

# Caregivers' Burden and Financial Distress in Parents of Children with Cancer: A Descriptive Correlational Study

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## Abstract

**Background:** Cancer and its treatment pose a challenge to the child and the caregiver. The lengthy treatment and the suffering of the child from the side effects are highly demanding on the side of the caregiver in terms of the physical, social, and financial aspects. This study aims to measure the caregivers' burden and financial distress among parents of children with cancer. **Materials and Methods:** A cross-sectional study design using a convenience sample of 158 parents of children with cancer completed two surveys on caregivers' burden and financial distress. **Results:** Parents of cancer experienced moderate financial distress, with most reported mild to moderate level of caregiver burden. This study highlights that caregivers of children with cancer experience a significant level of burden and financial distress that may affect them negatively and affect their role as caregivers. Early assessment of caregiver burden and financial status is essential to improve treatment adherence and prevent adverse outcomes. **Conclusion:** The study shows significant financial and caregiver burden, highlighting the need for better support services.

**Keywords:** Caregivers' Burden- Financial Distress- Pediatric- Cancer- cross-sectional

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## Introduction

Cancer is the leading cause of mortality among children and adolescents, with an estimated 400,000 children and adolescents aged 0 to 19 years developing cancer each year around the world [1]. Leukemia, brain malignancies, lymphomas, and solid tumors, including neuroblastoma and Wilms' tumor, are the most prevalent forms of juvenile cancers [1]. In high-income countries, 80% of children with cancer are cured; in low- and middle-income countries, less than 30% are cured [2].

Cancer affects not only the patient but also the entire family. Cancer-related challenges immediately affect patients and their caregivers, with caregivers' primary concern being the burden of care [3]. Caregiver burden is defined as "the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning" [4]. Caregivers usually feel burdened due to the excessive demands on their financial, social, and physical demands or many conflicting responsibilities,

yet it is highly individualized. In the context of cancer, this role of caregiving may differ or change based on several factors, such as the type of cancer for the patient, the presence of metastasis, the response to treatment, and the side effects of the treatment, which will affect how dependent the patients will be on the caregiver [5].

More than half of parents of children with cancer were found to be distressed in a study conducted in Singapore [6]. Parents most frequently reported cognitive issues, with social issues coming in last. Distress was statistically associated with practical, emotional, physical, and cognitive challenges of caregiving [6]. Similar patterns of worrying were demonstrated by parents in China [7]. Likewise, it was found that 56% of parents of children with cancer in Lebanon experienced parental burden, which was found to have a strong positive correlation with the severity of financial troubles in the family and strongly negatively associated with the duration of the child's illness [8].

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In Jordan, 67.6% of parents of children with cancer showed clinically significant levels of worry [9]. The perceived amount of burden is influenced by the characteristics of both parents and children. Among parents, chronic disease, work problems due to caregiving, financial problems, anxiety, or depression were among the factors that influence the level of burden. Among children, advanced stage of cancer, having pain, or complaining of nausea and vomiting were found to be predictors of a higher level of parental burden [9].

When compared to parents of cancer-free children, parents of cancer-affected children are more likely to have anxiety severe enough to require medical attention. Parents with children with a poor prognosis, as well as those with a low level of education or a low income, are particularly vulnerable [10].

Parents of children with cancer face psychological, existential, physical, and social challenges. During treatment, parents may find themselves in an emotionally unstable situation and devote all of their time to caring for and safeguarding their child, neglecting their own psychological needs in the process. Following curative therapy, parents face difficulties returning to life as it was before the diagnosis, and their focus shifts from caring for their kids to dealing with their own emotional scars and worries [11]. In addition to the burden that caregivers experience as a result of caring for children with cancer, pediatric cancer induces financial distress as well due to the impact of the diagnosis and its treatment on family finances [12]. It was found that 63.6% of parents reported that childhood cancer had a significant financial impact on their family [13]. The direct (out-of-pocket expenditures of the child's medical care) and indirect (lower family income due to job loss) financial implications of a child's cancer diagnosis can lead to poorer family financial outcomes, including poverty, over time [13]. Furthermore, childhood cancer can have both short- and long-term financial and employment consequences for parents. Travel to and from the hospital, as well as the necessity to limit working hours during their child's cancer treatment, were all mentioned as causes of financial distress by parents [14].

