

Caregiver's Burden and Its Associated Effect among Parents of Children Suffering from Cancer in Kenyatta National Hospital

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Abstract: Childhood cancers affect caregivers in various ways; physically, socially, psychologically and economically which lead to caregiver burden. Caregivers of children with cancer suffer significant stress, loneliness, job loss, and family conflict during the time of care. Approximately 1110 children aged between 0 and 12 years are diagnosed with cancer in Kenyatta National Hospital annually. There is a great need to know how the caregivers of these children are affected.

Study objective: Determining the burden on caregivers of children diagnosed with cancer and its associated effects at Kenyatta National Hospital.

Methodology: A hospital-based cross-sectional descriptive study. 74 caregivers were recruited using Fischer's formula. Data were obtained using the Zarit Caregiver Burden Interview scale and a researcher administered a questionnaire. Data were cleaned, entered and analyzed using SPSS computer package, version 21. Data was presented in textual, tables and pie-charts.

Results: On average, the caregivers reported moderate to severe (58.6+/- 11.2 SD) caregiver burden with majority 73% (n= 54) being females of middle age 30-39 years. More than half 57% (42) having severe caregiver burden. The majority of the respondents had a low economic status with 95% (70) reporting strain in finances as they cared for their children. Psychologically insertion of intravenous cannulas influenced caregiver burden with a P-value of 0.028.

Conclusion: The degree of caregiver burden as measured by the ZBI Scale was moderate to severe in the majority of the respondents with an average score of 58.6 which is way too high than the normal 0-20.

Keywords: caregivers, burden, cancer.

Introduction

Cancer is a long-term illness that affects not only the child but also the family as a whole [1]. Such a serious illness causes the child to undergo an aggressive treatment regimen accompanied by a magnitude of burdens to the parents [2]. Childhood cancers burden families at many levels [3]. Caregiver burden can be explained as a level where a caregiver feels holistically drained that is economically, socially and psychologically as a result of caring. The burden of Care'' is the reflection of the undesirable events and difficulties brought about by the disease upon the members of the family [1]. The majority receive satisfaction from taking care of loved ones however the burden still exists [4].

Kahrma and Zaybak [5] in their study to find out the caregiver burden using the Zarit caregiver burden interview, reflected that 50% of the caregivers experienced mild caregiving burden and only 7.5% experienced severe caregiving burden and they related this to the Turkish culture that says that

it is only natural for the relatives to provide care to the sick relative. They also found out that the levels of care burden increase with a high level of dependency condition of the patient since it increases the need for assistance in even simple tasks such as eating bathing and toileting. However, there was a low perceived care burden among mothers of children with cancer which they related to the account of their motherly instincts.

Caregiving can easily cause negative health status and related behaviors through constant fatigue, sleep deprivation and reduced nutrition [6]. The physical impact parents experience is in unison with the day-to-day tasks that these caregivers must perform so symptoms of caregiving burden gradually increase. The performance status of these children may greatly reduce and so caregivers must intervene in the activities that these children used to perform [7]. Over a given duration of time, with the ill child taking the center stage the caregivers become physically wanting with an expression of like high blood pressure, joint pain, and insomnia [8].

The study therefore assessed: the socio-demographic characteristics of caregivers and children diagnosed with that influence caregiving burden at KNH, the degree of caregiver's burden among the caregivers of children diagnosed with at KNH, how the diagnosis of cancer of the children has caused economic burden among the caregivers and the psychological effects of caring of children diagnosed with cancer at KNH among the caregivers.

2.0 Materials and Methods

2.1 Study Design and Setting

A cross-sectional descriptive using a quantitative method that sought to determine the burden on caregivers of children diagnosed with cancer and its associated effects at Kenyatta National Hospital in pediatrics wards. KNH is the largest and oldest referral hospital in Kenya established in 1901. It is located in Nairobi 3.5km west of the business center. Due to the availability of many pediatrics specialists like the hematologists, most of the childhood cancer cases are referred to Kenyatta National Hospital and also the availability of the radiotherapy machines in Kenyatta makes it more suitable for childhood cancer treatment.

The pediatric wards are located on the third floor and are labeled as 3A, 3B, 3C, and 3D. These wards admit all children from the age of 0-12 years with all medical conditions inclusive of the children suffering from cancer. Each of these wards divided into several cubicles with a capacity of about 70 beds. Each ward has a cubical dedicated to the children suffering from cancer. Each ward has 25 nurses that take care of these children and there are several medical specialists that are consulted on the different medical conditions. The caregivers of these ill children are constantly with the children in the wards until discharge. Ward 1E located on the first floor is also a specialized ward that specially admits children with hematological aged 0-13 years and has a bed capacity of 28 beds. Unlike the pediatric wards on the third floor, parents in ward 1E only come once in a while to check on how the child is fairing. This is because the ward is too small to accommodate the caregivers also.

