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Brief Report

Treatment Cost and Psychological Impact of Burkitt Lymphoma on Ghanaian Families and Caregivers

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ABSTRACT

Objective: Before June 2022, the treatment cost of Burkitt lymphoma (BL) in Ghana was mainly borne by the child's family or caregiver. We determined the treatment cost of BL in children and its psychological impact on parents and caregivers.

Method: This prospective observational study assessed the direct medical and nonmedical costs (US dollars [USD]) incurred during the treatment of a child with BL for 6 consecutive months using a cost diary. Productivity losses and the psychological impact on parents and caregivers were assessed using a self-administered questionnaire and the Caregiver Quality of Life Index-Cancer (CQOLC).

Results: Of the 25 participants, 7 abandoned the treatment of their children, and 4 withdrew because the children passed away. The median (Q1, Q3) cost for treating BL per child for caregivers/parents (N = 12) was USD 947.42 (USD 763.03, USD 1953.05). Direct medical costs formed 71% (USD 11 458.97) of total treatment costs. Working hours of parents before the child's cancer diagnosis decreased from a median (Q1, Q3) of 44.00 (20.00, 66.00) hours to 1.50 (0, 20.00) hours after the diagnosis. The mean (SD) CQOLC score was 107.92 (15.89), with higher scores in men (111.00 [17.26]), married participants (111.26 [17.29]), Higher National Diploma certificate holders (113.00 [1.41]), and participants earning a monthly income more than USD 84.60.

Conclusion: Treatment costs reduced the overall household income of 5 families. Parents and caregivers experienced reduced work hours and loss of employment. CQOLC scores were higher in married participants, those with a higher educational background, and those with higher income.

Keywords: Burkitt lymphoma, Children, Cost, Caregiver Quality of Life Index-Cancer, Ghana.

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Introduction

Childhood cancer has been a major health concern in Ghana in recent times. The chances of survival for childhood cancer in Ghana is approximately 20% because the healthcare sector is challenged by a lack of awareness of the disease, adverse socioeconomic-cultural practices, poverty, limited access to health facilities, and inadequate health personnel.[1] Caring for a child diagnosed as having cancer affects the family's emotional, social, and financial aspects.[2-8]

A nurse at the Komfo Anokye Children's Cancer Care Unit in Ghana noted, "We see so many lapse cases where a child comes back in a worse state because of the financial situation. Most of them die."[9] Families of children with cancer face relatively high expenditure and productivity losses due to treatment that may affect their socioeconomic status and lead to financial toxicity.[9,10] Financial toxicities have been associated with overwhelming symptoms associated with the condition, such as health-related quality of life (QoL),[11] survival,[12] and compliance.[13] Most children diagnosed as having cancer receive treatment on an outpatient basis and are mostly home. Hence, parents alter their schedules to spend time and effort to provide the needed support for their children.[14] Some parents and caregivers adapt quickly whereas others do not, causing distress, which may affect their QoL.[14] Consequently, it is essential to understand the psychological effects to offer families of children with cancer comprehensive support.

Public health financing in Ghana is mainly channeled through the National Health Insurance Scheme (NHIS).[15] The NHIS covers approximately 95% of common diseases in Ghana; however, disease conditions and services, such as cosmetic surgeries, anesthesia, organ transplantation, dialysis for kidney failure, cancers other than breast and cervical cancers, and assisted reproduction, are excluded.[15,16] In November 2021, the costs of consultation, diagnosis, and treatment of the 4 most common childhood cancers in Ghana, namely Burkitt lymphoma (BL), acute lymphoblastic leukemia, retinoblastoma, and Wilms' tumor, were announced to be included in the NHIS and took effect in June

2022.[16] Although the inclusion marked a significant step in reducing the disease burden on parents and caregivers,[17,18] it is imperative to grasp the broader financial and psychological ramifications experienced by caregivers to ensure the provision of holistic support. Before June 2022, childhood cancer treatment costs were mainly borne by the parents or caregivers of the child. However, despite these challenges and advancements, few studies have explored the cost of treating cancer in children and its impact on the family or caregivers.[17–19] We determined the direct and indirect costs associated with BL at 3 treatment centers over and the psychological impact on the primary caregiver.

