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# Caregiver Burden in Caring for Post-Cardiac Surgery Patients

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### **ABSTRACT**

Post-cardiac surgery patients in recovery depend on caregivers to meet their physical needs because of weakness and reduced physical ability. Caregivers provide care, including assistance in meeting daily needs, self-care, and socializing in the environment. Many caregivers feel unprepared to assume the burden and demands of care on patients. This study aimed to describe the caregiver burden in caring for post-cardiac surgery patients. The research design was quantitative descriptive with an accidental sampling technique with a sample size of 23 respondents. The study was conducted in the outpatient department of a private hospital in Western Indonesia. The instrument used was the caregiver burden inventory, which was analyzed using descriptive analysis. The results showed that the most respondents were female. The highest age of the respondent was 74 years, and the lowest was 18 years, with an average age of 44 years. There were 7 (30.34%) respondents who indicated the risk of fatigue, 6 (26.09%) respondents indicated the need to seek treatment, and 10 (43.48%) respondents did not feel the burden. As conclusion, caregivers were at risk for burden because of their roles and responsibilities. Nurses were expected to provide for the needs of caregivers during the surgical preparation to help reduce the burden and provide support in carrying out their roles during the care of post-cardiac surgery patients.

Keywords: cardiac surgery; burden; caregiver

## INTRODUCTION

The prevalence of cardiovascular disease nearly doubled in 20 years, from 271 million in 1990 to 523 million in 2019. (1) Data from Indonesia Basic Health Research showed that heart disease increased from 0.5% in 2013 to 5% in 2018. (2) Data from the World Health Organization (WHO) in 2015 showed that 70% of global deaths were caused by non-communicable diseases, namely 39.5 million out of 56.4 million. Of all these deaths, 45% were caused by cardiovascular disease.

Heart disease is a very life-threatening disease. One of the treatments for heart disease is cardiac surgery. Cardiac surgery is performed to repair damage and abnormalities in the heart, replace heart valves, install pacemakers, and replace a damaged heart with a healthy heart. One of the most popular revascularization techniques for severe and advanced cardiovascular heart disease is the coronary artery bypass graft (CABG). Depending on their health, age, and the severity of their underlying ailment, CABG patients can often expect to recover in two to three months after the procedure and are usually released from the hospital within a week.<sup>(3)</sup> Patients frequently require support from caregivers throughout recovery because of postoperative sternal limitations.<sup>(4)</sup>

Post-surgery patients who are in the treatment stage have various physical symptoms that can lead to weakness and reduced physical ability to carry out their activities, such as eating, bathing, dressing, going to the toilet, and ambulation, so patients are very dependent on caregivers to be able to meet their physical needs. (5) Caregiving for someone who has undergone a CABG differs from caring for someone with dementia, cancer, or any chronic illness. A CABG caregiver can anticipate their caregiving responsibilities to start at the time of the surgery and end two to three months later, as opposed to caring for a patient with a progressing illness, which is a long-term experience that frequently results in the patient's death. (3)

As many as 90% of care given to patients with chronic diseases is carried out by caregivers, and they are the ones who have complete responsibility for caring for patients. More than 78% of caregivers come from

families.<sup>(6)</sup> In Indonesia, most caregivers who care for patients with chronic diseases are family members. Caregivers provide care, including assistance in meeting daily needs, self-care, administering medication, and assisting with environmental socialization.<sup>(7)</sup> Caregivers are also the backbone for someone with a chronic illness to provide care and social support.<sup>(6)</sup> The caregiver is the primary source of support in responding to the patient's status and accompanies the patient 24 hours during the phase of the disease.

Caring for patients can negatively affect family caregivers' physical, psychological, emotional, and social health. The caregiver burden is a multifaceted reaction to physical, psychological, emotional, social, and financial difficulties involved with caregiving. Caregiver burden as the multifaceted strain the caregiver perceives from caring for a family member and/or loved one over time.

Based on data from a private hospital in western Indonesia from August 2022 to October 2022, 29 patients underwent CABG, one underwent Mitral Valve Replacement (MVR), and one underwent Aortic Valve Replacement (AVR). In November 2022, the researcher conducted an interview regarding caregiver burden with a caregiver who had taken care of post-heart surgery patients for three weeks for the first time. The caregiver reported that the patient was very dependent after heart surgery. Her sleep hours were disrupted because she often wakes up at night to pay attention to the patient's condition, gives medicine because there are drugs that must be given to patients at night, and helps patients go to the toilet or when patients need help. The caregiver feels tired, and her neck often feels sore from sleeping on the floor during postoperative care at the hospital.