2.2 Inclusion and Exclusion Criteria

Caregivers with children diagnosed three or more months ago and were started on either chemotherapy or radiotherapy treatment within the period of their stay in the hospital, Caregivers who were the real parents to the child, caregivers who voluntarily consented and agreed to participate in the study. Caregivers who could have lost their child in the course of the day of data collection and those whose children had not started on either chemotherapy or radiotherapy were excluded from the study.

2.3 Sampling Technique

KNH was purposefully selected, is the largest teaching and referral hospital in Kenya. Wards 3A, 3B, 3C, 3D and 1E were purposefully selected because its where pediatric patients suffering from cancer are admitted. A list of children suffering from cancer was obtained from the senior nursing

officer-in-charge of each ward. A simple random sampling method was used to pick the eligible participants from each ward. "YES" was written on small pieces of paper (based on proportionate allocation for the specific ward) an equal number of papers were left blank. All the pieces of paper were folded and put in a basket. The caregivers who picked a paper with "YES" were included in the study.

2.4 Data Collection and Quality Control

The data was collected using the researcher administered semi-structured questionnaires at any given time apart from the morning hours when the ward rounds were taking place or nursing procedures were being performed. The participants were identified and sampled from each selected wards. The researcher or research assistant approached the identified participant and introduced him or herself and informed them about the intended study. When the sampled participant agreed, she/he was explained the process and this enabled him/her to give informed consent. She/ he was asked to respond to the questions in the semi-structured questionnaire. She/he would then give a response to the questions in the Zarit burden interview scale.

The questionnaires were pretested in ward 1F (9D) in KNH, a ward that also admits pediatric oncology patients but with ophthalmology conditions. This ward falls under the ophthalmology department not under pediatrics and is not part of the selected wards under this study. The tools were pretested on 7(10%) of the sample size. This helped in the verification of the data collection tool before data was collected. It also helped identify some important questions that have been left out, some ambiguous and unnecessary questions to also establish how much time respondents were requiring to fill the questionnaire.

2.5 Data Analysis

The data were analyzed using inferential and descriptive statistics Quantitative data were entered and analyzed using SPSS computer package, version 21.0 Chi-square test was done in a bi-variant analysis to assess how caregiver burden index varies among the economic and psychosocial factors a p-value equal to or < 0.005 indicated statistical significance. Percentages were used for categorizing data and data were presented in the form of pie charts, tables, and bar graphs.

2.6 Ethical Consideration

Ethical clearance of the study from the Kenyatta National Hospital/University of Nairobi- Ethics and Research Committee (KNH/UoN-ERC). A clearance to conduct the study was also obtained from KHN department of research. Permission was sought from KNH administration as well as from the pediatrics wards in-charges.

The right to privacy and confidentiality of the study participants was maintained at all the stages of the study. This was achieved by not using participants' names in the questionnaires instead of serialization and the generation of unique codes was used. The data was stored using unique identifiers for any future reference or requirement.

3.0. Results

Based on the eligibility criteria, seventy-four caregivers were enrolled in the study from the different pediatrics wards. A questionnaire and a caregiver burden scale were used to gather the required data. All questionnaires were completely filled contributing to a response rate of 100%.

3.1.1 Social Demographic Characteristics.

Most of the respondents in the study were between 30-39 and 20-29 years 33% (n=26) and 32% (n=25) respectively. Only 1% (n=1) were aged 10-19, none of the respondents were above 49 years. The majority of the respondents were females 73% (n=54) and the males were 27% (n=20). Most 77% (n=57) of the respondents were married and only 1 (1%) was divorced. More than half 54% (n=40) of the respondents were residing outside Nairobi city and the rest were from Nairobi city.

Most of the caregivers 48.6% (n=36) attained education up to the secondary level and only 5% (n=4) attained education to the university level. The findings are presented in table 1 below

Table 1. Demographic Characteristics of Respondents (N =74)

Variables		Frequency (n)	Percent (%)
Age	10-19	1	1.4
	20-29	25	32.1
	30-39	26	33.3
	40-49	22	28.2
	50-59	0	0
Gender	Male	20	27
	Female	54	73
Marital Status	Single	14	19
	Married	57	77
	Separated	2	3
	Divorced	1	1
Residence	Nairobi	34	46
	Not from Nairobi	40	54
Level of education	None	3	4
	Primary	9	12.
	Secondary	36	48.6
	College	22	30
	University	4	5.4

Bivariate analysis was further done to determine the relationship between their caregiver’s burden scores and demographic characteristics, this revealed that more females 74% (n=31) experienced severe caregiver burden than the male caregivers 26% (n=11) and most married respondents 74% (n=31) also experienced severe caregiver burden than the singles, divorced and separated. The chi-square test revealed no significant relationship between the categorical ZBI scores and demographic characteristics of the parents. The results are presented in Table 2 below.