Methods

Study Design

A quantitative, prospective observational study was conducted to determine the cost associated with the treatment of BL and assess the psychological impact on parents or caregivers. Two self-administered structured questionnaires and a cost diary were used to collect data.

Development of the Self-Administered Questionnaires and Cost Diary

The first questionnaire was developed to collect baseline demographic and socioeconomic data such as sex, age, marital status, occupation, health insurance, educational background, employment status and sector, region of residence, number of people in the household, and income level from the study participants. The second questionnaire consisted of 2 parts. Part 1 assessed the indirect cost (ie, productivity losses), whereas part 2 addressed the intangible cost (measured by using a QoL score) associated with caring for a child diagnosed as having BL. The human capital approach in cost-of-illness (COI) studies was used in measuring productivity losses. The questionnaire on productivity losses focused on indicators such as wage losses, changes in employment status, absence from work, and decrease in working hours due to caring for a child diagnosed as having BL. The QoL of parents and caregivers was assessed using the Caregiver Quality of Life Index-Cancer (CQOLC) self-administered questionnaire developed by Weitzner et al.[20] The CQOLC was selected because it is specific to parents and caregivers of patients diagnosed as having cancer. The self-administered questionnaire includes 35 items on burden, disruptiveness, positive adaptation, and financial concern using a 5-point Likert scale to assess the QoL of caregivers of patients with cancer.[20] The score is determined by calculating the sum of the scores of the 35 items on the list. The total score on the CQOLC is 140. Participants with higher scores have a better QoL and vice versa[20] (see Appendix 1 in Supplemental Materials found at https://doi.org/10.1016/j.vhri.2024.101016).

A cost diary (see Appendix 2 in Supplemental Materials found at https://doi.org/10.1016/j.vhri.2024.101016) was used to collect data on resource use on direct medical costs and nonmedical costs for 6 consecutive months. The bottom-up approach method in COIs was used in this study to identify, measure, and value costs[21] borne per visit. Cost units measured in Ghanaian cedis (GHC) during the study were obtained from patients' medical folders and converted to US dollars [USD] (1 USD equaled 5.91 GHC on November 30, 2021).[22] Cost units measured included direct medical costs such as consultation fees, diagnostic tests, chemotherapy, other medications such as antiemetics and analgesics, and ancillary services such as counseling sessions. Direct nonmedical costs comprised accommodation during treatment, food, transportation to the hospital, and childcare.

The content validity of the data collection tools was determined by reviewers and a statistician, with guidelines for conducting COI studies recommended by Larg and Moss.[23] The official language used in Ghana is English. Therefore, the questionnaires, cost diary, and informed consent forms were in English.

Data Source and Study Population

The target population involved all parents or caregivers of a child diagnosed as having BL during the study period who attended 3 tertiary hospitals in Ghana: Korle Bu, Komfo Anokye, and Tamale Teaching Hospitals. These centers are recognized facilities in the country for the treatment of cancer. These hospitals were chosen based on their geographical location to ensure national representativeness. Permission was sought from the facilities to use their names in the study.

The Korle Bu Teaching Hospital is the primary referral center in Ghana. All health cases that require specialist care are referred to this hospital. Korle Bu Teaching Hospital is situated in Accra, the capital of Ghana, in the southern part of the country. The Komfo Anokye Hospital referral center is located in the country's middle belt, Kumasi, the regional capital of the Ashanti region, which provides healthcare services to patients from the 3 northern regions and Brong Ahafo, Western, Central, Eastern, and Volta regions. Tamale Teaching Hospital is located in Tamale, the regional capital of the northern part of Ghana. The hospital provides healthcare for Ghana's Northern, Upper East, and Upper West regions.

The data collection period commenced in April 2021 and ended in November 2021. The prevalence-based approach in COI studies was applied in this study; hence, all pre-existing and new cases of BL were considered. The study population consisted of parents or guardians of children diagnosed as having BL who consented in writing to participate. Study participants were followed for 6 consecutive months, based on the hospital's protocol for the treatment of BL in children (treatment ranges from 4 to 6 months). Parents or guardians of children diagnosed as having BL having less than 4 months of treatment were excluded from the study.

