

Strategies Adopted by Families to Overcome Financial Burden of Childhood Cancer

Islam S¹, Zafreen F², Karim S³, Islam MZ⁴

DOI: <https://doi.org/10.3329/jafmc.v13i2.41369>

Abstract

Introduction: Childhood cancer imposes considerable financial burden which ultimately leads to serious economic consequences for the family. Families have to cope up these costs by adopting various strategies.

Objective: To find out the strategies adopted by the families to mitigate financial burden of childhood cancer.

Materials and Methods: This cross sectional observational study was conducted among 220 childhood cancer patients at selected specialized hospitals of Bangladesh. Face-to-face interview of the parents or guardian with semi-structured questionnaire following systematic random sampling technique data were collected.

Results: Mean age of the children was 7.30±4.203 years and majority (66.4%) was male. Most of them (78.6%) were from rural and average monthly family income was BDT 11634.09±8740.630. Among all the children majority (39.1%) had leukaemia followed by blastoma (28.2%), sarcoma (15.9%), lymphoma (10.0%) and adenocarcinoma (6.8%). Average treatment cost was BDT 45593.59±12187.637. Sources of fund for treatment included; family savings (35.9%), loan (70.5%), receiving donation (56.8%), support from relatives (75.0%) and property selling (59.5%). Strategies adopted by parents to overcome the situation all (100%) of them accepted as reality and started various religious activities. It also included changing life style (94.5%), taking social support (54.1%) and minimizing family investment (22.3%).

Conclusion: Childhood cancer is a growing public health problem in Bangladesh, so different cost effective measures like subsidized or free of cost treatment should be adopted to reduce the financial burden of the families of the victims of childhood cancer.

Key-words: Childhood Cancer, Financial burden, Overcoming strategies.

Introduction

Childhood cancer is growing fast as an important paediatric problem in Bangladesh. Beyond the age of 1 year, the second leading cause of death after accidents is cancer among children¹. Globally, an estimated 2,50,000 children develop cancer each year, and 80% of them live in developing countries². About 7,000-9,000 children are diagnosed with cancer every year in Bangladesh but less than 500 receive treatment while the survival rate is only around 10-20%³. The diagnosis of cancer in a child can send a family into crisis. The crisis drastically changes normal routine of family interactions as the family attempts to cope. The family's ability to cope up with cancer in a child depends on their resources⁴. For families, the financial issues emerge as a significant concern. This economic burden can have long-term effects on the financial security and quality of life of the entire family⁵. Despite help from other sources for the majority of families, extra costs are associated with money worries⁶. Coping is an ongoing process and families cope up with these costs by restricting normal family activities, obtaining loans, borrowing money, relying on household savings, mortgaging their home, selling property and receiving support from family members, government or other philanthropic agencies⁷. Childhood cancer is a growing public health problem in Bangladesh and poses huge financial burden to the families of the victims. To find out the strategies adopted by the families or parents this study was conducted.

Materials and Methods

This cross-sectional observational study was carried out among 220 childhood cancer patients of 3 tertiary level hospitals of Bangladesh: Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka Medical College Hospital (DMCH) and National Institute of Cancer Research and Hospital (NICRH) from July 2013 to June 2014. Financial burden of cancer was estimated by "Cost of Illness" approach. All children with cancer attended and treated at these selected specialized hospitals during data collection period were selected as study population. A total of 220 children were selected and parents/caregivers of children were respondents of the study.

1. Lt Col Shafiqul Islam, MBBS, MPH, MPhil, Medical Officer, OKP-5, Kuwait 2. Dr Farzana Zafreen, MBBS, MPH, Associate Professor & Head, Department of Community Medicine, Medical College for Women, Uttara, Dhaka 3. Dr Sabina Karim, MBBS, FCPS, MD, Consultant Paediatrics, Kurmitola General Hospital, Dhaka 4. Professor Dr. Md Ziaul Islam, MBBS, MPH, MSc, PhD, Head of the Department of Community Medicine, NIPSOM, Mohakhali, Dhaka.

