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Evaluation of the financial and economic cost of childhood cancer care in Lubumbashi: a mixed study

Abstract

Context: The experience of childhood cancer imposes a considerable financial cost on a household. This financial and economic cost is often the cause of abandonment of care. The objective of this study was to determine the average total costs of childhood cancer management from diagnosis to one year of follow-up while exploring its impact on households.

Methods: We used a mixed study, with a micro-costing approach, to calculate the financial and economic costs of households when they support the cancer of one of their members. To analyze the data, we used descriptive statistics and descriptive qualitative methods.

Results: Our study covered 129 households, the average age of guardians being 36.1±9.3 years. Households traveled an average distance of 77.2±41.36 km to reach the hospital. The majority of households financed their own health care (95.9%). The tutors spent an average total cost of $524.4±$50, of which with a direct cost ($378.1±$61) representing 72.1% of the total cost and 27.9% of the indirect cost ($146.3±$39). Nephroblastoma had an average annual cost of $1042 higher compared to other types of cancers followed by leukemia ($977.3), lymphoma ($831.7), neuroblastoma ($803.1), and retinoblastoma ($797.5), bone tumors ($733.8)

Findings: The results of this study suggest the importance for the government to create a system of insurance or mutual health insurance which will make it possible to alleviate the costs and which would play an important role in alleviating the financial burden of households in patients with cancer.

Keywords: financial and economic cost, care, cancers, child

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Criss Koba Mjumbe,[1,2] Eric Mafuta,[3] Henry Limbaka,[4] Desire Mashinda Kulimba,[3] Chadrack Kabeya Diyoka,[2] Benjamin Kabyla Ilunga[1,2]

[1]Department of Public Health, University of Lubumbashi, Democratic Republic of Congo
[2]School of Public Health, University of Lubumbashi, Democratic Republic of Congo
[3]School of Public Health, University of Kinshasa, Democratic Republic of Congo
[4]Department of Economics, University of Kinshasa, Democratic Republic of Congo

Correspondence: Criss koba Mjumbe, Department of Public Health, University of Lubumbashi, DRC, Tel +243 997125685, Email cryss_koba25@yahoo.fr

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Introduction

A childhood cancer diagnosis is a major life-changing event for children and their families.[1] Children and their families face many challenges[2] and also face obvious financial consequences.[3] In the Democratic Republic of Congo (DRC), more precisely in Lubumbashi, children aged 0 to 17 living with cancer represent 3.27%,[4] but the economic burden of cancer for households remains unknown even though treatment is demanding and resource-intensive.[5,6] Families can pay financially, socially and personally to participate in the hospital care of their child, on the other hand are lost sight of for lack of financial means and others manage to stop the treatment.[10]

Studies describing the cost of care are analogues of descriptive epidemiological studies.[5-10] They characterize the burden of disease as the financial burden borne by patients, households and health systems. This information is useful for generating hypotheses and for planning budgets, prioritizing research and reporting on financial indicators of the performance of the cancer system, which is almost non-existent in our country.[7] More importantly, cost studies provide a scientific basis for robust and reliable inputs for cost-effectiveness studies of cancer treatments.[8,9]

The objective of this study determines the average financial and economic costs of childhood cancer care from diagnosis to one year of follow-up while exploring its impact on households. The study was guided by a conceptual framework that integrated the social and economic factors of illness believed to influence costs with the direct components and those related to the indirect costs of illness.[11-13]

Methodology

An approach mixed has summer used with tutors of children with cancer at university clinics in Lubumbashi. The University Clinics of Lubumbashi (CUL) are located in the city of Lubumbashi which is the second largest city in the DRC in terms of density and socio-economic development which is under the management of the University of Lubumbashi.[17] The relevance of using qualitative and quantitative methods combined is sustained in studies program evaluation, particularly in public health.[14-16]

In this study, we used administrative databases on the costs of care at CUL, then we identified and analyzed two groups of children with cancer diagnosed according to the International Classification of Childhood Cancer, third edition (ICCC)[3] in 12 groups.[18]

The design of the study was the subject of an exploratory-sequential analysis; the first analysis concerned qualitative data and aimed to identify the costs engendered by pediatric oncology care in children recently diagnosed with cancer. The second analysis was quantitative and initiated after the analysis of the qualitative data, and it aimed to measure the burden imposed on households. We performed the analysis qualitative between December 2017 and March 2018 with 19 subjects, among them 7 health professionals providing care in the pediatric oncology unit and 12 members of different households in which there was a child with cancer.