Table 2. Correlation between the caregivers’ Demographic characteristics and the ZBI Scores (N= 74)

Variables		Burden score category				p-value
		Mild	Moderate	Severe	Total	
Ages of caregivers	10-19	0	0	1	1	0.979
	20-29	2	10	13	25	
	30-39	2	9	15	26	
	40-59	2	7	13	22	
Caregiver’s gender	Male	3	6	11	20	0.629
	Female	3	20	31	54	
Marital status	Single	1	5	8	14	0.837
	Married	5	20	31	57	
	Divorced	0	1	0	1	
	Separated	0	0	2	2	

3.1.2 The Children’s age

The majority of the children 46% (n=34) were of age between 0 and 4 years. The results are presented in figure 1 below.

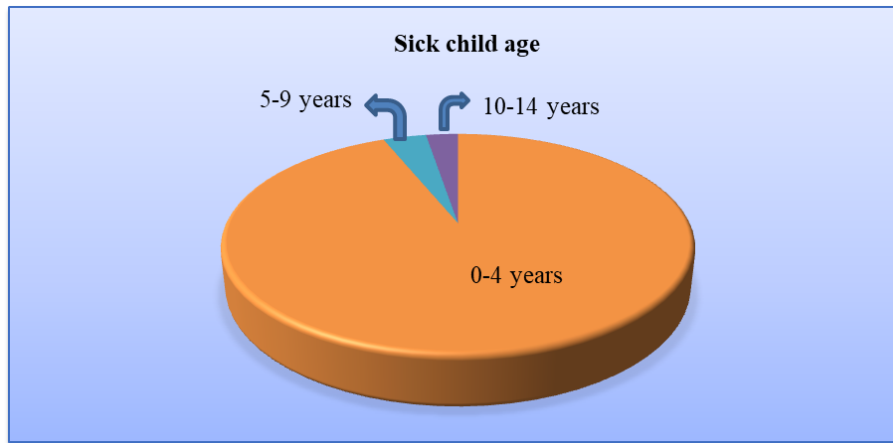


Figure 1. Children’s Ages

3.1.3 The Sick Children’s Birth Order

Most of the children 43% (n=32) were the firstborns to their parents, 30% (n=22) were second borns and only 1% (n=) was the fifth born. The results were presented in table 3 below.

Table 3. Child’s Birth Order

Birth order	Frequency (n)	Percentage (%)
1 st born	32	43
2 nd born	22	30
3 rd born	14	19
4 th born	5	7
5 th born	1	1
Total	74	100

3.1.4 Number of Months since Child’s Diagnosis

The study revealed that most participants had children diagnosed with cancer for a period of 0-6 months 37.8% (n=28) and only 6.8% (n=5) have had cancer between 25-36 months. The findings are presented in figure 2.

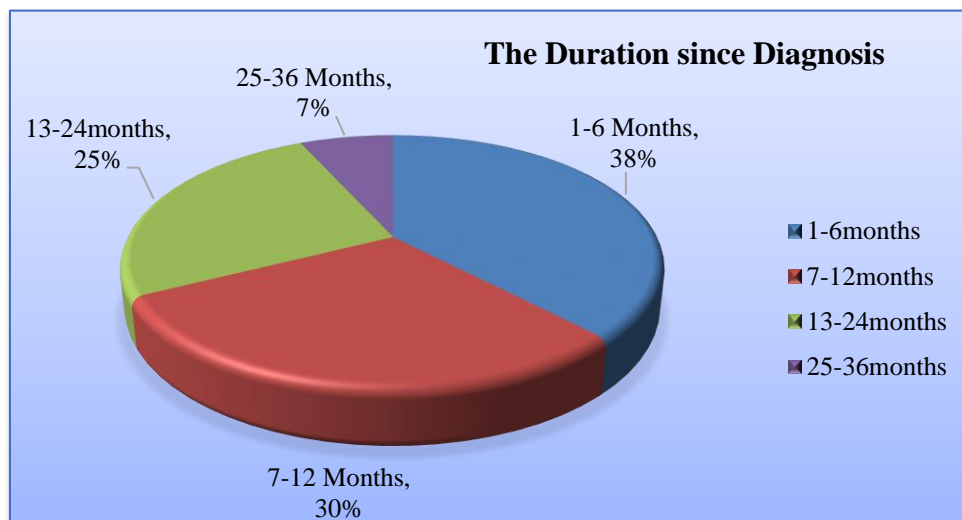


Figure 2. Duration of Diagnosis

3.1.5 Parent’s Views on Treatment Outcomes

Forty-two percent (n=31) respondents graded the treatment outcome of their children as good and only 12% (n=9) reported poor prognosis. The findings are in table 4 below.

Table 4. Treatment Outcomes

Treatment Outcome	Frequency (n)	Percentage (%)
Excellent	17	23
Very good	17	23
Good	31	42
Poor	9	12
Total	74	100

Bivariate analysis was further done to determine the relationship between caregiver’s burden and children’s characteristics, it revealed that more than half of the caregivers 52% (n=22) with children aged between 0 and 4 years reported severe caregiver burden. The chi-square test did not reveal any statistical significance between the two variables. The results were presented in table 5.

