

RESEARCH ARTICLE

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## Economic and Social Burden of Childhood Cancer in Bangladesh

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### Abstract

**Background:** Cancer is a major cause of morbidity and mortality worldwide. This study aimed to investigate the scale and nature of the socio-economic burdens that face families of children with pediatric cancer in Bangladesh on a day-to-day basis and the reasons for delays in diagnosis and treatment of the disease. **Methods:** A cross-sectional exploratory study including 54 families in Bangladesh who had children with cancer. A structured questionnaire was used to collect quantitative data, supplemented by open-ended questions to gain in-depth information about specific issues. **Results:** The majority of children were male (n=39, 72.2%) and aged 6–15 (n=38, 70.4%). Blood cancer (n=20, 37%) and acute lymphocytic leukemia (n=25, 46.3%) were the most common diagnoses. Many parents stopped working after their child's cancer diagnosis (n=28, 51.9%). Many families (n=21, 38.90%) spent more per month (e.g., USD 471–1,179) on their child's treatment than their income. No external financial support was available to cover this high expenditure, putting families under financial pressure. Social issues included fear, lack of cancer awareness, stigma in rural communities, low-quality facilities, inappropriate service provider behavior, poor facility hygiene, and high fees. **Conclusion:** This study revealed that childhood cancer has a substantial impact on parents' socioeconomic status, and many families face financial, social, and psychological challenges. This highlights the need for urgent collaborative action to address these problems.

**Keywords:** Cancer- childhood cancer- social burden- economic burden- health systems- Bangladesh

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### Introduction

Childhood cancer is a serious health problem in Bangladesh that takes the lives of thousands of children and young adults each year (Ariful et al., 2021; Khasru, 2017; Rahman et al., 2019). The annual incidence of pediatric cancer in Bangladesh is estimated at 9,000 cases, but only 5% of these patients receive hospital treatment (Clark, 2015; Ariful Islam et al., 2021; Khasru, 2017). Hospital treatment is concentrated in two cancer centers Bangabandhu Sheikh Mujib Medical University Hospital (BSMMU) and Dhaka Medical College Hospital (DMCH) in the capital city, Dhaka, and there are major disparities in access to services between rural and urban areas. Most childhood cancers are curable if they are diagnosed early and if treatment is available. However, over 80% of children in Bangladesh with cancer die without a proper diagnosis and adequate medical treatment (Clark, 2015; Khasru, 2017). Childhood cancer also requires long-term treatment, and many low-income Bangladeshi families are unable to pay for treatment. Other families cannot

stay in Dhaka city waiting for their child's next round of treatment but are reluctant to return to their homes because travelling back and forth for treatment is costly and time-consuming. Therefore, discontinuation of treatment and dropout are widespread problems (Clark, 2015; Afiquel et al., 2013; Ariful et al., 2021; Khasru, 2017).

Childhood cancers affect the child's whole family, including the family's income, social life, and emotional health. Social stigma related to cancer is also an issue in Bangladesh (Else-Quest et al., 2014; Long et al., 2011; Neal et al., 2015; Yılmaz et al., 2020). However, no in-depth study has been conducted in Bangladesh to investigate these issues. Such information is important for the public and private sectors to design and initiate programs to support children with cancer and their families. In addition, no systematic information is available on the scale and nature of socioeconomic problems faced by these families on a day-to-day basis. This means many important questions remain unanswered, including why only 5% of children receive treatment, and what barriers to accessing services exist. For example, it is unclear if

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poor access to treatment is related to socioeconomic status or inadequate services.

This study was conducted to gather first-hand information about socioeconomic and other barriers to accessing treatment for pediatric cancer in Bangladesh. The findings will help researchers and policy makers to better understand these issues and initiate appropriate programs to address these problems.

## Materials and Methods

### Study design

This study used a cross sectional exploratory design. Data were collected using a pre-designed questionnaire administered in interviews based on a structured interview guide. Some questions were open-ended to allow participants to add information, explain their perspectives, and express further opinions on issues covered/not covered during the interview.

### Study sample and setting

Study participants were parents or guardians of children aged 0–19 years who were receiving treatment from the main governmental and private hospitals that provide childhood cancer care in Dhaka city. Families with different economic status were included in this study: low income families (approximate income <5,000 Taka per month), medium income (<8,000 Taka per month), and high income (>8,000 Taka per month).