A questionnaire written in French was used during the interview to collect data on the impact of cancer-related costs in households, it was pre-established and set up to collect information during interviews of 30 and 45 minutes on the assessment of household costs. The latter was pre-tested on 12 parents before the implementation of the study. We examined the socio-demographic characteristics of caregivers and children, type of cancer, household consumption expenditure and health expenditure. These health expenditures were related to the financial cost borne by households to obtain pediatric oncology care.

We had developed a questionnaire integrating social and economic factors related to the disease. And to record the answers to the questions, we used an HP 320 computer and an XL23 AWT Dictaphone. Guardians of children diagnosed with cancer and aged 0 to 17 who consulted the university clinics of Lubumbashi (CUL), receiving treatment were eligible. Households were excluded from the study if their child had been diagnosed elsewhere and came just for treatment or if the child was terminally ill classified for palliative care.

We collected information from households about difficulties in paying for care, strategies for recovering funds, changes in lifestyle within the household, family relationships, relationships between caregivers and sick children.

We used descriptive statistics to categorize the type and value of costs expressed in US dollars at the exchange rate observed at the time of the survey in mid-2019 which was 1450Fc for 1 USD. The annual average after-tax family income served as the basis for the interpretation of the family cost burden.[19,20] We used two units of analysis to identify direct and indirect household costs. The indirect cost was considered to be the monetary value of lost productivity and lost time related to leisure. Loss of productivity included hours lost from work providing child care. The main unit of analysis included all parents, to identify and determine independent predictors of direct and indirect household costs.

After analyzing the qualitative data on the basis of the NVivo 20.2.0.426 software, we then conducted a quantitative analytical cross-sectional study in the same pediatric oncology unit of the CUL. We collected data over two years, from January 3, 2018 for the first tranche and for the second from January 2, 2019 to December 31, 2019 in two separate cohorts of 2018 and 2019. The survey was exhaustive among all guardians of children diagnosed with cancer during the study period and meeting our criteria. These criteria allowed us to select 129 households of children with cancer during our study period.

Tutors who consented signed their enrollment in the study and provided their resource uses and costs incurred at 3 appointments and each appointment was after 4 months over a one-year period. At each appointment, caregivers should note the resources used by the household to get to the hospital or care for the child; the volume of resource use, the number of kilometers traveled. At the end of each recording period and after a telephone message, a trained member of the research team conducted an in-person interview with the guardians at the hospital to collect and verify their cost over the four months between a appointment.

Since the costs over the previous four months could be deferred, we adopted a *micro-costing approach* which had intended to encourage parents to remember other costs incurred during appointment intervals. The *micro-costing approach* allowed for a weekly inventory to ensure the most accurate and complete data possible. After cost data collection was completed, tutors were asked to discuss the impact of cancer-related costs in a pre-recorded audio interview.

Analysis of the cost of illness data collected was done using the same analytical approach as the household costs.[21] To allow comparisons between studies, we analyzed costs according to a uniformly determined set of cost categories for childhood cancer.[22] Direct costs included health service costs and management costs. Indirect costs included travel for those in the city of Lubumbashi and those coming from outside the city of Lubumbashi, food, communication costs, and others, sick care nurses for the child with cancer.[23] Each cost element has been categorized accordingly. For example, cost items such as mileage have been categorized as travel or trips.