In Jordan, the majority of childhood cancer treatment costs are covered by insurance and the Ministry of Health (MoH), but certain indirect expenses, such as transportation, accommodation, or non-standard treatments, may not be fully covered. To date, no published data exist about financial distress among parents of children with cancer, and only limited research studies investigating the caregivers' burden among Jordanian parents have been conducted.

### *Study Hypothesis*

There is a positive relationship between caregivers' burden and financial distress among parents of children with cancer.

### *Aim of the study*

This study aimed to measure the caregivers' burden and financial distress among parents of children with cancer.

The objectives of this study were

- To determine the prevalence of caregivers' burden and financial distress levels for parents of pediatric patients with cancer.
- To determine the relationship between caregivers' burden and financial distress among parents of children with cancer.
- To evaluate demographic factors associated with caregivers' burden and financial distress among parents of pediatric patients with cancer.

## **Materials and Methods**

### *Design*

A descriptive, correlational design was used to examine the relationship between caregivers' burden and financial distress among parents of children with cancer. The design involved collecting quantitative data to assess the prevalence and severity of these variables and their interrelationship. The study was conducted at a specialized cancer center located in Amman, Jordan.

### *Data Collection Methods*

Participants were recruited from all pediatric settings (inpatient, outpatient, and day-case settings). Participants who met the inclusion criteria and agreed to participate in the study were asked to complete a demographic data form and study surveys, including the Zarit Burden Interview scale (ZBI-22). The Arabic version of this tool was obtained through the Mapi-Research Trust; the financial impact scale (FIS) was translated into the Arabic language for this study. Data collection was completed in a private room for the outpatient in order to protect the participant's privacy and confidentiality, and to allow enough time and a suitable place for the participant to complete the surveys. For in-patients, data collection was performed in the patient's room.

After explaining the study purpose, the study surveys were distributed by the research team to the participants as hard copies. Both instruments were completed within 15-20 minutes. Completed surveys were collected by a research team member to help reduce the possibility of missing data.

### *Inclusion and Exclusion Criteria*

Eligible participants were parents (either the mother or the father) of children diagnosed with cancer, currently receiving treatment as newly diagnosed or relapsed. The parent was present with the child at the time of the survey and was able to read and write Arabic. However, parents of non-oncological patients (hematological disorders) and parents with mental disabilities were excluded.

### *Recruitment Strategy*

For the outpatients, participants were recruited by tracking the outpatients' visits to the center for any reason (day-case or clinic). For in-patients, all admitted patients (with parents) were potential participants; in addition, all new admissions were checked daily by the research team based on the inclusion and exclusion criteria. If

found eligible, participants were invited to participate in the study.

### Sample Size

The required sample size was calculated according to the Cochran Formula, given that the margin of error is 5%, the population size was around 350–400 patients each year (obtained from the cancer registry) and the estimated proportion of the population having psychological distress is 75% according to previous studies. The final sample size was 158 participants. A convenience sampling technique was used for selecting the study participants.

**Demographic Variables:** The following variables were collected for parents: Age, gender, relationship, marital status, nationality, level of education, having a chronic disease, working status, work problems due to caregiving (Yes, No), financial status, type of housing (owned vs. rented), and number of family members. For children: Age, gender, type of cancer, and time since diagnosis (duration of caregiving).