Table 5. Association of the ZBI Scores and Children’s Characteristics

Variables		Burden score category (N=74)				P values
		Mild	Moderate	Severe	Total	
Age of children	0-4	2	10	22	34	0.441
	5-9	1	10	12	23	
	9-14	3	6	8	17	
Birth order	First	3	11	18	33	0.959
	Second	2	7	13	22	
	Third	1	5	8	14	
	Forth	0	2	3	5	
	Fifth	0	1	0	1	
Duration of cancer diagnosis	0-6months	2	9	17	28	0.752
	7-12months	1	8	13	22	
	13-24months	3	6	10	19	
	25-23 months	0	3	2	5	

3.1.6 Social Concerns of the Caregivers

Most of the respondents 35% (n=26) had two children and only 4% (n=3) had 5 children. Most of the caregivers 74% (n=55) had children who optimally depended on them. More than half 54% (n=40) of the caregivers reported having spent more than a month in hospital as they cared for the sick child. The above results have been shown in table 6 below.

Table 6. Caregiver’s Social Status N=74

Variables	Frequency (n)	Percentage (%)	
Number of children	1	16	22
	2	26	35
	3	14	19
	4	15	20
	5	3	4
Time spent in the hospital	0-7days	2	3
	1week	7	9
	2weeks	6	8
	3weeks	3	4
	1month	16	22
	More than a month	40	54

3.1.7 Effects of the Child’s Illness on the Family Unit

Majority of the respondents 95% (n=70) reported that the child’s illness caused a strain in finances, more than half 55% (n=41), 51% (n=38) reported increased tension and restriction on their social interaction respectively. The results are presented in figure 3 below.

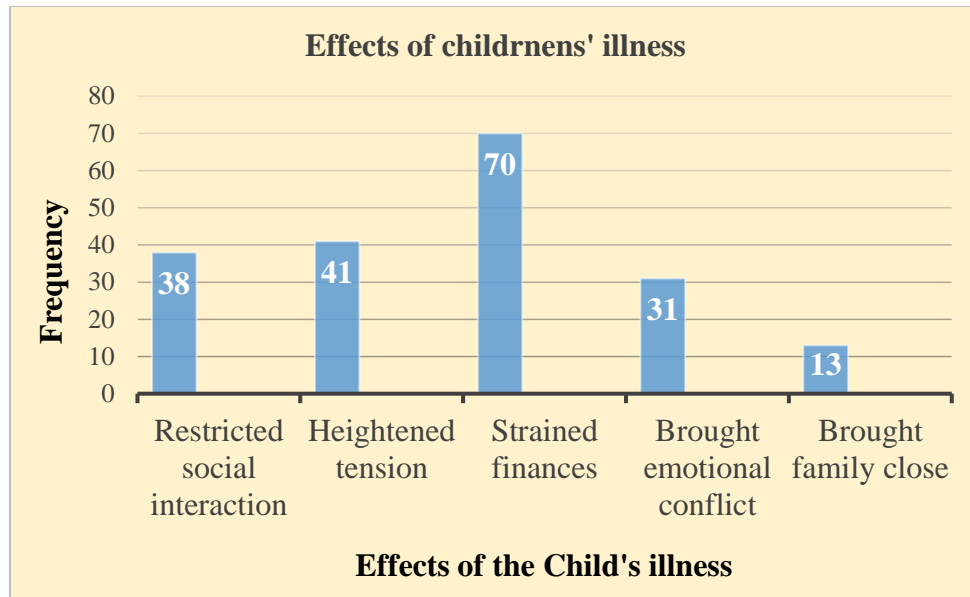


Figure 3. Effects of the child’s illness on the Family Unit

3.1.8 Family Pressure to Reject Medicine

Figure 4 shows the respondents who received pressure from family members to reject therapeutic practices and they were 26% (n=19)

