and middle socioeconomic levels should be given special attention and educated about cancer, and the problem of

stigmatization of individuals with a cancer diagnosis should be studied.

### Financial Burden

Cancer can have a devastating economic impact on the patient and family. Economic burden is an increasingly important issue affecting cancer patients and their families, especially those of low socioeconomic status. In addition, the economic burden of cancer negatively impacts an individual's quality of life. Family caregivers face difficulties such as reduction in work hours, termination of employment, and economic burden on caregivers due to expenses not covered by health insurance. For advanced cancer patients, differences in determining the urgent needs of caregivers can be observed depending on the culture (Cui et al., 2014). Studies in the USA have found that one-third of their patients' families have lost most or all of their economic savings, and nearly half have given up work to provide care. For these reasons, the studies suggest that treating physicians should take into account the financial burden when treating burden is one of the factor that most affects the quality of life patients and their families, particularly following physical symptoms (Mosher et al., 2013; Giap and Chino, 2021; Fong et al., 2022). In Japan, a study involving 510 cancer patients showed that the vast majority of patients and their families were not affected by the economic burden of cancer and that those who have affected were individuals living in more rural areas with low socioeconomic status (Sasaki et al., 2022). A systematic review in India found that more than 65% of cancer patients and their families in India were unable to bear the economic burden of cancer, which negatively affected their quality of life. This is because there are not enough facilities for early diagnosis and treatment of cancer, there is not enough medical equipment, and most treatment options are imported (Boby et al., 2021). Another important issue in the Asian countries of Lebanon and Jordan is the financial burden of cancer patients among Syrian refugees. The already low quality of life of cancer patients and their families who have had to migrate for various reasons decreases with the financial burden of cancer, and at the same time, this financial burden increases healthcare expenditures in the countries which took in the refugees (Abdul-Khalek et al., 2020). In examining studies conducted in China, problems with payments in the Chinese healthcare system have been reported. In a study comparing different countries, it was found that the greatest decline in financial status after diagnosis occurred in China. It was reported that most of the expenses incurred by caregivers were transportation/travel costs and drug costs (Xiao, et al., 2022). Another study that looked at 16 European and 5 Latin American countries showed that countries with lower economic levels pay higher prices for cancer treatments. The quality of life of cancer patients and their families in most Latin American countries and a small part of European countries was severely affected by the financial burden due to this high cost of cancer drugs (Moye-Holz & Vogler, 2022). In sub-Saharan African countries, caregivers have been reported to have financial difficulties accessing palliative drugs or interacting with healthcare providers, keeping the patient and the environment clean, and meeting the patient's physical needs (O'Neil et al., 2018). In Turkey, cancer patients have to pay 16.9% of the treatment costs themselves due to the universal health insurance introduced at the national level by

the governmental social health support system and the active work of the Centers for Early Cancer Detection, Diagnosis, and Education (Kanser Erken Teşhis, Tarama ve Eğitim Merkezi). While this amount is not a financial burden for people in the Marmara, Aegean, Central Anatolia, and Mediterranean regions, it is a financial burden for people in other regions, especially in rural areas, and affects their quality of life (Urek & Ugurluoglu, 2021).

The economic burden of cancer treatment, regardless of country or culture, worsens family relationships for both individuals and caregivers, complicates the coping process for individuals and their families, and prevents individuals from continuing treatment. For this reason, economic support programs for individuals with low socioeconomic status and caregivers should be used at the level of health systems and health professionals in countries, and more emphasis should be placed on early detection and treatment of cancer.