CABG caregivers report a significant burden during the first year following the patient's surgery. Caregivers feel insecure and overwhelmed and lack clear/concise discharge information and follow-up support during the early at-home recovery period. (4) Increased caregiver burden and decreased social support are predictors of poor caregiver psychological distress. (3) The role of caregivers is vital, so caregivers also need support from healthcare providers to provide quality care to patients and promote the recovery process for patients after heart surgery.

Based on the background, this study aimed to describe caregiver burden on caregivers who care for patients after heart surgery.

## **METHODS**

This study was a quantitative descriptive method to describe the caregiver burden on caregivers who care for post-cardiac surgery patients in a private hospital in western Indonesia. The population was all caregivers of post-cardiac surgery patients from January 2023 to April 2023 in an outpatient department of a private hospital in western Indonesia. The sample size was 23 with the accidental sampling technique. Data collection was carried out from January 2023 to mid-April 2023. The instrument used to measure caregiver burden was the Caregiver Burden Inventory (CBI). The CBI is a multiple-choice 24-item instrument with five dimensions: time-dependent burden, evaluating stress caused by the restriction of caregivers' personal time; developmental burden, referring to the sense of failure regarding personal hopes and expectations; physical burden, referring to physical stress and somatic disorders; social burden, caused by conflicts on the job or with family; and emotional burden, referring to feelings of shame caused by a patient's behaviors. [11] Each item used a 5-point self-report scale, with a score system ranging from 0 (minimum burden) to 4 (maximum burden). All of the scores on the 24-item scale are summed, and a total score >36 indicates a risk of burning out, whereas scores near or slightly above 24 indicate a need to seek some form of respite care. The data were analyzed using descriptive statistics methods.

All the caregivers signed written informed consent after giving information about the study's purpose and procedure and before completing the questionnaires. This study was approved by the Ethics Committee of the Faculty of Nursing Universitas Pelita Harapan with number 032/KEPFON/I/2023. The data was analyzed using univariate analysis. Descriptive statistics were used to report the characteristics of the caregivers and the caregiver burden.

## **RESULTS**

Most respondents were female, as many as 18 people (78.26%) of the 23 respondents (Table 1). Based on Table 2, most respondents were aged 15-64, namely 22 (96%) respondents. The highest age of the respondent was 74 years, and the lowest was 18 years, with an average age of 44 years. There are five caregiver burden factors: time-dependence burden, developmental burden, physical burden, social burden, and emotional burden.

Table 3 showed that the time-dependence burden factor had the highest average, with a mean of 2.52 (SD 0.50), followed by the physical burden factor, which had a mean of 1.44 (SD  $\pm 0.48$ ). After all of the scores on the 24-item scale were summed, 10(43.48%) respondents did not feel the burden, but seven (30.43%) indicated the risk of burning out.

Table 1. Distribution of Respondents by Gender in an OPD Western Indonesian private hospital in 2023

Gender	Frequency	Percentage
Male	5	21.74
Female	18	78.26

Table 2. Distribution of respondents by age in an OPD Western Indonesian private hospital in 2023

Age (year)	Frequency	Percentage
<15	0	0
15-64	22	96
<u>≥</u> 65	1	4

Table 3. The average caregiver burden factors for caregivers who care for post-cardiac surgery patients in the OPD of a private hospital in Western Indonesia in April 2023

Caregiver burden factors	Mean	Standard deviation
Factor 1 Time-dependence burden	2.52	0.50
Factor 2 Developmental burden	0.92	0.57
Factor 3 Physical burden	1.44	0.48
Factor 4 Social burden	0.60	0.47
Factor 5 Emotional burden	0.15	0.40

Table 4. Distribution of caregiver burden who care for post-cardiac surgery patients in the OPD of a private hospital in Western Indonesia in 2023

Caregiver burden	Frequency	Percentage
Caregiver did not feel the burden	10	43.48
Caregiver indicated the need to seek for of respite care	6	26.09
Caregiver indicated the risk of burning out	7	30.43

