Family Caregiver Burden of Children with Cancer

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Abstract

Childhood cancer remains a leading cause of death from disease in children. Families caring for children with cancer are at risk of experiencing caregiver burden. Family caregiver burden can affect the child's healing process and quality of life. The purpose of this study was to determine the description of family caregiver burden in caring for children with cancer at the Yogyakarta Shelter House. This study was a quantitative study with a descriptive design. The sample in this study were 55 family caregivers of children with cancer. The sampling technique used was total sampling. The tools used for data collection were the Zarit Burden Interview. Univariate analysis used a frequency distribution table to analyze family caregiver burden. The results showed that most respondents had a caregiver burden in the light-moderate category of 28 people (51%), while 14 people (25%) had little or no caregiver burden, and 13 people (24%) had a moderate-severe caregiver burden. Family caregiver burden in children with cancer can be reduced through a multidimensional approach, namely a combination of social support, education, role sharing, self-care, psychological counselling, and a supportive health care system.

Keywords: caregiver; family; burden; children; cancer

1. Introduction

Cancer is a disease that has a serious impact on public health. Although the incidence of cancer in children is not comparable to that in adults, childhood cancer remains the leading cause of death from disease in children. Approximately 15,590 children and adolescents aged 0-19 years were diagnosed with cancer in 2021, and 1,780 children died from cancer. Childhood cancer differs from adult cancer in that it accounts for only 2% of all human cancers, yet it has a significant impact and causes death in children. Cancer is the progressive, abnormal growth of cells that disrupt physiological functions, resulting in a disease characterized by genetic mutations, cell proliferation, and abnormal cell growth.

According to World Health Organization data, in 2018, there were 300,000 cases of childhood cancer annually in the 0-19 age range (WHO, 2018). Meanwhile, according to data from the International Agency for Research on Cancer (IARC) in 2014, the number of cancer cases increased from 12.7 million in 2008 to 14.1 million in 2012. In the United States, the most common cancers in children aged 0-14 are acute lymphocytic leukemia (26%), brain and central nervous system (CNS) cancer (21%), neuroblastoma (7%), and non-Hodgkin's lymphoma (6%) (Lupo & Spector, 2020).

In Indonesia, data from the 2013 Basic Health Research (Riskesdas) showed a prevalence of 16,291 cancer cases among children aged 0-14. According to the (Kemenkes RI, 2015), the potential for new cancer cases in children is 4,100, with cases increasing annually. Among children aged 0-14, the prevalence of childhood cancer is 9 per 100,000. Meanwhile, in children aged 0-5 years, the prevalence of childhood cancer is 18 per 100,000 population. Each year, an estimated 90,000 children die from cancer, with a mortality rate exceeding 50 percent (Mahayaty et al., 2022).

The cancer prevalence is also quite high in Yogyakarta, at 4.1% in 2013 to 4.86% in 2018 (Prihantono et al., 2023). Based on estimates of cancer sufferers, Central Java and East Java are the provinces with the highest number of cancer sufferers, with approximately 68,638 and 61,230 cases, respectively (Kemenkes RI, 2015). Dr. Sardjito Hospital Yogyakarta is the central referral hospital for cancer treatment in Yogyakarta and Central Java. There were 1,839 new cases registered in Yogyakarta Pediatric Cancer Registry during the study period. The mean age at diagnosis was 6.3 years and male-to-female ratio was 1.4: 1.0. Fifty-six% of cancers were diagnosed in the 0-5-years age group. The number of patients registered in 2000-2009 study was 1,124 case. Therefore, there was an increase of 63.6% in the number of childhood malignancies registered in 2010-2019 compared to the 2000-2009 study (Supriyadi et al., 2023).