Data were collected with a pre-tested semi-structured questionnaire by face-to-face interview and by a checklist reviewing medical documents of the respective child with cancer. Analysis of data was done by SPSS 19.0. Chi-square test was done to find out association between different variables and p value less than 0.05 considered as significant.

Results

The mean age of the children was 7.30±4.203 years and range was 1-17 years (Table-I). Other socio-demographic characteristics are shown in Table-I. Majority (39.1%) children had leukaemia followed by blastoma 62(28.2%), sarcoma 35(15.9%), lymphoma 22(10.0%) and 15(6.8%) had adenocarcinoma (Table-II). The Mean and range of different cost are shown in Table-III. Table-IV shows that sources of fund for treatment included family savings (35.9%), loan (70.5%), donation (56.8%), support from relatives (75.0%) and selling property (59.5%).

Table-I: Socio-demographic characteristics of children (n=220)

Characteristics		n	%
Age (years)	1-5	91	41.4
	6-10	77	35.0
	11-17	52	23.6
	(Mean±SD 7.30±4.203)		
Gender	Male	146	66.4
	Female	74	33.6
Place of residence	Rural	173	78.6
	Urban	40	18.2
	Peri-urban	7	3.2
Education	Illiterate	2	0.9
	Primary	82	37.3
	Secondary	35	15.9
	Higher Secondary	1	0.5
Father's Occupation	Pre-school	100	45.5
	Farmer	70	31.8
	Business	59	26.8
	Service	53	24.1
Monthly family income in BDT	Day labourer	37	16.8
	Retired	1	0.5
	3000-10000	135	61.4
10001-20000	67	30.4	
20001-50000	18	8.2	
(Mean±SD 11634.09±8740.630)			

Table-II: Distribution of children by types of cancer (n=220)

Types of childhood cancer	Frequency	%
Adenocarcinoma	15	6.8
Leukaemia	86	39.1
Lymphoma	22	10.0
Sarcoma	35	15.9
Blastoma	62	28.2
Total	220	100.0

Table-III: Distribution of children by monthly costs (n=220)

Cost in BDT	Mean±SD	Range
Direct	40952.13±11949.05	15000 - 66000
Indirect	4802.82±2264.46	1000 - 13000
Total	45593.59±12187.63	17000 - 70000

Table-IV: Distribution of children by sources of fund for treatment (n=220)

Sources of fund for treatment	Frequency	%
Family savings	79	35.9
Taking loan	155	70.5
Receiving donation	125	56.8
Support from relatives	165	75.0
Selling property	131	59.5

Coping strategies included changing life style (94.5%), taking social support (54.1%), adopting various religious activities (100%), minimizing family investment (22.3%) and accepting the reality (100%) (Table-V). The variation in total cost by cancer types was statistically significant (p<0.01) (Table-VI).

Table-V: Distribution of the children by coping strategy (n=220)

Coping Strategies	n	%
Changing life style	208	94.5
Taking social support	119	54.1
Adopting various religious activities	220	100.0
Minimizing family investment	49	22.3
Accepting the reality	220	100.0

*Multiple responses

Table-VI: Association between types of childhood cancer and total cost of treatment (n=220)

Types	Total Cost in BDT			Total
	17000-30000	30001-50000	50001-70000	
Adeno-carcinoma	3 (20.0%)	8 (53.3%)	4 (26.7%)	15 (100.0%)
Leukaemia	2 (2.3%)	37 (43.0%)	47 (54.7%)	86 (100.0%)
Lymphoma	4 (18.2%)	11 (50.0%)	7 (31.8%)	22 (100.0%)
Sarcoma	1 (2.9%)	23 (65.7%)	11 (31.4%)	35 (100.0%)
Blastoma	13 (21.1%)	32 (51.6%)	17 (27.4%)	62 (100.0%)
Total	23 (10.5%)	111 (50.5%)	86 (39.1%)	220 (100.0%)