**Caregivers' burden:** Caregivers' burden was measured by Zarit Burden Interview (ZBI-22 item), Arabic version, which was obtained from the e-provide website (ZBI-22). The tool was developed by Zarit and Zarit [4]. It is composed of 22 items distributed over five domains: Burden in relationships, emotional well-being, social and family life, finance, and loss of control over one's life. The tool was designed to measure the extent to which a caregiver perceives his or her level of burden as a result of caring for a person with a particular diagnosis. Participants rate their responses on a scale from 0 (no burden) to 4 (high burden), and the total score was calculated by summing the responses to the individual items with the range of 0 to 88. Interpretation of Score: 0–21 (little or no burden), 21–40 (mild to moderate burden), 41–60 (moderate to severe burden), 61–88 (severe burden). The ZBI is a reliable tool, with Cronbach's  $\alpha = 0.92$  [9].

**Financial Distress:** Financial distress was measured by the Financial Impact Scale (FIS). This tool consists of 20 items with a 5-point Likert scale response (1 = Strongly agree; 5 = Strongly disagree). The FIS was developed to assess the financial effect of long-term caregiving. The FIS was found to be a unidimensional scale that measures general financial impact. For the current study, the tool was translated into the Arabic language by two bilingual healthcare providers (HCPs), and then the two Arabic (translated) versions were checked against the original English version by a third bilingual HCP, who recommended minor modifications. Finally, a final translated version of the tool was produced. Three questions were omitted because they did not apply to our participants. A possible range of scores was from 17–85. The lower the FIS score, the greater the financial impact. The purified 20-item FIS had an alpha of .91 [15].

### Statistical Analysis

Descriptive statistics were used to calculate the mean, range, frequency, percentage, and standard deviation (SD). The relationships between the mean burden score, the mean financial distress score, and parents' age, the number

of family members, and the child's age were estimated using the Pearson correlation coefficient. A point-biserial correlation was used to test the correlation between the main study variables and other categorical variables.

### Ethical Considerations

This study was conducted following ethical guidelines and approved by the Institutional Review Board. A written consent form was obtained from all participants after explaining the study procedure, its potential risks, and benefits. Participants were asked to sign two copies of the consent form: one copy was given to the participant, and the other was retained by the research team. Participants were informed that their participation was voluntary and that they could withdraw at any time during the study without prior notice and without affecting the treatment of their child. They were assured of the confidentiality and anonymity of the data they provided. Informed local support services were available for any possible distress related to the study. If a participant became upset, they were transferred to the hospital social worker who could offer assistance from trained personnel. Participation in the study was not associated with any financial compensation. However, the research addressed participant well-being to ensure informed and non-coerced consent.

## Results

A total of 158 parents participated in the study. In the study sample, mostly, the companion (caregiver) of the child was the mother (80.4%). The majority of participants were fairly young (below the age of 40 with a percentage of (70.3%), female (79.7%), married (89.2%), and Jordanian (89.2%). The highest percentage of the participants obtained a higher education degree (university education) (48.1%), followed by secondary education (45.6%). More than half of the participants were not employed (55.7%), and of the employed, around half received a salary of less than 500 Jordanian Dinars, which is below the national average salary (51.9%). More than half of the participants rented their houses (55.1%), and had five to seven family members living in the house (58.2%). The majority of the participants did not have a health problem or a chronic disease (88.5%) and did not have any work-related problems (90.5%). The mean age of the children admitted for treatment in this study was around 7 years ( $M = 7.07$ ,  $SD = 3.89$ ), the majority were male patients (57%), admitted for a diagnosis of leukemia (57%), and diagnosed within less than six months (78.5%). More details are in Table 1.

Table 2 shows the average scores of the financial distress as measured by the FIS and the caregivers' burden as measured by the Zarit Burden Inventory scale (ZBI). The mean score of financial distress in this sample of parents was 47.08 ( $SD = 14.66$ ), noting that according to the tool developer, the lower the score, the greater the financial distress. The scores were distributed into three equal categories: scores (19–41) indicate high financial distress; scores (42–63) represent moderate financial distress, and scores (64–85) represent low financial