One therapy that can be used to treat cancer is chemotherapy. However, chemotherapy can have negative physical and psychological effects on children. This occurs because chemotherapy is a systemic therapy using cytotoxic agents that can inhibit the growth of rapidly dividing cells in the body

(Wecker, 2019). Physical effects can include pain, nausea, and fatigue, while psychological effects include mood disorders, anxiety, and low self-esteem. Cancer in children is a complex problem because not only the child suffers the pain, but the parents also bear the heavy burden of caring for them (Fitri, 2020).

Childhood cancer is a particularly complex problem, as it involves not only the child but also the parents, the community, the school, and others. This is said to be complex because treating the disease experienced by children with cancer requires the involvement of others. In addition to medical personnel, parents, family, siblings, schoolmates, and the community also play a crucial role. This is because children are at a relatively young age when they need others to meet their daily needs (Bahtiar et al., 2018).

Children with cancer require long-term care, and treatment can impact the psychological, biological, and psychosocial well-being of parents. Furthermore, it can also lead to changes in parental roles and responsibilities, such as parents trying to protect their children, supporting them to cooperate with treatment, feeling unable to care for their other children, seeking information about their child's illness, and seeking emotional support regarding the situation. In this regard, each parent naturally has different mindsets and perspectives. For example, a mother must be stronger in facing life for her child and family, while a father feels that their child's treatment is the primary priority (Saraswati et al., 2018). The role of parents in this regard is crucial, but also challenging, as they must accompany their child with cancer throughout the treatment program. Smith et al. in (Saraswati et al., 2018) state that parents are one of the primary caregivers for children during illness, acting as caregivers. Family members are the patient's closest caregivers, and they are aware of the patient's symptoms. Caring for sick family members is a cultural practice in Asia, where families have a responsibility to care for them. In Indonesia, close family ties encourage family caregivers to be involved in patient care, both in the hospital and at home. Family care activities encompass daily activities, physical, social, psychological, and spiritual issues (Putriana, 2021).

High caregiver burden can be influenced by the patient's functional status. Research shows that caregiver burden increases when the patient's functional condition declines. Children with cancer become a burden and become dependent on caregivers for daily activities, which can impact the caregiver's work schedule and health. Caregivers with cancer patients must alter their lifestyles to accommodate the patient's demands, including limiting free time and interactions with other friends. When caregivers need relaxation, they often lack quality time. Caregivers prioritize the patient over themselves. This can lead to numerous health problems, such as sleep disturbances, fatigue that worsens physical function, and symptoms of burden (Puspitasari, 2017).

(Bevans & Sternberg, 2012) conducted a study on a 53-year-old caregiver caring for her 56-year-old husband, who had acute myelogenous leukemia and had undergone an allogeneic hematopoietic stem cell transplant. The results showed that the caregiver experienced high levels of anxiety, worry, loneliness, and distress, especially before the transplant. Research by (Kim & Schulz, 2008) shows that the burden on family caregivers of cancer patients is greater than that of family caregivers caring for elderly or dementia patients.

Shelters are temporary residences for cancer patients, designed to facilitate patient and family care and transportation to the hospital. Cancer patients are provided with various facilities, including accommodation, affordable meals, and special transportation to the hospital where they are receiving cancer treatment. Facilities at each shelter vary. The presence of these shelters provides convenience for patients and families who live in different cities than the hospital.

Based on the background above, the researcher is interested in understanding the burden on family caregivers caring for children with cancer. The purpose of this study was to determine the burden on family caregivers caring for children with cancer at the Yogyakarta Shelters.

2. Method

This quantitative study, using a descriptive design, aimed to determine the caregiver burden experienced by families with children with cancer at the Yogyakarta Cancer Shelter. The study was conducted in February 2025. The population comprised all 55 caregivers of children with cancer at the Yogyakarta shelter. The inclusion criteria included parents willing to participate, parents able to read and write, paediatric cancer patients undergoing chemotherapy, paediatric cancer patients aged 2 to

18, and parents willing to participate. Exclusion criteria included conditions that prevented the child from participating, such as decreased consciousness, pain and inability to concentrate during the study, cognitive and functional impairments, and children unaccompanied by family members. Total sampling was used, drawing samples from the entire population.