Chi-square=27.988; df=8; p<0.01

Discussion

Regarding age group this study results revealed that out of total 220 children, majority (41.4%) were 1-5 years old followed by 6-10 years (35.0%). A study conducted in Singapore found highest age group were <5 years (50%) and another study in Nigeria showed 0-5 years age group 54.5% and 6-12 years 33.8% which are almost similar to the present study^{8,9}. Among all the children, 66.4% were male and male female ratio was 1.98:1. A study conducted by Jabeen et al¹⁰ in NICRH found similar findings where 62% were male and 38% female with a male female ratio 1.6:1. Another study in Pakistan¹¹ revealed male female ratio 2:1. In present study, 78.6% children were rural and 18.2% urban areas. A study in Sudan revealed 66.1% rural with predominance of rural population like present study¹².

Maximum (45.5%) were pre-school and 37.3% children were primary level educated. A study in Singapore⁸ revealed primary/secondary education 40%. This variation is because of different grading of education level between Bangladesh and Singapore and also due to age difference of study population.

The mean of monthly family income was Tk. 11634.09±8740.63 while range was Tk. 3000-50000. A study in NICRH, Dhaka¹⁰ showed similar findings of monthly family income. Majority (39.1%) had leukaemia followed by blastoma (28.2%) and sarcoma (15.9%). A study in ASHIC palliative care unit, Dhaka showed leukaemia 37% and solid tumours 63% which supports the present study¹³. Saddik IA¹⁴ in Yamen in his study revealed leukaemia (33.1%), lymphoma (31.5%) and sarcoma (5.2%) which was consistent with this study. Mean total direct cost was Tk.40952.13±11949.05 and the main component of direct cost was drug cost. A study in Canada¹⁵ found average monthly direct cost of childhood cancer treatment \$CAD 1167.67 (BDT 93413.6 approx.). The mean total indirect cost was Tk.4802.82±2264.46 and indirect costs included loss of income and mean unofficial payment. A study in Canada¹⁶ revealed mean indirect cost (3 months) of childhood cancer treatment \$CAD22873±9594. The mean total cost was Tk.45593.59±12187.63 and range was Tk.17000-70000. Total costs included mean monthly direct cost and indirect cost of treatment. A study by Argerie et al¹⁶ in Canada revealed that mean total cost (3 months) of cancer treatment was \$CAD 28475±12670. The amount of total cost of treatment was found more in Canada because of variation of components of direct costs and indirect costs.

Among all the children, 35.9% used various types of family savings for cancer treatment. A study in Philipines showed that 80.9% families of childhood cancer patients spent their family savings for cancer treatment⁴. 70.55% took loan from various sources for cancer treatment. A study conducted in United Kingdom revealed that 68.3% families took loan from different sources for cancer treatment which is consistent with the present study⁶. Regarding donation, 56.8% children received various types of donation. In this study, a significant number of affected children (19.2%) received donation from childhood cancer nonprofit organizations. Around 75% children got financial support from relatives for cancer treatment. A study in Singapore showed that 61% families took financial support for cancer treatment⁸, 59.5% families had to sell their property for cancer treatment and 94.5% families changed their life style to cope up with financial burden of cancer treatment. A study conducted in Canada showed 61% fathers and 86% mothers changed their working hours during the child's treatment⁵.

To cope up with the financial burden of childhood cancer, all parents adopted various types of religious activities and majority (65.5%) of them started regular prayer. A study carried out in Philipines showed 97.8% families of childhood cancer patients had adequate faith on religion which is consistent with the present study⁴. Majority accepted the reality of childhood cancer as fate (50.0%). A study conducted in Singapore found that all parents accepted the reality of childhood cancer as fate¹⁷. Among all, 22.3% families had to cope up with financial burden of cancer treatment by minimizing family investment, 63.3% reduced monthly deposited money in the bank followed by reducing investment in business (20.4%) and decreasing the amount in provident fund (16.3%).