Data Analysis

Data were analyzed descriptively. Continuous data were described using means and SDs or median and interquartile ranges. Categorical variables were summarized as frequencies and percentages.

Results

Demographic Characteristics of the Study Population

A total of 25 caregivers of children diagnosed as having BL responded to the poster invitation and agreed to be part. Two participants were withdrawn during the study due to demands for reimbursement, whereas the parents of 7 children abandoned treatment, and 4 children passed away; hence, the caregivers withdrew from the study. Twelve participants remained in the study for 6 months.

The study participants comprised 8 females and 4 males (ratio 2:1) with a mean (SD) age of 40.17 (9.64) years (Table 1). Seven study participants resided in the Ashanti region; 3 were from Greater Accra and 1 from the Western and Bono Ahafo regions, respectively. Eight participants were married, and all participants were insured under NHIS during the study. However, the treatment cost of childhood cancer was not covered by the NHIS during the study period.

Table 1. Description of study participants.

Indicator	n*
Number of participants (N)	12
Sex, n	
Male	4
Female	8
Age (in years), mean (SD)	40.17 (9.64)
Female	42.38 (8.67)
Male	37.00 (11.24)
Region of residence, n	
Ashanti	7
Greater Accra	3
Western	1
Bono Ahafo	1
Marital status, n	
Married	8
Divorced/separated	2
Living together	1
Never married	1
Health insurance, n	
Yes	12
No	0
Type of health insurance, n	
NHIS	12
Private health insurance	0
Both	0
Educational level, n	
SHS/SSS	1
Primary education level	3
JHS/JSS	5
HND/teacher or nursing training/ university diploma	1
Employment status, n	
Yes	11
No	1
Employment sector, n	
Service	10
Agriculture	2
People per household, mean (SD)	6.17 (2.25)
Income before the child's illness, n	
Less than USD 84.60	1
More than USD 84.60 to USD 253.81	10
More than USD 253.81 to USD 423.01	1

HND indicates Higher National Diploma; JHS, junior high school; JSS, junior secondary school certificate; NHIS, National Health Insurance Scheme; SHS, senior high school; SSS, senior secondary school certificate; USD, US dollar (1 USD equaled 5.91 Ghanaian cedis [GHC] on November 30, 2021).[22]
*Values presented in this table are n-values, except for age and number of people in the household.

All participants were educated. A total of 10 of the study participants were employed in the service sector. The mean (SD) number of people in each household was 6.17 (2.25), ranging from a minimum of 3 to 10 individuals per household. Ten study participants earned between USD 84.60 and USD 253.81 before their child's cancer diagnosis.

Treatment Cost of BL

A breakdown of the cost involved in treating BL for all 12 families is presented in Table 2. From the study, the total cost of treatment of BL in children over the 6 months for 12 families was USD 16 213.28 with median (Q1, Q3) spending of USD 947.42 (USD 763.03, USD 1953.05) per caregiver. Direct medical costs formed approximately 71% of the total cost (n = USD 11 458.97) of the study period. The cost of chemotherapy constituted 36% of the total cost (n = USD 5965.23). This was followed by the cost of diagnostic tests at 22% (n = USD 3542.13).

Direct nonmedical costs formed 29% of the overall cost of treatment (n = USD 4754.32). The cost of accommodation formed 44% of direct nonmedical costs (n = USD 2082.23) and 13% of the overall treatment cost. Six study participants earned less than USD 84.60 per month (USD 2.82 per day; the daily minimum wage in Ghana is 12.53 GHC [USD 2.12])[24] whereas 5 earned between USD 84.60 and USD 253.81 monthly at the time of treatment.

Productivity Losses

In Table 3, productivity losses due to caring for a child diagnosed as having BL were evident in reduced work hours and loss of employment. Participants experienced interruptions in their work schedules, causing fewer working hours. The study participants' median (Q1, Q3) work cessation period was 6.00 (1.50, 8.50) months. Nine participants worked fewer hours or stopped working entirely to cater for their child's condition, and 5 were replaced at their workplaces. The median (Q1, Q3) working hours before the child's cancer diagnosis decreased from 44.00 (20.00, 66.00) hours to 1.50 (0, 20.00) hours after the diagnosis.