The interviews on the financial situation and the impact of cancer-related costs took place at the university clinics of Lubumbashi in the pediatric oncology unit (n=129). Data from semi-structured interviews recorded on an XL23 AWT dictaphone were transcribed verbatim, imported into qualitative software (Nvivo 20.2.0.426 ; QSR International Pty Ltd) and analyzed using content analysis techniques involving an iterative process of data reduction, data display, conclusion drawing and verification.[24] For each category generated to highlight particular points in the tutors' discussions of the impact of cancer-related costs on the household.

The encoded data was then imported into SAS 9.4 TS Level 1M5 2016 (SAS Institute Inc., Cary, NC, USA). At the significant level of $p<0.05$ (two-sided) for analysis. Backup copies of the electronic data have been kept via the institutional email address Koba.mjumbe@unilu.ac.cd . The electronic database was only accessible by the research team by username and password. Sample characteristics, descriptive statistics were used to describe children with cancer and their household members. Our primary outcome measures were total household medical costs. The study was approved by the medical ethics committees of the University of Lubumbashi (UNILU/CEM/135/2018).

Results

Sociodemographic characteristics

A total of 129 households were selected for our study. The majority of the children's guardians (83%) were married; the others were divorced (10%), single or widowed (7%). The male gender in sick children was predominant in our study (61.2%) with a sex ratio of 1.3 and the age of the patients was between 8 months and 17 years with an average age of 5.2±3.9 years (Table 1).

Table 1 Sociodemographic parameters of guardians and children with cancer

Characteristic	Frequency NOT(%)
Marital status of guardians (129)	
Married	107(83)
Divorce	13(10)
Singles/Widowed	9(7)
Sex of children with cancer	
Male	79(61.2)
Female	50(38.8)
Age range (years)	
0-8 ans	62 (62,6)
9-17 ans	37 (37,3)
Origin of sick children	
City of Lubumbashi	75(58.1)
Outside Lubumbashi	54(41.9)
Method of financing care	
Households	119(92.2)
Employers	7(5.4)
Mutual/Insurance	3(2.3)

Note also that a significant number of children with cancer came from outside the city of Lubumbashi (41.9%).

Urban households accounted for (58.1%), those living in rural areas (41.9%). The analysis of qualitative data revealed to us that urban households traveled a distance of 3.9 km to 17.1 km from the residence house at the University Clinics of Lubumbashi (CUL) while those living in rural areas (41.9%) were far away. from 29.3 km to 2007 km.

The majority of households financed their own health care (92.2%) and a minority were insured by the employer or health insurance (4.1%) to cover their child's prescription drugs. Qualitative data analysis revealed to us that at the time of their child's diagnosis, most guardians (73.5%) reported having a low average annual income, revealed to be between $412 and $1,162 and only about 11 .6% of them reported having an average annual income. high average annual household income, earning more than $8,000 per year. On the number of people per household, nearly 81 households (62.8%) had an average of 5.1±2.9 people per household in the residential roof of the sick child.

Characteristics of guardians of children with cancer and care

The results presented in the first study demonstrate the characteristics of the selected health personnel and households. During the first hospitalization, guardians spent an average total cost of 524.4±$50, of which with a direct cost (378.1±$61) representing 72.1% of the total cost and 27.9% of the indirect cost (146.3±$39) (Table 2).

Table 2 Cost and accessibility to care during the first post-diagnosis hospitalization

Financial costs during diagnosis	Cost Medium NOT (%)
Direct cost (Laboratory, Medicines, Bed occupancy, etc.)	378.1± $61 (72.1)
Indirect costs (Travel, Catering, Communication, etc.)	146.31± $39 (27.9)
Accessibility of support	
Yes	15 (78.9)
No	4(21.1)

The analysis of qualitative data revealed to us that when the cost of care is too high for households (78.9%), it becomes unaffordable for them. The loss of sight in sick children and the cessation of treatment have been recorded due to a lack of financial means. guardians reported that the average number of days in hospital for children was 7±3 days at diagnosis.