## **DISCUSSION**

The results showed that most respondents experienced the highest burden on the time dependence factor. This aligns with research conducted by Dalirirad et al., which aimed to determine the effect of educational support programs on caregiver burden among caregivers who care for patients undergoing CABG surgery in Iran. (8) The results showed that most respondents experienced the highest burden on the time dependency factor. Another study conducted by Durante et al. revealed the same result that the dimension for which caregivers reported higher levels was a time-dependence burden, and lower levels were an emotional burden. (12) Research conducted by Werdani, as well as Jackson et al., stated that there is an effect of caregiving on caregiver burden of 69.9%, and the more complex the duration of the care provided, the more it will cause an imbalance between personal time and work time, resulting in stress. If the stress lasts long, it will cause a burden. (13,14)

Valer et al. also stated that research in different countries, such as China and Canada, found that the highest level of burden was in the time dependence factor, with an average of 15.7.<sup>(15)</sup> Brazil has the highest burden on development factors, with an average of 12.3. Meanwhile, when a study was conducted in China, the mean score was 41.80, and the mean global score was 48.8. This may be because the Chinese population has a good economy; therefore, they can hire caregivers such as homecare nurses so that their families are not directly involved in care. Even though China and Canada have better support structures than Brazil, caregivers who have become family caregivers often have to change their future due to patients' dependence on caregivers, which ultimately causes caregivers to feel out of control and emotionally exhausted. This differs from Brazil, where the patient's family is directly involved as a caregiver, causing an imbalance between personal and work time due to the patient's dependence on the caregiver.

The results of this study are also different from the research conducted by Suksatan et al., which aims to describe caregiver burden and the relationship between health outcomes and describe caregiver-focused interventions that treat heart failure patients. (16) The results of the study stated that there is a burden on caregivers in Brazil, with the highest burden being physical, social, and emotional factors.

This study found that developmental, social, and emotional scores are lower than time-dependence and physical factors. This can be related to family and cultural aspects. Cultural gender expectations relegate tasks associated with caring for women as part of their household duties to a cultural norm. (17) Religion can also influence the perceptions of caregiving. This result is consistent with a study by Subih et al. that found the lowest score regarding emotional burden. (18) Like other studies, the time-dependence burden was the highest among the five CBI subscales, the more complex the patient's condition, the higher the patient's dependency on the caregiver.

Based on the results obtained, there is a fairly even distribution in the three categories of caregiver burden caring for post-cardiac surgery patients: 10 (43.48%) respondents did not feel the burden, six (26.09%) respondents indicated the need to seek respite care and seven (30.43%) respondents indicated the risk of burning out. Most respondents were in the category of not feeling the burden, which can be related to the possibility of discussion between the two parties in advance regarding the recovery process that will be undertaken at home and the support from the family during post-heart surgery. This result aligned with research conducted by Durante et al., which found that the mean caregiver burden score was 16.29 (SD 16.96) in the category where the caregiver did not feel the burden. (19) Ariska et al. explained that the higher the support provided by the family, the lower the

burden on the caregiver; the lower the family support, the higher the burden experienced by the caregiver because the caregiver who is directly involved as the patient's life partner experiences a heavier burden because of the interdependence of each partner and the existence of negative emotional conditions in the marriage can affect the burden of care. (20) A study reported that high-quality patient-partner relationships reduce caregiver burden. (21) Ariska et al. also stated that caregivers who have a relationship as children and parents are influenced by various factors, including customary law, norms, and beliefs that apply in society that children must be devoted to their parents. (20) Caregiving was also associated with positive emotional responses, such as caring, closeness, and responsibility. (4)

Gracia and Mansoer also stated that the role of a caregiver in the family requires support from partners and extended family because if there is no support from family or partner, the caregiver can experience burdens in carrying out their duties. (22) Research conducted by Perry and Lestari also explains that the support of the people around can reduce the pressure or stress experienced in carrying out the role of a caregiver. (23) Disease and symptom-management tasks are burdensome and associated with stress and physical exhaustion for many caregivers. (4) Family caregivers often experience a great deal of physical and emotional distress and require additional support to alleviate the burden of caregiving. (8)

## CONCLUSION

Caregivers are at risk for burden because of their roles and responsibilities. Interventions should target caregivers reporting the burden. There are caregiver screening tools that are useful for nurses to identify caregivers at risk for burden so they can be linked to resources in the hospital and community. Various opportunities exist that could prevent or minimize the caregiver burden, such as tailored interventions providing emotional support, self-management education, home care services, and optimizing communication and collaboration between healthcare personnel, patients, and caregivers.

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