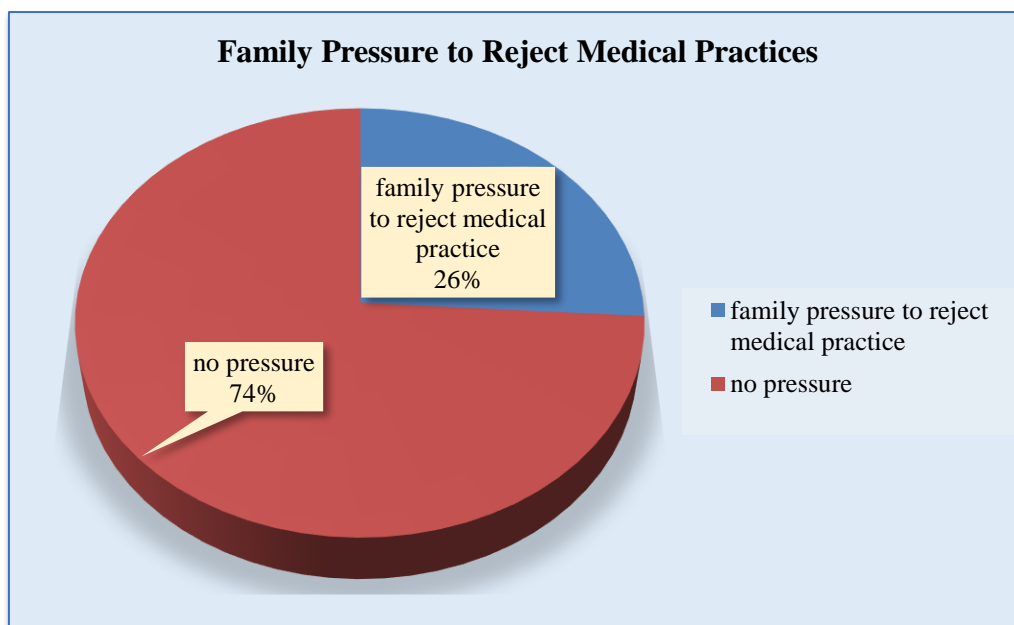


Figure 4. Family Pressure to reject medical practices

3.2.0 Caregiver Burden among the caregivers of Children Diagnosed with Cancer at KNH.

3.2.1 Zarit Burden Interview Score Categories

The ZBI score is a scale used to determine caregivers’ burden through a score that is rated. The range between 0-88, with scales of 0-20 indicating no burden, 21-40 for mild burden, 41-60 for moderate to severe burden and finally 61-80 for severe burden. In this particular study, the minimum ZBI score was 28 and the maximum was 79, the average score (mean) was 58.6 which revealed moderate to

severe caregiver burden. The standard deviation was 11.25 and a median of 61. The findings are presented in table 7 below.

Table 7. Statistics of the ZBI Scores

	Statistics (N=74)	Value
Measure of Central Tendency	Mean	58.675
	Median	61.000
	Mode	61.00
Measure of Dispersion	Standard deviation	11.258
	Variance	126.743
	Range	51.00
	Minimum score	28.00
	Maximum score	79.00

3.2.2 The Respondent’s Categorical Scores of the ZBI.

The majority of the respondents 74% (n=42) reported severe caregiver burden, 35% (n=26) reported moderate burden, 8% (n=6) experienced mild burden and none of the respondents reported no burden at all. The above results are represented in table 8 below.

Table 8. Respondents’ Categorical Scores of the ZBI

Burden	Frequency (n)	Percentage (%)
None	0	0
Mild	6	8.1
Moderate-severe	26	35.1
Severe	42	58.6
Total	74	100

3.3.0 Economic Status and concerns of Caregivers that Influence Caregiver Burden.

3.3.1 Employment status of the Respondents

The majority of the respondents 93% (n=69) were casually employed, though more than half 70% (n=52) abandoned their work since the child started on cancer treatment and only 7% (n=5) continued to work. More than half of the respondents earned between 0-5000 Kenyan shillings (Ksh). The results are represented in table 9 below.

Table 9. Economic Status of the Caregivers

Variables	Frequency (n)	Percentage (%)
Employment	Regular/permanent	5
	Causal employment	69
Status of the job	Continue to work	7
	Paid leave	4
	Unpaid leave	11
	Abandoned work	52
	Total	74
Monthly income	0-5000 Ksh	38
	5001-10000Ksh	12
	10001-15000Ksh	10
	15001-20000Ksh	4
	20001-25000Ksh	5
	25001-30000Ksh	3
	Above 30000Ksh	2
	Total	74

3.3.2 Insurance Coverage

The insured respondents were 89% (n=65), 97% (n=63) of these were insured with NHIF and 3% (n=2) had private insurance. Those who reported complete payments of the hospital bills by the insurance company where only 3% (n=2). Despite many being insured with the National Hospital Insurance Fund (NHIF), the majority 86% (n=64) reported failure to pay the child’s hospital bills and only 14% (n=10) reported the ability to pay all hospital bills. The findings are represented in figure 5 below.

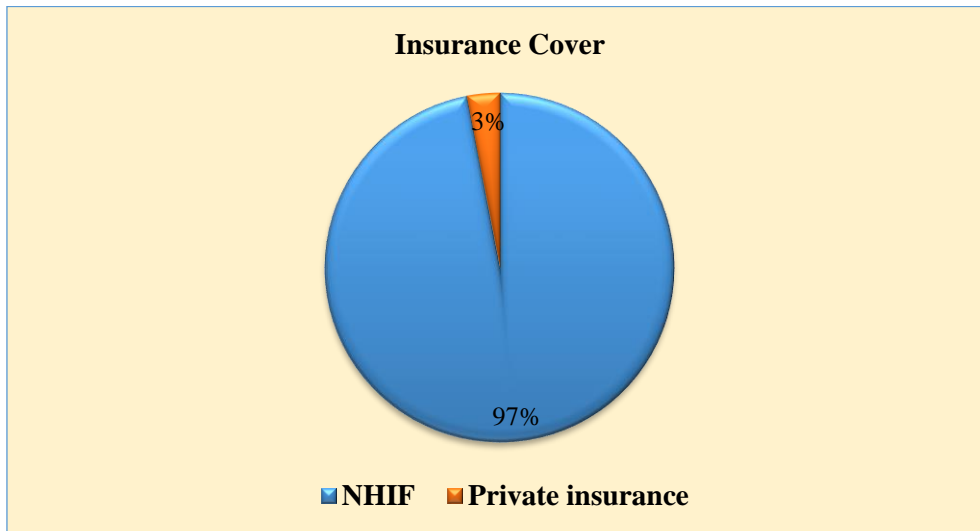


Figure 5. Insurance Coverage

Bivariate analysis was further done to determine the relationship between caregiver’s burden the economic status of the respondents. This revealed that most 69% (n=29) of those who had abandoned their work suffered severe caregiver burden. The chi-square test did not reveal a significant relationship between caregiver burden and the economic status of the caregivers. The findings are presented in table 10.