Table 1. Demographic and Clinical Characteristics

Variable	Category	N	Percent %	
Age of the Caregiver	21-40	111	70.3	
	> than 40	47	29.7	
Gender of the Caregiver	Male	32	20.3	
	Female	126	79.7	
Relationship (Caregiver)	Father	31	19.6	
	Mother	127	80.4	
Marital Status	Married	141	89.2	
	Divorced	13	8.2	
	Widowed	4	2.5	
Nationality	Jordanian	141	89.2	
	Non-Jordanian	17	10.8	
Educational Level	Primary Education	10	6.3	
	Secondary Education	72	45.6	
	Higher Education	76	48.1	
Employment Status	Full Time	46	29.1	
	Part Time	24	15.2	
	Not working currently	88	55.7	
Income	< than 500 JD	82	51.9	
	500-1000 JD	65	41.1	
	> than 1000 JD	11	7	
Caregiver's Work Problem	Yes	15	9.5	
	No	143	90.5	
Type of Residence	Owned	71	44.9	
	Rented	87	55.1	
Health Status of the Caregiver (Presence of Chronic Diseases)	Yes	19	12	
	No	139	88	
Number of Family Members	2-4	48	30.4	
	5-7	92	58.2	
	8-10	17	10.8	
	More than 10	1	0.6	
Patient (Child) Gender	Male	90	57	
	Female	68	43	
Patient (Child) Diagnosis	Leukemia	90	57	
	Brain Tumors	12	7.6	
	CNS Tumors	2	1.3	
	Lymphoma	21	13.3	
	Genitourinary Cancer	4	2.5	
	Bone Tumors	13	8.2	
	Other	16	10.1	
Time Since Diagnosis	< than 3 months	58	36.7	
	3-6 months	66	41.8	
	> than 6 months	34	21.5	
	N	Minimum	Maximum	Mean (SD)
Age of the patient (Child) in years	158	0.5	18	7.07 (3.89)

distress; the mean score of the sample in this study would fall under moderate financial distress, and the majority had moderate to high financial distress (82.3%).

In terms of the level of caregiver burden as measured by the ZBI, the mean score of the study sample was 29.35 (SD = 12.68), noting that the higher the score, the greater the caregiver's burden. According to the interpretation of scores proposed by the tool developer, the mean score

would fall under (mild to moderate caregiver burden); noting that 47.5% reported mild to moderate burden, and 21.5% reported moderate to severe burden. More details are presented in Table 2.

Table 3 displays the correlation between the main study variables. The results show that there was a significant correlation between financial distress and the caregiver's burden ( $r = -0.525$ ,  $p < 0.01$ ). The correlation is negative

since for the financial impact scale, the lower the score, the higher the financial distress, so this means that the higher the financial distress, the higher the caregiver's burden.

Tables 4 and 5 present the correlation of the demographic and clinical variables with the outcome variables, in addition to the post hoc analysis for the variables that showed a significant correlation with the outcome variables. It can be noted that income level has a significant correlation with financial distress ( $r = 0.40$ ,  $p < 0.01$ ). The post hoc analysis showed that there was a significant difference between those with a salary of less than 500 JD, and those with higher salaries (the lower the mean score of the category, the higher the financial distress). In addition, the type of residence (whether the house is owned or rented) has a significant correlation with financial distress and the caregiver's burden ( $r = -0.33$ ,  $p < 0.01$ ;  $r = 0.27$ ,  $p < 0.01$ ; respectively). The post hoc analysis shows that those who have their houses rented are experiencing higher financial distress and higher caregiver burden. Moreover, the health status of the companion shows a significant negative correlation with the caregiver's burden ( $r = -0.16$ ,  $p < 0.05$ ). The t-test shows that participants who have a health problem, exhibit a higher caregiver's burden. Furthermore, the caregiver's work problem shows a significant correlation between the financial impact and the caregiver's burden ( $r = 0.20$ ,  $p < 0.05$ ;  $r = -0.18$ ,  $p < 0.05$ ; respectively). The post hoc analysis demonstrates that participants (caregivers) who have work problems experience significantly higher financial distress and a higher caregiver burden. Lastly, the age of the child has a significant negative correlation with financial distress ( $r = -0.18$ ,  $p < 0.05$ ) which means that as the child gets older, the parents experience more financial distress; however, the correlation is not significant with the caregiver's burden. Other variables do not show a significant correlation with the outcome variables. For more details, please refer to Tables 4 and 5.