### Spiritual Burden

The spiritual burden of caregivers varies from society to society. In particular, the spiritual burden of caregivers is strongly influenced by the beliefs and value judgments of the society to which they belong. In traditional Chinese culture, caring for a sick person is considered the responsibility of each family member, and the family is an integral part of the patient's treatment decisions. Family members are reported to be a burden because their patients feel responsible for almost all caregiving tasks. Increased caregiving burden has been shown to be associated with anxiety, depression, and many other negative emotions in those affected. Chinese society believes that the topic of death can negatively affect the patient's emotions and bring misfortune, and so the topic of death is generally avoided. Despite the burden of caregiving, the grief that family caregivers feel before the death of a cancer patient is often not accepted or socially supported by society. This places a significant burden on the person caring for an advanced cancer patient in the Chinese society (Li et al., 2022). In East Asia culture, aging is accepted as a natural process for patients. Therefore, the development of the disease and the acceptability of impending death are considered more normal in elderly individuals. Because of that, Taiwanese caregivers experience low levels of grief due to the loss of their relatives (Tang et al., 2013). A study conducted in Korea reports that religiosity promotes hopefulness. The hopeful attitude of caregivers has been shown to positively affect their and the patient's psychological state and they experience fewer depressive symptoms, developing an active coping strategy (Kim et al., 2014). In studies conducted in Muslim-majority countries, Allah is believed to be the cure for all the diseases in Islam. This belief helps keep patients and their caregivers hopeful. Sometimes, they associate hope with miracles. They may entertain thoughts such as "Allah helped us through divine intervention, and I have been good. Belief in death and the afterlife and the belief that caregivers will be in heaven in the afterlife they love and that illness is a divine test of Allah have been shown to have a positive effect on caregivers' psychological distress" (Abdullah et al., 2020). Researches show that with Turkey being a majorly Islamic country, Turkish patients and their caregivers also generally use spiritual ways or praying as an effective method of coping with cancer-related burden.

Spiritual burden may be a factor that both increases and decreases the other dimensions of caregiver burden. People with religious faith may use spiritual methods to cope effectively with cancer-related problems, which reduces their overall burden. However, if these people begin to believe that the disease was given to their loved one as punishment for their or their loved one's bad behavior, this may increase their overall burden by affecting other dimensions of burden, particularly emotional burden. It should also be remembered that some people are not affected by religious or spiritual concepts at all. Nonetheless, spiritual burden is an important concept to address when caregivers or their patients need support related to spiritual burden.

### Emotional Burden

At each stage of life, individuals may be affected in different ways by the problems they experience. Although everyone reacts differently, and the nature and severity of reactions vary according to personality structure, age, sociocultural level, religious beliefs, and culture, some of these problems can be life changing for the individual. The Kubler-Ross model explains these life-altering problems as having five stages. These stages are referred to as "denial," "anger," "bargaining," "depression," and "acceptance." Although these stages do not always occur in the same way, everyone goes through these processes at some point. A cancer diagnosis is described by most cancer patients and their loved ones as a "life-changing experience." While a cancer diagnosis is devastating, it can also cause emotional problems for patients and their loved ones as they struggle to get through the stages. These emotional problems can be listed as follows: feelings of agitation, decrease in self-esteem, depression, anxiety, social isolation, loss of self-esteem, difficulty in problem solving, guilt, anger, weakness, frustration, and hopelessness. In the study conducted in the USA, individuals caring for patients with advanced cancer reported that caring for their loved ones, while satisfying, was also highly stressful (Dionne-Odom et al., 2017). In Germany, family caregivers are the most affected in terms of their emotional role and mental health, with more than half suffering from symptoms such as post-traumatic stress disorder, anxiety, or depression. In Italy, studies show that there is a great deal of general demoralization in family caregivers and that this demoralization is associated with mental and psychological suffering rather than difficulties related to caregivers' personal time, social roles, physical conditions, and financial resources (Ullrich, et al., 2017; Oechsle et al., 2020; Baddeley et al., 2022; Bovero et al., 2022). The results of the studies also show that caregivers in countries with a high socioeconomic level in Europe often go through a process of denial and cannot accept that their patients cannot be saved or that they have symptoms that reduce their quality of life, despite the institutional facilities of the country in which they live. In Turkey, the cancer diagnosis is usually not given to the patient, especially if the patient is old, and the process is usually taken over by the patient's family. This situation increases the emotional burden on family caregivers and prevents them from developing effective coping mechanisms against the emotional stress they experience. In addition, the family, who is in the role of caregiver, has difficulty making decisions at all stages and seems to feel guilty as the disease progresses (Yasar et al., 2020).

Emotional burden is one of the overlooked aspects of caregiver burden. The patient and their loved ones may view their emotional distress as a natural reaction to the cancer diagnosis, but if this emotional distress is too great for the caregiver, they may develop ineffective coping mechanisms that benefit neither the patient nor the caregivers during the disease process. Caregivers and patients need to be regularly screened for emotional and psychological symptoms in order to properly identify and effectively address these issues.