The data collection instrument used the Zarit Burden Interview (ZBI) questionnaire, which consists of 22 questions. The Indonesian version of the ZBI questionnaire, translated by (Rahmat LAE & R Endawati, 2009), consists of 22 items focusing on the caregiver's physical or health burden (4 items), emotional or psychological burden (5 items), economic burden (1 item), social burden (5 items), and the relationship between the patient and family (7 items). Each question is closed-ended, so respondents are not required to answer in their own words. Answers are scored from 0 to 4. 0 = never, 1 = rarely, 2 = sometimes, 3 = quite often, and 4 = almost always. The results of this questionnaire are the sum of each selected score and grouped into four categories. A score of 0-20 is considered to have little or no burden, a score of 21-40 is considered to have a light to moderate burden, a score of 41-60 is considered to have a moderate to heavy burden, and a score of 61-88 is considered to have a heavy burden. The data analysis used was univariate analysis in the form of child respondent characteristics (age, gender, and duration of treatment), child caregiver characteristics (age, gender, education), and a description of the burden on family caregivers in children with cancer. This study has passed the ethical feasibility test from the Unisa Yogyakarta Ethics Commission with No. 4159/KEP-UNISA/1/2025.

3. Results and Discussion

3.1. Respondent Characteristic

Table 1. Characteristic of Children (n=55)

Characteristic of Children		Frequency	Percentage (%)
Age	2-4 years old	22	40
	5-7 years old	9	16,4
	8-18 years old	24	43,6
Sex	Male	28	50,9
	Female	27	49,1
Length of treatment	0-2 month	3	5,5
	3-4 month	9	16,4
	5-24 month	36	65,5
	>24 month	7	12,7

Based on Table 1, it shows that the majority of respondents were aged 8-18 years, as many as 24 people (43.6%), were male, as many as 28 people (50.9%), and underwent treatment for 5 to 24 months, as many as 36 people (65.5%).

Table 2. Characteristic of parent (n=55)

Characteristic of parent		Frequency	Percentage (%)
Age	Early adulthood (19-40 years)	35	63,6
	Middle adulthood (41-60 years)	20	36,4
Sex	Male	10	18,2
	Female	45	81,8
Education	Elementary	7	12,7
	Junior high school	21	38,2
	Senior high school	23	41,8
	Bachelor	4	7,3

Based on Table 2, it shows that the respondents' parents were mostly early adulthood aged 19-40 years, as many as 35 people (63.6%), female as many as 45 people (81.8%), and had a high school/senior high school education as many as 23 people (41.8%).

3.2. Burden on family caregivers of children with cancer

Table 3. Burden on family caregivers of children with cancer (n=55)

Burden Caregiver	Frequency	Percentage (%)
Little or no burden	14	25
Light-moderate burden	28	51
Moderate-severe burden	13	24

Based on Table 3 show that the majority of respondents (28 respondents) had a light-moderate caregiver burden, representing 51% of the respondents. Meanwhile, 14 (25%) had little or no caregiver burden, and 13 (24%) had a moderate-severe caregiver burden.

This study was conducted to determine the level of family caregiver burden for children with cancer at a cancer shelter in Yogyakarta. The results showed that 51% of families experienced a light-moderate caregiver burden. This finding aligns with (Chaghazardi et al., 2022), who stated that 50% of caregivers experienced a moderate burden. A similar study by Naing et al. (2020) found that the average caregiver burden ranged from moderate to severe. This finding also aligns with Chavan et al. (2023), who found that the majority (55%) of caregiving burden fell into the light-moderate category, although some were severe.