## Discussion

Cancer is a stressful and costly disease, and its treatment often leads patients to have financial issues. The

terms financial distress, financial hardship, and financial toxicity reflect the financial burden experienced by cancer patients as a result of their treatment [16]. In this study, it was found that the majority of the participants had moderate to high financial distress. This perception is apparently multifactorial. Although the treatment for the majority of the patients is covered by insurance in the study site, families still have other financial obligations; for example, they need to pay for transportation and accommodation of their child to get their treatment. In addition to that, some parents may take unpaid leave in order to be with his/her child (if the parent who is working is accompanying the child), noting that 55% of the caregivers in this study did not have a job at the time of the survey. Besides this, more than half of the participants have reported that they get a monthly salary of less than 500 JD/month, which could be insufficient to compensate for the daily expenses in addition to paying for house rental. It is worth noting that the majority had a fairly big family, which itself puts an extra burden on the family finances. For all these factors, family income might not be enough to cover all the expenses of the family, even without considering the inflation that is occurring worldwide. These results are consistent with other studies; for example, [17] reported that 38% of families have borrowed money from moneylenders to cover the expenses of cancer, which creates financial distress.

Also, a study by Santacroce & Kneipp (2020)[13] reported that more than 63% of families of children with cancer reported financial distress. In terms of the effect on patients, a study conducted by Yu et al. [18] found that 47.9% of patients with cancer reported financial toxicity. Arastu et al.'s [19] study on older adults with advanced cancer reported that only 18.3% of patients reported financial distress; however, this proportion was higher compared to financial distress reported by older adults with other chronic diseases. In addition, the increase in financial toxicity was associated with decreased quality of life according to several studies [19-21].

Cancer and its treatment side effects can create a great deal of burden on the caregivers, which can increase in severity when the child cannot cope well with the

Table 2. Mean Scores of the Financial Distress and Caregivers' Burden

	N	Mean (SD)	High Financial Distress	Moderate Financial Distress	Low Financial Distress	
			N (%)	N (%)	N (%)	
Financial Distress	158	47.08 (14.66)	60 (38.0%)	70 (44.3%)	28 (17.7%)	
			Little or no burden	Mild to moderate	Moderate to severe	
			N (%)	N (%)	N (%)	Severe Burden
						N (%)
Caregivers' Burden	158	29.35 (12.68)	48 (30.4%)	75 (47.5%)	34 (21.5%)	1 (0.6%)

Table 3. Correlation between Financial Distress and Caregiver's Burden

Variable	Caregiver's Burden	
	Pearson Correlation	-0.525**
Financial Distress	Sig. (2-tailed)	< 0.01
	N	158

\*\*Correlation is significant at the 0.01 level (2-tailed).

Table 4. Correlation of the Demographic and Clinical Variables with the Outcome Variables

Variable	Financial Distress		Caregiver's Burden	
	r	p	r	p
Age of the parent	-0.04	0.64	0.12	0.14
Gender of the parent	-0.12	0.12	0.02	0.77
Companion (father or mother)	-0.13	0.11	0.03	0.74
Marital Status	-0.1	0.21	0.08	0.29
Educational Level	0.08	0.34	0.08	0.32
Employment Status	-0.14	0.09	0.01	0.94
Income	0.40**	< 0.01	-0.13	0.1
Type of Residence	- 0.33**	< 0.01	0.27**	< 0.01
Health Status of the companion	0.12	0.13	- 0.16*	< 0.05
Number of family members	0.07	0.36	-0.03	0.75
Caregiver's work problem	0.20*	< 0.05	- 0.18*	< 0.05
Child Age	- 0.18*	< 0.05	0.11	0.18
Child Gender	-0.01	0.87	0.06	0.44
Child Diagnosis	-0.13	0.12	-0.11	0.15
Time Since Diagnosis	-0.07	0.36	0.03	0.74

\*\*Correlation is significant at the 0.01 level (2-tailed).