Conclusion

Childhood cancer is a growing public health problem in Bangladesh and poses huge financial burden to the families of the victims. To compensate the financial burden, families adopted various coping strategies. Different cost effective measures like subsidized or free of cost treatment should be adopted to reduce the financial burden of the families of the victims of childhood cancer.

References

1. Choudhary R. Childhood Cancer: The Second Leading Cause of Death Among Children. Available at <http://www.cancersurgery.com/Articles/Childhood-Cancer-The-Second-Leading-Cause-of-Death-Among-Children-178.html>.
2. Holewa H. Addressing Childhood Cancer in Resource Limited Countries: The Need for An International Collaborative Effort. Available from <http://www.australiancancer.org/journal-article/view/addressing-childhood-cancer-in-resource-limited-371>.
3. Hossain SA. Cancer affects 9,000 kids a year. Available at <http://www.bangladeshnews.Com.bd/2010/04/02cancer-affects-9,000-kids-a-yr>.
4. Avegille T, Corales P, Medina MF. Family resources study: part 1: Family resources, family function and caregiver strain in childhood cancer. *Panganiban-Corales and Medina Asia Pacific Family Medicine* 2011; 10:14.
5. Miedema B, Easley J, Fortin P et al. The economic impact on families when a child is diagnosed with cancer. *Curr Oncol* 2008; 15(4):173-8.
6. Eiser C, Upton P. Costs of caring for a child with cancer: A questionnaire survey. *Child: Care, Health and Development* 2007; 33(4):455-9.
7. Tsimicalis A, Stevens B, Ungar WJ et al. The cost of childhood cancer from the family's perspective: A critical review. *Pediatr Blood Cancer* 2011; 56:707-17.
8. Aung L, Saw SM, Chan MY et al. The Hidden Impact of Childhood Cancer on the Family: A Multi-Institutional Study from Singapore. *Ann Acad Med Singapore* 2012; 41(4):170-5.
9. Agboola AOJ, Adekanmbi FA, Musa AA et al. Pattern of childhood malignant tumours in a teaching hospital in south-western Nigeria. *Medical Journal Aust* 2009; 190(1):12-4.

10. Jabeen S, Haque M, Islam MJ et al. Profile of paediatric malignancies: A five year study. *J Dhaka Med Coll* 2010; 19(1):33-8.
11. Jamal S, Mamoon N, Mushtaq S et al. Pattern of Childhood Malignancies: Study of 922 Cases at Armed Forces Institute of Pathology (AFIP), Rawalpindi, Pakistan. *Asian Pacific Journal of Cancer Prevention* 2006; 7:420-22.
12. Harun HM, Mahfouz MS, Elahi AM. Patterns of childhood cancer in children admitted to the Institute of Nuclear medicine, Molecular biology and Oncology (INMO) Wad Medani, Gezira State. *Journal of Family Community Medicine* 2006; 13(2):71-4.
13. Khan ZJ, Kabir S, Masud Z. Pediatric Palliative Care in Bangladesh- An overview.
14. Saddik IA. Childhood cancer in Aden, Yamen. *Epub* 2013; 37(6):803-6.
15. Tsimicalis A, Stevens B, Ungar WJ et al. A prospective study to determine the costs incurred by families of children newly diagnosed with cancer in Ontario. *Psychooncology* 2012; 21(10):1113-23.
16. Argerie T. Costs Incurred by Families of Children Newly Diagnosed with Cancer in Ontario. *Journal of Pediatric Oncology* 2007; 50(7):112-20.
17. Aung L, Saw SM, Chan MY et al. The Hidden Impact of Childhood Cancer on the Family: A Multi-Institutional Study from Singapore. *Ann Acad Med Singapore* 2012; 41(4):170-5.