Managers of the relevant hospitals were approached and presented with full details about this study, and approval to recruit participants from these settings was secured. Non-probability convenience sampling was then used to recruit a sample of 54 parents or guardians to participate in an interview. Parents or guardians were presented with complete information about this study, including the study goals, their role in the study, their right to withdraw at any time, and how the data would be processed. Written consent was obtained from all participants. If present with their parents, children were also briefed about this study using language appropriate to their developmental level. Their consent or assent was not obtained as they had no active role in the data collection process.

### Data collection

Data were collected in structured interviews using a pre-designed questionnaire. The questionnaire generated quantitative data through structured questions with limited choice answers. In addition, qualitative information was collected during the interview as participants were asked to answer open-ended questions embedded in the questionnaire. The written consent of the family member was taken before undertaking the interview as well as authorization from the institution the study was ethically approved by the Bangladesh Medical Research Council (BMRC).

### Data analysis

Quantitative data were entered into SPSS for analysis as appropriate. Qualitative data were analyzed manually

by looking for key phrases and similarities among participants' comments and identifying emerging themes.

## Results

### Demographics

Most children were aged 6–10 years (n=19, 35.2%) or 11–15 years (n=19, 35.2%), with the remainder aged 1–5 years (n=16, 29.6%). Most children (n=39, 72.2%) were male (n=39) and over half of the accompanying parents were mothers (n=31, 57.4%). The most common childhood cancer diagnosis was ALL (acute lymphoblastic leukemia) (n=25, 46.3%), followed by blood cancer (n=20, 37%). The majority (n=23, 42.6%) of children had been diagnosed in governmental and non-governmental hospitals. Table 1 presents' participant's demographic data.

### Treatment burden

Most children (n=52, 96.30%) had started the treatment immediately after their diagnosis, and only two children (3.70%) had delayed treatment. One child (1.9%) who had delayed treatment started treatment within 1–10 days, and the other child (1.9%) within 11–20 days. The reasons for treatment delay were lack of money and delay in identification. The most common duration of treatment was 1–5 months (n=19, 35.20%), followed by >12 months

Table 1. Participants' Demographic Characteristics

	Count	%
Child's age, years		
1–5	16	29.6
6–10	19	35.2
11–15	19	35.2
Child's sex		
Male	39	72.2
Female	15	27.8
Relationship to the child		
Father	19	35.2
Mother	31	57.4
Others	4	7.4
Occupation		
Business	25	46.3
Service providers	29	53.7
Child's cancer type		
Acute lymphocytic leukemia	25	46.3
Blood cancer	20	37.0
Myelodysplastic syndrome	4	7.4
Brain cancer	1	1.9
Others	4	7.4
Treatment facility		
BSMMU	14	25.9
Cancer Institute	6	11.1
DMC	11	20.4
Others	23	42.6

BSMMU, Bangabandhu Sheikh Mujib Medical University Hospital; DMC, Dhaka Medical College Hospital

Table 2. Treatment Burden on Participants

	Count	%
<b>Social burden</b>		
Neighbors' reaction to diagnosis		
Pray for the child	22	40.7
Reduced visits	8	14.8
Wanted to help	24	44.4
Others	0	0.0
Relatives support and visitation		
Yes	8	14.8
No	46	85.2
Reasons for decreased social presence		
Think it is communicable	4	50.0
Fear about lending money	4	50.0
Delay in treatment		
1–10 days	1	50.0
11–20 days	1	50.0
Treatment burden		
Reason for the delay		
Money	1	50.0
Identification delay	1	50.0
Delay in diagnosis		
Less than a month	5	9.3
1–5 months	12	22.2
6–12 months	2	3.7
More than 12 months	35	64.8
Economic Burden		
Monthly expenditure on treatment (Taka)		
<40,000	9	16.7
40,001–70,000	12	22.2
70,001–100,000	21	38.9
>100,000	12	22.2
Monthly hospital stay cost		
<10,000	36	66.7
10,001–20,000	12	22.2
>20,000	6	11.1
Dropping from work because of child cancer		
Yes	28	51.9
No	26	48.1
Receiving financial help from any source		
Yes	13	24.1
No	41	75.9
Taking loan for the treatment		
Yes	9	16.7
No	45	83.3
Selling property to pay for the treatment		
Yes	26	48.1
No	28	51.9

(n=13, 24.10%). Most children (n=35, 64.80%) had been sick for more than 12 months before their cancer diagnosis, 12 (22.20%) had been sick for 1–5 months,

five (9.30%) had been sick for less than a month, and two (3.70%) for 6–12 months. Many children had experienced physical problems before their diagnosis, including fever (n=25, 46.30%), toothache (n=8, 14.80%), hand/leg/stomach pain (n=7, 13%), vomiting (n=4, 7.40%), and headache (n=4, 7.40%). Six children (11.0%) had other symptoms, including swollen fingers, blood discharge from the root of the teeth, and eye pain (Table 2).