Table 5. Post-hoc Analysis of the Variables that Showed Significant Correlation with Outcome Variables

Variable		Financial Distress			Caregiver's Burden		
		N	Mean	p value	N	Mean	p value
Income <sup>1</sup>	< than 500 JD	82	42.01	< 0.01**	82	30.68	0.21
	500–1000 JD	65	50.46		65	28.91	
	> than 1000 JD	11	64.82		11	22	
Residence <sup>2</sup>	Owned	71	52.52	< 0.01**	71	25.46	< 0.01**
	Rented	87	42.63		87	32.52	
Caregiver's work problem <sup>2</sup>	Yes	15	38.4	< 0.05*	15	36.73	< 0.05*
	No	143	48		143	28.57	
Health Status of the companion <sup>2</sup>	Yes	19	41.95	0.104	19	34.79	< 0.05*
	No	139	47.78		139	28.6	

\* The mean difference is significant at the 0.05 level, \*\* the mean difference is significant at the 0.01 level, 1ANOVA test, 2 t-test

symptoms and side effects of treatment for example pain, fatigue, sleeplessness, and oral mucositis. In terms of the caregiving burden as measured by the ZBI, our study found that the majority of the participants have reported mild to severe burden. Parental caregiving burden can be attributed to several factors, including but not limited to the care needed by the child, especially when sick; isolation from the parents' usual social life and personal relationships; the loss of control over the parents' own lives; difficulties in balancing work and family responsibilities; and the uncertainty about the future and the prognosis of their child's illness. Nemati et al. [22], in their qualitative study, reported that family caregivers experience a great deal of disintegration, confusion, and uncertainty as a result of caring for a child with cancer.

The results of the current study are consistent with other studies conducted on cancer patients. For example, Akgul & Ozdemir [23] found in their study that caregiver burden among primary caregivers of patients undergoing

stem cell transplantation was mild to moderate and the mean score was 28.41. Similarly, other studies [7, 24] found that the majority of parents of children with cancer reported mild to severe levels of burden; however, the reported burden mean scores measured by the ZBI were 38.1, 37.74, respectively, which is higher than the reported mean in our study. Meanwhile, other studies have reported lower levels of burden; for example, Harding et al. [25], Likhmana et al. [26], and Unnikrishnan et al. [27] reported that caregiver burden mean scores measured by ZBI were 23.3, 20.0, and 20.0; respectively.

In the current study, it was found that around 22% of the caregivers reported moderate to severe burden. Likewise, Chaghazardi et al. [28] found that caregivers of children with cancer reported moderate to severe burden. Ahmadi et al. [29] & Motlagh et al. [30] discovered that the majority of the parents caring for children with cancer reported a moderate level of burden, but few have experienced a high level of burden; however, Akpan-Idiok et al. [31] reported

that around 80% experienced moderate to severe burden, while Unnikrishnan et al. [27] reported that only 14% of the parents have reported moderate to severe burden and 50% of the caregivers had no or minimal burden, and Lukhmana et al. [26] found in their study that only 5% of the caregivers had moderate to severe burden. These differences in the level of burden experienced by parents might be attributed to the variation in cultural, social, and financial support systems that children with cancer and their caregivers might have and the differences in the healthcare services. Other variables that might contribute to this variation could be the methodological differences among the studies, the patients' population, treatment protocols, length of treatment, and the coping mechanisms of the parents.

Our study also shows that there is a significant relationship between financial distress and the caregiver's burden so the higher the financial distress, the higher the caregiver's burden. This is logically sound, since the financial issues and difficulties can create a great deal of burden on the caregiver, knowing that part of the caregiving responsibilities is to afford the cost of treatment (if not ensured), transportation, housing, and food, in addition to other needs. Generally, people who have fewer financial issues, will in turn feel less burdened, and this is confirmed by the current study. The study by Yu et al. [18] also found a significant relationship between financial toxicity and psychological distress.