(Chaghazardi et al., 2022) stated that several factors influence the burden on family caregivers, including the caregiver's gender, education level, length of care, and the age of the child patient. Based on the gender of caregivers of children with cancer, the results showed that 45% of parent respondents were female and had a mild-moderate level of caregiver burden. This study's results are inconsistent with the study by (Chaghazardi et al., 2022) which stated that the majority of caregivers were female (70%) and found that the care burden was 8.5 times higher in female caregivers than in male caregivers ($p = 0.004$). (Swinkels et al., 2019) also stated that the caregiver burden was higher in women than man. Mothers as caregivers (female) showed a heavier burden than men. (Heller & Melnikov, 2025) also found that the majority of caregivers were mothers (female) (~80.6%), and the study showed a high caregiver burden. Although in theory, women (especially mothers) are often identified as primary caregivers who are at risk of experiencing a higher burden, this study did not find a significant relationship between gender and caregiver burden. This is likely due to the dominance of other factors such as the level of social support, economic conditions, and time spent caring for children, which are more decisive in determining the level of burden felt.

Based on parental education level, most parents had a high school or college education. This may influence the caregiver burden parents experience when caring for a child with cancer. The results of this study align with those of (Chaghazardi et al., 2022) and (Adib-Hajbaghery & Ahmadi, 2019), which stated that caregivers with higher education experienced lower caregiving burden than those with lower education. However, several studies have shown no relationship between education and caregiving burden (Arab et al., 2020). Caregivers with higher education may be better able to manage stress and have better problem-solving skills (Ahmadi et al., 2018) and (Arab et al., 2020). On the other hand, caregivers with low levels of education may have lower socioeconomic status and therefore have fewer resources to meet patient care needs (Govina et al., 2015). A study in Mesir (2024) found that caregiver education is a sociodemographic factor significantly associated with caregiver stress levels. Parents with higher education generally report lower stress levels than those with lower education. Research by (Wang et al., 2022) also found that parents with lower education (middle/high school level) were more likely to be classified as having "high caregiving ability."

Based on the duration of treatment, most respondents had undergone treatment for more than 5 months. (Chaghazardi et al., 2022) stated that treatment duration is a significant factor influencing caregiver burden, although they did not explicitly state that treatment duration of more than 6 months resulted in a lighter burden. Research by (Maurice-Stam et al., 2008) also showed that at 6 and 12 months, there was a significant decrease in parental emotional distress, indicating that the longer the treatment, the lower the burden. The better the family manages the stress/burden they feel. This is in line with research by (Bona et al., 2014), which states that the highest emotional and financial burden occurs in the early stages of treatment. Over time, families demonstrate more stable coping

mechanisms. Caregiving burden tends to be higher at the time of diagnosis and decreases over time, especially after caregivers adapt to treatment routines and receive support.

Based on the age of children with cancer, the study results showed that most children aged 8-18 years (43.6%) experienced a mild to moderate burden on family caregivers. School-age children/adolescents are more physically independent and can assist with self-care, and can communicate about pain, side effects, and emotions. However, new psychological challenges can arise, where adolescents may feel angry, rebellious, or refuse treatment, resulting in caregivers having to bear an additional emotional burden. This is in line with research by (Chaghazardi et al., 2022), where patient age (child) was one of the demographic variables examined as a factor associated with care burden. Researchers also found that the caregiving burden is quite high for young patients due to intensive care requirements. Research by (Arega et al., 2024) shows that caregivers of children under 5 years old experienced a greater likelihood of a "severe/very severe" burden compared to caregivers of older children (children aged >10 years). Older children aged over 10 years were associated with a decreased odds of a very severe burden compared to children under 5 years old.

4. Conclusion

Family caregiver burden for children with cancer was mostly in the mild-moderate category, with 28 (51%) experiencing mild-moderate burden, while 14 (25%) had little or no caregiver burden, and 13 (24%) had moderate-severe caregiver burden. Based on this, a peer support group program is needed for caregivers to share experiences and coping strategies to reduce caregiver burden.

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