Difficult payment and detention at the place of care

The tutors who agreed to respond to our study reported that they had a low socio-economic level and most of whom worked in the informal sector (liberal or a survival profession). For the tutors who came outside of Lubumbashi, they reported that they live from the field and/or from the collection of minerals which do not bring in much, with the implication of a lack of money and a lot of loans.

"I sell maize, palm oil and earn close to $68.9 to $82.8 for children's food. Since the diagnosis of our child's cancer, we no longer know how to go about small businesses, everything is ruined... What we earn cannot keep the children alive at home with a child hospitalized with cancer…. «[MMY Tutor].»

There are households that are lucky enough to be taken care of by their employers and see their care paid for by the latter, but by observing them, we realize that they are struck by discouragement... Generally s It was the households with small trades who found themselves in the hospital with a child sick with cancer... And the guardians generally had an insignificant salary...

If he is not taken for daily work, he is at home and he has nothing..." [KMC healthcare provider].

Cost of treatment according to the type of cancer

By comparing the type of childhood cancer to the average total annual cost during cancer treatment, nephroblastoma had an average annual cost of $1042 higher compared to other types of cancer followed by leukemia (977.3 $), lymphomas ($831.7), neuroblastoma ($803.1), and retinoblastomas ($797.5), bone tumors ($733.8) (Figure 1).

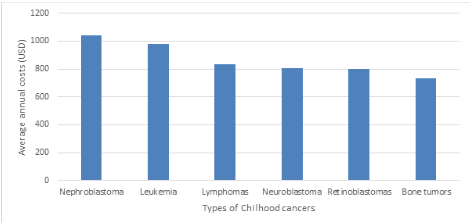

Figure 1 Types of childhood cancers according to their average annual costs

Discussion

We have led a study mixed on the evaluation of the financial cost and economics of child cancer treatment in Lubumbashi from the diagnosis to one year of follow-up while exploring its impact on households. The majority of the parents (83%) were married. In a Canadian study it was reported that most parents were married.[25,26] This is consistent with our study.

Of the sex of the children in our study, the male sex was predominant at (61.2%) and the age of the patients was between 8 months and 17 years with an average age of 5.2±3.9 years. In sub-Saharan Africa, the average age of children with cancer was 6.7±4.3 years, which is slightly higher than the age found in our environment.[27,28] The age group most affected is that of less than 9 years and represents 57.6% of the cases, but the curve of the ratio of cases to the population according to age indicates a progressive increase with age. The average age being 5.2±3.9 years, it is slightly higher in boys (5.2 years) than in girls (4.9 years). This is approximately a decade younger than patients in developed countries, and similar to developing countries. It could be favored by a young population, the predominance of contributing factors such as infections, poor hygienic conditions, etc.

Note also that a significant number of children with cancer came from outside the city of Lubumbashi (41.9%). Households (n=129) traveled an average distance of 77.2±41.36 km and a median of 39.81 km from home to the hospital.

Urban households accounted for (58.1%) and lived from 3.9 km to 17.1 km with a median of (8.9 km) distance from the house of residence to CULs while those living in rural areas (41 .9%) were 29.3 km to 2007 km apart with a median of 278 km. In Zambia and Rwanda, on the other hand, most children with cancer came from large cities, which is the opposite of our study.[28,29] Nephroblastoma had an average annual cost of $1042 higher compared to other types of cancer followed by leukemia (977.3 $), lymphomas ($831.7), neuroblastoma ($803.1), and retinoblastomas ($797.5), bone tumors ($733.8).

The largest component of direct costs in households was the performance of paraclinical examinations and the purchase of certain

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prescription products. Claire Neal in Rwanda[30,31] on the other hand reports a large part was affected in the indirect cost as underlined by two studies that of Senegal and Cameroon.[32] The difference between these two observations and undoubtedly the fact that elsewhere we observe the health insurance system something almost non-existent in our environment.

The indirect cost did not represent the major part in the management of our patients with cancer. Travel, catering and the cost of communication did not take precedence over the direct cost. Comparing our results to other authors we note a challenge because little published research refers to indirect costs.[33-36] However, the cost categories and items borne by households are not typical childhood cancer-related costs reported by parents in other settings.