Table 10. Association of the ZBI Score and the Parent’s Economic Status

Variables		Burden score category (N=74)				p-value
		Mild	Moderate	Severe	Total	
Employment	Regular/permanent	0	0	1	1	0.979
	Causal employment	2	10	13	25	
Status of job	Continue to work	2	0	5	7	0.297
	Paid leave	0	1	3	4	
	Unpaid leave	0	6	5	11	
	Abandoned work	5	18	29	52	
Covered with health insurance	Yes	6	22	37	65	0.72
	No	0	4	5	9	

3.4.0 Psychological Effects of Caring for Children Diagnosed with Cancer at KNH among the Caregivers.

3.4.1 Psychological Effects of the Child’s Illness on the Caregivers

The child’s illness psychologically affected the respondents in many ways; sadness, worries, denial, emotional pain, fatigue, lack of sleep, and if it also caused confusion. The findings are summarized in figure 6 below.

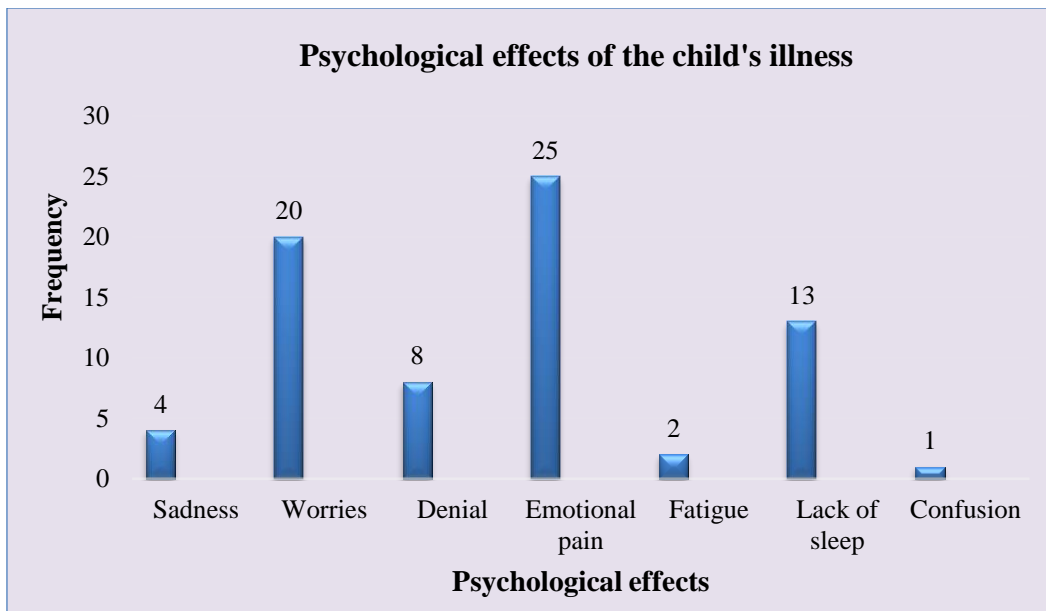


Figure 6. Psychological Effects of the Child’s Illness on the Caregivers

3.4.2 Caregiver’s Report on Anxiety

The majority of the respondents 90.5% (n=67) experienced anxiety due to their child’s illness and this manifested in different ways. Only 9.5% (n=7) did not report anxiety due to the child’s illness. The results were presented in figure 7 below.