Psychological Impact on Caregivers

The psychological impact of the disease on the family was observed in 5 caregivers obtaining mean scores less than the total mean CQOLC score (Table 4). The CQOLC scores of the study participants ranged between 85 and 130, with a mean (SD) CQOLC score of 107.92 (15.89). Seven study participants obtained CQOLC scores above the calculated mean CQOLC score. The mean CQOLC score of male and female participants was 111.00 (17.26) and 106.38 (16.15), respectively. Married caregivers had a mean CQOLC score of 111.26 (17.29), the highest in this category. Participants with Higher National Diploma certificates obtained a mean CQOLC score of 113.00 (1.41); participants with a senior high school education had the lowest score of 86.

Participants who earned a monthly income more than USD 84.60 to USD 253.81 and more than USD 253.81 to USD 423.01 obtained mean CQOLC scores above the overall mean CQOLC score. Participants who earned less than USD 84.60 during the study period obtained a mean CQOLC score of 103.00, which was less than the overall mean (SD) CQOLC score of 107.92 (15.89).

Table 2. Direct costs of Burkitt lymphoma of 12 children for 6 months.

Family	Direct medical cost (USD)					Direct nonmedical cost (USD)			Total cost (USD)
	Consultation fee	Medications	Diagnostic tests (laboratory and imaging)	Chemotherapy	Counseling	Transportation costs	Food and childcare	Accommodation	
1	13.54	223.35	176.14	1362.10	-	10.15	87.99	297.12	2170.39
2	12.69	82.06	185.11	207.28	-	101.52	52.45	-	641.12
3	8.46	47.38	411.00	245.35	-	67.68	19.46	-	799.32
4	15.40	45.69	272.76	169.20	-	50.76	78.68	118.44	750.93
5	19.63	58.71	249.92	220.81	13.54	67.68	157.36	262.27	1049.92
6	11.17	43.99	261.59	170.22	-	33.84	119.46	296.11	936.38
7	9.48	51.61	353.30	372.25	-	25.38	99.83	389.17	1301.02
8	11.17	46.53	210.83	592.72	5.08	23.69	57.87	-	947.89
9	89.85	467.01	525.72	1124.03	-	253.81	363.11	406.09	3229.61
10	-	96.45	161.76	1.86	-	36.89	25.04	-	320.14
11	-	214.55	262.44	429.86	-	20.64	19.46	-	946.95
12	53.47	310.83	471.57	1071.40	-	363.79	535.53	313.03 03	3119.63
Total cost (USD)	244.84	1688.16	3542.13	5967.09	18.61	1055.84	1616.24	2082.23	16 213.28

USD indicates US dollar (1 USD equaled 5.91 Ghanaian cedis [GHC] on November 30, 2021).[22]

Discussion

Childhood cancer has been a major health concern in Ghana in recent times. However, few studies have been conducted exploring its epidemiology, cost of treatment, and impact on families and caregivers. This is the first study determining the treatment cost from the perspective of the caregiver/parent for children with BL in Ghana. This study aimed to determine the direct and indirect costs associated with childhood cancer treatment and the impact on the primary caregiver.

Although 25 participants were recruited for the study, 7 patients abandoned treatment and 4 children died during the study. According to the World Health Organization,[25] approximately 50% of children abandon treatment due to relatively high treatment costs. Treatment abandonment is common, especially in LMICs, where resources for treatment are limited.[26-28] The cost of treatment, poverty, the educational background of the parents, access to treatment centers, and the type of cancer have been cited as possible causes of treatment abandonment in LMICs.[26,28]

The study revealed more females than men (ratio 2:1) as primary caregivers. According to Kim et al[29] and Schrank et al,[30] mothers feel more capable of caring for their children than other household members. Mothers spend more time with their children than their fathers and are likely to be the primary caregivers.

The cost of chemotherapy, diagnostic tests, and accommodation were the main cost drivers from the study results. The cost of drugs comprised approximately 50% of the overall direct cost of treating cancer over 6 months. Dawson et al[18] in their study at the Komfo Anokye Hospital reported direct medical costs comprising approximately 97% of the total treatment cost of BL in children. Mardakis et al[31] also reported hospitalization and treatment as the main cost drivers for childhood cancer treatment at a hospital in India. Results from the study showed that although parents and caregivers mainly bore the cost of treatment, they received financial support from family, friends, and philanthropists. Organizations such as World Child Cancer and other foundations support the procurement of medicine at hospitals to ensure their availability for treatment.