### Social Burden

Social support is an important coping mechanism that can also help family caregivers manage stress and promote effective coping by sharing responsibilities and helping to frame challenging situations in a more positive way. Perceptions of social support are defined as the satisfaction individuals experience from the support they receive from others in a social network. For this reason, social support is recognized as an important social determinant of caregiver health. Depending on the intensity of caregiver duties and caregiver exhaustion, it may be difficult for caregivers to access formal support services. Minority caregivers may not be considered culturally appropriate to access formal support services. Cancer is a complex process that involves uncertainty, depression, and fear of death for both patients and their families. The way individuals perceive cancer is directly related to their preferred coping mechanisms. One of the most important factors in the development of effective coping mechanisms is society's attitude toward cancer patients and their families (Yilmaz et al., 2017; Howard-Jones et al., 2022). As individuals' perception of social support increases, their social relationships and their quality of life improves, while their perceived physical symptoms decrease.

A study conducted in Iran showed that patients most expect social support from their families and want to spend time with their families when they are near death (Mirsoleymani et al., 2017). In a study conducted with 212 families in Korea, it was found that individuals who were not married or had poor family relationships had a higher symptom burden, and 73% of patients received support from their family to cope with psychosocial symptoms (Rha et al., 2015). A study of 210 African patients showed that patients expected social support not only from their family but also from their coworkers, friends, and the entire community. The responsibility of caring for advanced cancer patients in sub-Saharan Africa is mostly assumed by family members due to the lack of institutional facilities. In Nigeria, as in most sub-Saharan African countries, the extended family system, which is increasingly fragile, must bear the brunt of chronic illness in the absence of national social services (Jite et al., 2021).

The fact that the expectation of social support varies between societies is due to the geographical, cultural, and economic characteristics of the societies. In societies where the concept and culture of family is more common, the individual expects social support from his family, while in cultures that attach importance to social integrity rather than the family, the individual wants to see social support from the whole society. On the other hand, in societies where the culture of individuality is widespread, the individual may perceive the perception of social



support as weakness or weakness. However, the common feature of all these is that there is a parallel proportion between the perception of social support and the quality of life of most individuals. For this reason, it is of great importance to make the necessary directions and trainings for both individuals and caregivers to receive social support, to improve the quality of life of individuals, and to help them adapt to treatment processes.

### Changes in Daily Routines

Daily routines are the habits and hobbies of people which are repeated daily. Individuals who care for cancer patients may experience problems in their own routines. Since individuals who care for advanced stage cancer patients must dedicate a large part of their lives to the care of their patient, eventually their routines will get negatively affected. When the studies were examined, it was found that the changes experienced by caregivers in their daily routine were highest in China and lowest in France. The reason for this is France's high socioeconomic level, developed healthcare system, and home follow-up system for advanced cancer patients (Lambert-Obry et al., 2018). The same study showed that the home monitoring system introduced in Germany, similar to that in France, reduced the active nursing time of caregivers by up to 10 hours. In China, where there is no similar system, the burden on caregivers is increasing. In another study conducted across Asia, it was found that 85% of people caring for a person with advanced cancer prefer to take care of their patients themselves rather than taking them to the hospital. The reason for this is the strong bond among family members in Asian countries. In a study conducted in Turkey, 60.6% of caregivers said they could not devote enough time to their own lives because of caregiving (Yaman & Buyukyilmaz, 2022). Even though Turkey has a similar system for advanced cancer patients, both the cultural aspect of Turkish society and an overload of patients on this system is preventing this system to effectively alleviate the burden on caregivers.

Even though cultural differences have a major impact on caregivers, daily routines are an important part of a person's life. Although these changes in daily routines may seem insignificant, they are one of the most important factors in the burden placed on family caregivers. Family caregivers should have either time or opportunity to continue their daily routines to reduce their burden. This is possible by integrating an efficient system that provides temporary care for advanced cancer patients, so that caregivers can be presented with time for their own needs. Although caregiver burden in advanced cancer patients is universal, both similarities and great differences in the character and perception of burden are observed depending on the society in which the patients and caregivers are located. Therefore, caregiver burden varies according to the cultural, economic, and social structures as well as perspectives of each country. Caregiver burden is an important problem that directly affects the health of patients and caregivers. For this reason, caregivers should be supported socially, psychologically, and economically by society, the state, and their relatives, and efforts should be made to reduce the burden on caregivers by providing assistance. When the burdens of caregivers are defined by society, it is much easier to address these problems. Health professionals should be trained in effective caregiving methods according to the needs of caregivers in order to protect and improve the

health of caregivers. In this context, it is very important to support the patient's relatives, especially those who have a patient in the terminal phase, and prepare them for the grieving process.

**Data Availability Statement:** The data that support the findings of this study are available from the corresponding author upon reasonable request.

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