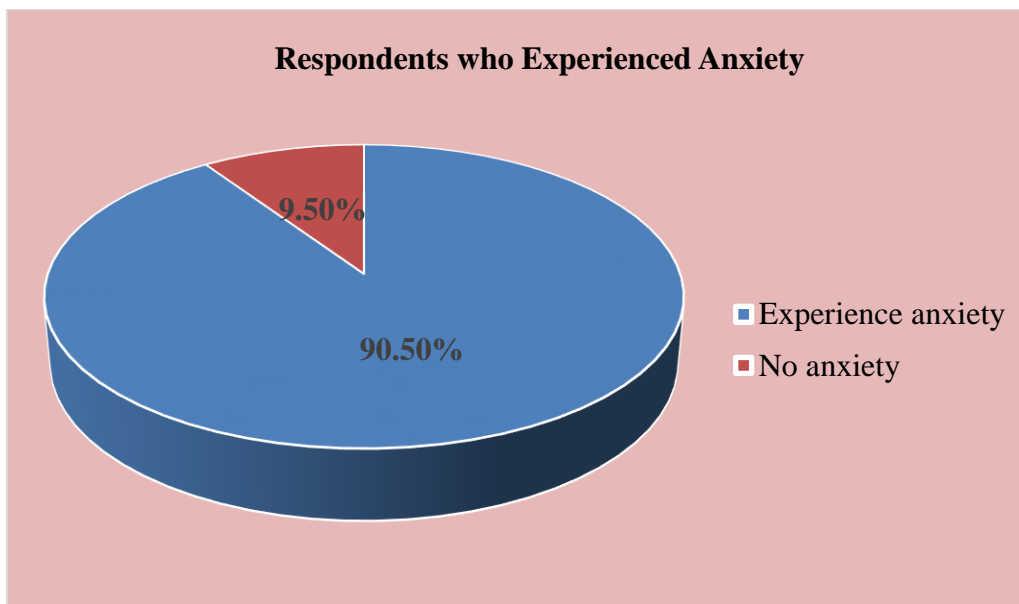


Figure 7. Caregivers who Reported Anxiety

3.4.3 Factors Associated to caregiver’s Anxiety

Most of the respondents 65% (n=48) reported a lack of sleep due to the child’s illness. More than half 55% (n=41) were uncertain of their child’s and only 8% (n=6) reported a lack of sense of control brought about by the child’s illness.

3.4.4 Medical Procedures that caused most anxiety to the Caregivers.

The majority of the respondents 84% (n=62) reported that they were always anxious when their children were receiving chemotherapy. Half of the respondents 50% (n=37) were distressed by bone marrow.

Bivariate analysis was further done to show the relationship between the caregiver’s burden and the procedure performed and this revealed that chemotherapy administration caused severe caregiver burden to most of the caregivers but the chi-square test didn’t reveal a significant relationship. The results showed that there was a significant relationship between the caregiver burden and insertion on intravenous cannulas at a p-value of 0.028. The results are presented in Table 11 below.

Table 11. Association between the ZBI Scores and the Performed Procedures

Procedure		Burden score category			P values
		Mild	Moderate	Severe	
Putting IV cannula	Yes	1	16	15	0.028
	No	6	6	26	
Bone marrow aspirate	Yes	3	14	20	0.677
	No	4	10	21	
Chemotherapy administration	Yes	5	21	35	0.968
	No	1	4	6	

3.4.5 Caregiver Suggestions on how to Reduce Burden

More than half 53% (n=39) of the respondents reported that adequate information from the health care team would help reduce the burden. The results are presented in figure 10.

4.0 Discussion

4.1 Social Demographic Characteristics of the Study Population

In this study majority, 73% of the caregivers were females and mostly middle-aged. These findings were consistent with Naidoo *et al.*, [9] that mothers contribute more to the family caring role and varied with Nguyen and Ngoc Dan [10] where the majority of the cancer caregivers were males. The results further revealed that the females in this age range still suffered more severe caregiver burden, this could probably be due to the great emotional attachment of mother and child. Further consistent with Motlagh *et al.*, [11] who reported that younger caregivers have scanty of experiences to help them use supportive resources and not financially stable which contributes to a higher level of care burden.

Most 46% of the children with cancer in this study were aged between 0 and 4 years this was consistency with the past reports from the United States of America (USA); Siegel *et al.*, [12] were pediatric cancers were diagnosed at the same age and lesser in those aged between 5 to 9 years. The findings varied with Utuk and Ikpeme [13], where the prevalence of cancer in Nigerian children was more in children aged between 5-10 years. Most 37.8% of children were diagnosed with cancer within a period of six months, this could probably be a reason for the increased care burden as Wang *et al.*, [14] also reported that there exists a higher care burden in the caregivers of children who are newly diagnosed with cancer.

More than half 57% of the respondents were married and had other children who also optimally depended on them, these were left either with their fathers or grandparents as the mothers had to attend to the child in the hospital for more than a month. This could also have contributed to the increased caregiver burden as mothers have to coordinate even the home affairs as in line with Naidoo *et al.*, [9] study that was conducted in Nigeria. More than half 51% of the respondents also reported restricted social interactions for a long period of time, this concurred with a study that was done in Morocco where 65% of the caregivers were no longer socializing and they had neglected their families [15]. Deniz and Inci [16], in their study of the burden of care and quality of life in leukemic children they found out that the less care time the parents had the lower the care burden. In this study, caregivers provided 24 hours care more than a month which contributes to a higher caregiver burden.

The lack of significance between the socio-demographic characteristics and caregiver burden in this study could be attributed to the parental attachment and consistency of the study population. The caregivers of children with cancer suffer a great magnitude of care burden and there is a need for the health care professionals to critically examine and provide educational sessions to reduce the burden.