Our study shows that the costs exceeded 15% of the annual gross income considered as a catastrophic burden for households.[37] These results suggest that households collectively bear a catastrophic financial burden due to the lifetime solidarity that low-income countries generally advocate. The interpretation of the costs took into account families with a high consumption as well as families with a low consumption of expenditure resources.

Basically, the households in this Childhood Cancer Costs Study show that expenditures resulted in catastrophic costs over the one-year period following their child's diagnosis, parents reported the average annual total costs of 2143.7±$729. Some theories on costs of illness, household perspectives are often excluded from consideration.[38]

The results of our study provide a unique contribution to the literature demonstrating the association of costs with the management of childhood cancer in Lubumbashi that extends beyond household resources with external help coming in support based on lifelong solidarity.

Our data was collected in a pediatric oncology unit which allowed us to have a real overview of the costs of childhood cancer in our environment. Reporting of indirect costs such as productivity and informal caregiving also addresses data gaps. Only 10%[39] to 21%[40] of cost studies report data on indirect costs. The methodology for *microcosting on households* in an economic evaluation was new. Finally, the results of our study revealed that households incur various direct and indirect costs previously reported by guardians of children with cancer.

The study also had several limitations. Considering that the socio-economic impact of childhood cancer diagnosis can be "upstream", most treatment programs extend beyond 3 months; therefore, the use of a short time horizon does not capture the cumulative nature of household costs. Using the parental proxy to report direct and indirect household costs may lead to an inaccurate estimate or an underestimate. At least one parent reported zero costs and 9 cost items were excluded, including some expensive items such as flights and hotel stays. The majority of parents were also unable to report the wages of their carers' members, justifying a national wage imputation. Using national wage data is a common practice in health economics, especially with small samples, to improve the generalizability of results. Although cost estimates reflect the «real world», these estimates may vary by facility, treatment phase, and healthcare system, for example. More emphasis can be placed on the type of cost item incurred, usage and recognition that there is a wide variation in cost estimates depending on the household.

In practice, it is imperative to recognize that the impact of cancer extends beyond the home of the child with cancer. Extended family and friends play a vital role, but little is known about their experiences.[41] In the adult literature, evidence suggests family members are dissatisfied with information about cancer provided by healthcare professionals ;[42-45] and could benefit from interventions to cope with the burden of caregiving. For example.[46-48] Although not commonly adopted in practice, clinicians should initiate discussions with households as they are people with their own needs for help or financial support.

Conclusion

The results of our study suggest that there are potentially catastrophic gaps in household resources, particularly the resources needed to manage a household with multiple children. Therefore, households also bear a cost which, in some cases, can also be considered catastrophic. Finally, with the increasing change in care delivery in the community the CUL has no coverage of any or all outpatient care services for households with child with cancer.

Perspective

Our study provides convincing evidence that cancer pathology goes beyond household boundaries in a country considered poor as the DRC. The implications for research, practice and health policies in our country should aim to optimally support the cancer program which almost does not exist in the country, and push to develop an in-depth study on the causes of cancer on the children in the province of Haut-Katanga (Lubumbashi). Also, we would like to propose a study on the acceptance of health insurance or mutual health insurance by the Lubumbashi population.

Author's contribution

All authors of this article made significant contributions to the design, implementation, and/or data analysis and interpretation, article development, and critical review of its intellectual content.

Contributors

Study design: Criss KOBA Mjumbe, Chadrack Kabeya and KABYLA ILUNGA Benjamin

Data collection: Criss KOBA Mjumbe, Chadrack Kabeya and Henry Limbaka

Data analysis: Criss KOBA Mjumbe and Chadrack Kabeya

Supervisor: Desire Mashinda, Benjamin Kabyla and Eric Mafuta

Drafting of the manuscript: all authors

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Conflicts of interest

The authors declare no conflict of interest.

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