In terms of the demographic and clinical variables, the current study showed that caregivers who have low income, rent their houses, and experienced a work problem have a greater level of financial distress; however, there was no effect of age, gender, marital status, educational level, and employment status on the level of burden. When parents have enough income, they can afford the cost of treatment and will have better access to different facilities and thus be less distressed; however, when they have a work problem, such as job loss or a need to take unpaid leave, this will affect their financial status, and subsequently, they will not be able to fulfill their needs. This is confirmed by a study by Warner et al. [32] who found that families with work problems such as quitting or changing jobs reported higher financial burden.

A study stated that patients with lower incomes and being employed but on sick leave reported higher financial distress. In this study, it was found that parents of younger children have higher financial distress, this could be related to the cost of care and support needs by younger patients such as toys, and recreational activities they need to provide to their children to alleviate their suffering from cancer [21].

In regard to the caregivers' burden, it was found in this study that caregivers who rent their houses, have work problems, and suffer from chronic health problems exhibited a greater level of burden. However, other variables such as caregiver's age, gender, marital status, level of education, income level, child age, and diagnosis were not related to the level of burden. When parents have a chronic health problem, they will not be able to help their children in their daily activities as much as they would

when they are healthy. This is partially consistent with a result of a study conducted by Unnikrishnan et al. [27], which reported that gender, marital status, educational level, employment status, and number of family members were not associated with caregivers' burden. However, older caregivers had significantly higher level of burden compared to younger caregivers. They explain it by the fact that older caregivers would be less energetic and might have health issues. Other studies have reported different results; for example, [29] found that younger parents with a lower income had a higher level of burden while the child's age had a positive correlation with burden. This may be related to the way parents adapt to their child's disease.

Chaghazardi et al. [28] found in their study that female, single, less-educated, and unemployed caregivers had higher levels of burden. In line with these studies, Motlagh et al. [30] found that parents who were older, more educated, and/or with better economic status experienced less caregiver burden; however, there was no effect of parents' gender or the family size on the level of burden. In our study, we did not find an effect of the child's age and time since diagnosis on the caregiver's burden; however, Arab et al. [33] reported that single mothers with younger children and who took care of their child for an extended duration have reported a higher level of burden, which they explain in relation to the social support that married mothers receive and the type of cancer the child has. Again, the variances in the results of these studies could be related to the differences in culture, insurance coverage, social support systems, the nature of the cancer, its duration of treatment, and the complications that might arise during the treatment. Lastly, Akpan-Idiok et al. [31] found a strong correlation between caregivers' perceived burden level and coping strategies. People with effective coping mechanisms experience less burden. This gives significance to the importance of enhancing coping strategies to diminish the burden caregivers might experience.

There are several limitations to this study. First, it was conducted in a single oncology center and used a convenience sampling method. This could limit the generalizability of the results. Second, it is difficult to establish causality in cross-sectional studies, since many factors might contribute to the results. Third, the study was completed using a self-administered questionnaire, and answers might be subjected to social-desirability bias as a result of self-reporting.

Future studies can focus on specific types of cancer and certain age groups of children and parents or employ a longitudinal design, which might give a better picture of the specific factors that contribute to caregivers' burden. In addition, experimental design research studies can be utilized to figure out the most effective strategies to alleviate caregivers' burden for parents of children.

In conclusion, caregivers of children with cancer suffer from an array of problems, among which is the burden they experience as a result of caregiving of their child, in addition to the financial issues they suffer from as a result of the cost of the treatment or its obligations.

Assessment of financial distress for caregivers may play a role in supportive care and help to structure a framework for financial counseling referrals. Early screening of parents' issues with caregiving and appropriate referrals may result in better adherence to treatment and improve patients' satisfaction and treatment outcomes. In addition, nurses are uniquely positioned to help parents of children with cancer in their adaptation through having psychological competencies that address the needs of those parents.

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### *Statement of Transparency and Principles*

- The authors declare no conflict of interest.
- The study was approved by the Research Ethics Committee of the authors' affiliated institution.
- The study data are available upon reasonable request.
- All authors contributed to the implementation of this research.

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