4.2 Degree of Caregiver's Burden among Caregivers of Children Diagnosed with Cancer at KNH

The degree of burden among the study population on average was moderate to severe (ZBI Score 58.3) with a majority 74% scoring severe caregiver burden. This was far beyond the normal levels according to Wang *et al.*, [14] who reported only 12% of caregivers had severe care burden and Kahrima and Zaybak [5] where 50% of the caregivers had mild burden and only 7.5% reported severe caregiver burden, the latter related these low burden scores to the Turkish culture that it's only natural for the relative to assist care for their sick relative and due to the motherly instincts the mothers of children with cancer don't suffer severe caregiver burden.

The findings of this study were in line with the results from Nigeria where the caregivers had an average score of 50.8 which revealed moderate to severe caregiver burden [17], and consistent also with Nguyen and Ngoc Dan [10] from Vietnam where the average burden score indicated moderate to severe caregiver burden, the females were most affected and none of the respondents reported no caregiver burden at all. A study in Iraq also revealed that 89% of the caregivers had moderate to severe care burden and the level of education had a significant effect on the lower caregiver burden. They recommended health care providers to pay some more attention to these parents and engage them in educational programs [11].

In this study the high caregiver burden could possibly be due to the low education level which contributes to lack of employment which compromises the finances, the majority of the children being young and optimally depend on their parents for everything. The caregivers were also uncertain of the children's future and what to do for them thus increasing the anxiety. Majority 84% of the caregivers were also burdened with the procedures performed in hospital especially cytotoxic drug administration this increased stress.

4.3 Economic Effects of Caring for a Child Diagnosed with Cancer at KNH.

The majority 93% of the respondents had causal employment were they earned approximately between 0- 5000 Kenyan shillings per month and had abandoned work in order to attend to the sick child in the hospital who would be admitted for more than a month. This was in line with Carrera *et al.*, [18] who mentioned that cancer care causes financial toxicity both objective and subjective. A study in the United States of America also reported that across all levels of income the caregivers' work status was interrupted, in 42% of families at least one of the parents had to quit work and the most affected were the majority and the poorest [19]. Motlagh *et al.*, [11] reported that caregivers with good income have lower caregiver burden reason being that they can better support their families and also avail excellent treatment for the ill child. The low-income state of the respondents in this study could have caused significant caregiver burden among the respondents. These caregivers must travel, feed and also provide for the family left at home and yet the cancer care is also way very expensive.

The majority 97% of the respondents reported being insured with the National Hospital Insurance Fund although the treatment costs are more than what the insurance offers so the treatment bills are not fully catered for and thus not solving the financial burden that the parents experience during the care of their children. Following a review of 24 studies that confirmed family financial burden due to childhood cancer treatment, Warner *et al.*, [20] reported the need for insurance models and the need to incorporate financial assessment into pediatrics care models as this could contribute to better management of cancer in children. From the results of this study maybe there is a need for the policymaker to consider complete funding of childhood cancer treatment.

4.4 Psychological Effects of Caring for Children Diagnosed with Cancer at KNH among Caregivers.

In this study, the respondents reported several emotional challenges; the most 65% reported lack of sleep which they had never experienced before their child's illness. Similar to Kazak *et al.*, [21], their study reported that the excessive responsibilities parents undertake during the caregiving process increases the chances of reactions like anxiety, sleep disturbances, and depression. This also coincided with a study in Malaysia where the caregivers provided care for more than 20hrs per week and these were likely to develop significant stress [22]. The reported psychological effects in this study could be probably because the caregivers did not share the caregiving responsibility with any other person in hospital and fear of their children's future. All the respondents reported to be anxious and this was still expressed by lack of sleep. The findings were also in line with the study findings in Jordan which revealed that mothers of ill children experience significant stress which makes them fail to sleep [2]. The respondents in this study reported overcoming the anxiety by praying and talking to church elders and friends who came to visit in the hospital.

The caregivers reported difficulty in coping with procedures done in hospital this was in line with Shiota *et al.*, [23] that whole journey of aggressive procedures and treatment is irritating to the caregivers which increases the care burden, these procedures included: insertion of intravenous cannulas, blood transfusion, and bone marrow aspiration among others. Of these, there was a significant statistical relationship (p-value 0.028) between caregiver burden and insertion of intravenous cannulas. The caregivers watch the children being pricked several times in a week while taking off blood samples, giving antibiotics, for chemotherapy drugs and for parenteral feeds for those who are malnourished. This procedure is emotionally draining since it causes the children to bitterly cry and almost a daily procedure.

Conclusions

The degree of caregiver's burden among the study population as measured with the ZBI scale was moderate to severe which is way too high than the normal 0-20. The economic status of the study population was low with 70(95%) reporting strained finances and this greatly contributed to the burden. Psychologically the procedures performed on the children caused anxiety to all the respondents and there was statistical significance (P-value of 0.028) between the Insertion of Intravenous into the sick children and caregiver burden.

Recommendations

Health care providers can formulate a holistic and family-centered program considering the factors that increase caregiver burden. There is a need for the health care team to provide adequate education concerning diagnosis, treatment, procedures to be performed during cancer management to the caregivers so as to promote cooperation and help reduce emotional distress and reduce caregiver burden.

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