The study's results showed that 5 participants' income fell 1 level below their initial income level after their child's diagnosis. Financial burdens have been associated with treatment abandonment. The financial burden of caring for a child with cancer causes families to fall below the poverty line. Consequently, financial burdens may pose psychological stress on the family.

Predictors of financial hardships by parents include low educational backgrounds, families who live in rural areas, unemployment, families with lower socioeconomic positions, and single parents.[29,30]

Disruptions in work schedules have been experienced by parents and caregivers of children with cancer and are evident in the study results. These disruptions include reduced working hours and work cessation observed in the study's results, extended leave, and changes in occupation. Studies have shown that some parents are unemployed due to their child's condition.[12,29,30] Most parents are the primary caregivers of their children and hence adjust their work schedules to cater for their children. According to Hiyoshi et al,[29] mothers, especially, adjust their work schedules to work for fewer hours to cater for their ill child. This was also seen in the results of the study.

The results from the CQOLC score showed that 5 of the 12 participants scored less than the average CQOLC score. Cancer diagnoses in children have been shown to have a significant psychological impact on family members and caregivers.[31,32] Psychological symptoms such as anxiety, depression, pain, a decline in the family member or caregiver's physical health, constraints in roles, and pressures in the marriage that families and caregivers of children diagnosed as having cancer undergo.[33,34] Participants who were married and male, Higher National Diploma degree holders, and participants who earned USD 253.81 to USD 423.01 obtained an average CQOLC score greater than the overall average score of all 12 study participants.

Katz et al[35] studied the trajectory of psychological adjustment by caregivers of children with cancer. The study showed that caregivers experienced heightened depression immediately after

Table 3. Indirect costs (productivity losses) of Burkitt lymphoma of 12 families.

Indicator	n
After illness earnings (USD), n	
Less than USD 84.60	6
More than USD 84.60 to USD 253.81	5
More than USD 253.81 to USD 423.01	1
Disease-related work cessation, n	
Yes	9
No	3
Work cessation duration (months), n	
Median, IQR	6.00 (1.50-8.50)
Work replacement status, n	
Yes	5
No	7
Work hours before child's illness (hours), n	
Median	44.00 (20.00-66.00)
Work hours after child's illness (hours), n	
Median	1.50 (0.00-20.00)
Change in work hours related to child's illness, n	
Yes	10
No	2
Financial assistance, n	
Yes	10
No	2

IQR indicates interquartile range; USD, US dollar (1 USD equaled 5.91 Ghanaian cedis [GHC] on November 30, 2021).[22]

Table 4. CQOLC scores categorized by study variables.

Variable	CQOLC score, mean (SD)	Cohen's *d* value
Sex		
Male	111.00 (17.26)	0.3
Female	106.38 (16.15)	
Marital status		
Divorced/separated	105.00 (9.90)	1.5
Living together	109.00 (0.00)	
Married	111.26 (17.29)	
Never married	86.00 (0.00)	
Educational background		
JHS/JSS	109.50 (17.57)	
Primary	108.67 (18.48)	
SHS/SSS	86.00 (0.00)	
HND	113.00 (1.41)	
Income level		
Less than USD 84.60	103.00 (0.00)	
More than USD 84.60 to USD 253.81	110.5.00 (0.00)	
More than USD 253.81 to USD 423.01	114.00 (0.00)	

CQOLC indicates Caregiver Quality of Life Index-Cancer; HND, Higher National Diploma; JHS, junior high school; JSS, junior secondary school certificate; SHS, senior high school; SSS, senior secondary school certificate; USD, US dollar (1 USD equaled 5.91 Ghanaian cedis [GHC] on November 30, 2021).[22]

the child's diagnosis due to worsening symptoms. However, depression declined as symptoms improved with treatment. This observation was confirmed by Arab et al,[36] Peterson et al,[37] and Peikert et al[38] in their studies assessing levels of anxiety and distress in parents with children diagnosed as having cancer. Parents experienced elevated levels of distress during the first 6 months after diagnosis, and this was common in parents with children diagnosed as having leukemia and solid tumors. The distress associated with a child's cancer diagnosis may cause disruptions in the sleep patterns of caregivers, as was shown by Rensen et al[39] reporting that 37% of parents experienced an interruption in their sleep whereas their child was being treated for cancer.

The provision of an information booklet on the disease to parents is useful.[40] Information booklets may include facts about the disease, disease management and self-care, consultation services, drug information, hospital facilities, and financial and social support for families. Effective communication has also been cited to help parents and caregivers cope with their child's condition.

Studies have reported various coping mechanisms families and caregivers use to help them throughout their child's treatment. For example, families and caregivers have leaned toward spirituality to help them cope with their child's condition.[41-43] Resilience, self-transcendence, and positivity have also been reported in caregivers who can cope with their child's condition. Some countries have established parent support groups to help families heal physically and emotionally.[44,45] Cutillo et al[46] and Nagelhout et al[47] reported using social media by parents and caregivers to receive emotional support and find more information about their child's condition. In Ghana, it was observed that parents and caregivers of children diagnosed as having cancer had formed support groups where they occasionally meet to provide emotional support for each other.

The provision of an information booklet on the disease to parents is useful.[47] Information booklets may include facts about the disease, disease management and self-care, consultation services, drug information, hospital facilities, and financial and social support for families. Effective communication has also been cited to help parents and caregivers cope with their child's condition.

Strengths and Limitations

This is the first study determining the treatment cost of BL before the inclusion of childhood cancer in the NHIS from caregivers' perspectives in Ghana and the psychological impact on parents and caregivers. The study provides evidence of the financial and psychological impact of BL on caregivers. However, selection bias may have occurred in the study given that participation was voluntary. Participants in the study may have different experiences compared with nonparticipants and hence may affect the generalizability of CQOLC scores. The small number of participants also hindered the analysis of the association and practical significance of the CQOLC scores by the study variables (age, marital status, educational background, employment, and income level). To mitigate attrition bias in the study, the cost diary provided made provision for daily data entry. In addition, participants were asked to keep receipts where necessary to validate records. Furthermore, the study did not include information on key patient

demographics, such as age, sex, clinical characteristics or cancer staging, and treatment duration, that could have enhanced the understanding of the financial and psychological impact of BL on caregivers and parents. Finally, the study did not explore coping strategies parents and caregivers used to cope with their child's condition.

Conclusion

The results from study participants with children diagnosed as having BL showed treatment abandonment, financial burden, and mortality as challenges in the Ghanaian setting in achieving favorable outcomes in childhood cancer. A child's cancer diagnosis also affects families and caregivers psychologically. Comprehensive and effective approaches are required at national and institutional levels to provide optimal support to families. Further studies should be conducted to evaluate the current treatment cost of BL and the QoL of parents and caregivers after its inclusion in the NHIS. The cost of accommodation was found to be a cost driver during the study. Only 1 hostel facility is available for parents at one of the hospitals in Ghana. Future research projects could also investigate the feasibility of housing projects at the other 2 hospitals to reduce parents' and caregivers' costs.

Ethical and Consent Statements

A written permission to conduct the study was obtained from the North-West University Health Research Ethics Committee (NWU-0045-19-S1), the Korle Bu Teaching Hospital-Scientific and Technical Committee and Institutional Review Board (KBTH-STC/IRB/000130/2019), Komfo Anokye Teaching Hospital Institutional Review Board (KATH-IRB/AP/028/20), the Department of Research & Development Tamale Teaching Hospital (TTH/R&D/SR/022), and the Chief Director for the Minister for Health at the Ministry of Health of the Republic of Ghana (MH/DP/042/20).

Participants gave a written informed consent at the beginning of the self-administered questionnaires and were informed that all data collected would be anonymous. All methods were performed in accordance with relevant guidelines and regulations.

Author Disclosures

Author disclosure forms can be accessed below in the Supplemental Material section.

Supplemental Material

Supplementary data associated with this article can be found in the online version at https://doi.org/10.1016/j.vhri.2024.101016.

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