Twenty-three children (42.60%) were receiving oral medicine as their main treatment, 19 (35.20%) were receiving injections, nine (16.70%) were receiving chemotherapy, and three (5.60%) had their blood taken regularly. Most children (n=44, 81.50%) had been in the healthcare facility for 1–10 days, followed by 16–20 and 26–30 days (each group: n=6, 11.2%), and 11–15 and 21–25 days (each group: n=4, 7.4%).

In over half of the cases, the whole family gathered and remained with the sick child during the day (n=30, 55.60%), whereas 15 (27.80%) children were accompanied by their father only during daytime, and 40 (74.10%) were mainly accompanied by the mother only during the nighttime. The main problems faced by participants in staying with their child were lack of accommodation (n=18, 33.30%), poor hygiene where they were staying, and the cost of accommodation (n=20, 37%). Some participants (n=9, 16.70%) reported other problems such as rude behavior of nurses and doctors, bad food, having older people at home that they needed to stay with, beds that were close together, and hospital policies that did not allow more than one person to stay with the child (n=7, 13%).

Eleven (20%) children did not attend school and 11% of parents reported their child had problems in school, although 37 (69%) parents reported their child did not face any problems in school. The main reason for not attending school was fear of getting infections (n=6, 11.2%). Most participants said their child's schoolmates behaved in a "good" (n=29, 53.70%) or "supportive" (n=8, 14.80%) way toward their child (Table 2)

#### Social burden

Many participants reported that their relatives and neighbors were sympathetic (n=22, 40.70%) and wanted to help (n=24, 44.40%) after their child's diagnosis, but some (n=8, 14.80%) reported reduced social support and visits after the diagnosis. Participants attributed the reduced social contact from neighbors and relatives to fear of getting infected or fear of being asked for financial assistance. Similarly, participants reported neighbors and relatives allowed children to play with each other as usual; although some (n=8, 15%) did not allow this contact after the child's diagnosis. Most participants had received unwanted comments when visiting outside the house with their children, such as others asking "about a mask" (n=36, 66.70%); offering "unnecessary help and support" (n=11, 20.40%); "praying for child" (n=7, 13%); and sometimes asking participants to "stop going to the market" (n=30, 55.60%) (Table 2).

#### Economic burden

For many participants (n=21, 38.90%), the monthly

expenditure for their child's treatment was around 70,001–100,000 Taka; only 12 participants (22.20%) needed less (i.e., 40,001–70,000 Taka) or more (i.e., >100,000 Taka). While examining the treatment related cost, it was found money was spent on medicine, doctors' fees, diagnostic tests, transport, food, and miscellaneous commodities apart from the cost relating to hospital stay.

Many participants had stopped working because of their child's cancer (n=28, 51.9%); however, in most cases, other family members continued to work to support the family (n=49, 90.70%). Most families reported they lost about 10,001–18,000 Taka per month because of stopping work.

Despite their high total expenditure on treatment since their child's diagnosis (100,000–800,000 Taka), most participants received no financial help from any sources (n=41, 75.90%) and had not taken any loans (n=45, 83.3%). However, over half of the participants (n=28, 52.90%) were forced to sell some of their property (e.g., land, gold, cows) to support their income.

### *Health system difficulties*

Fifty-eight participants had to travel more than 100 km to reach the hospital or treatment center at least two times per month. In addition to travelling this distance and dealing with the associated traffic issues, other difficulties included finding accommodation for an overnight stay or during treatment (n=9, 16.70%), high transport fares (n=7, 13%), no guidance (n=6, 11.10%), and doctors not being available (n=3, 5.60%). Most participants used public transport (n=43, 79.60%) to reach the doctor, but some participants used private transport (n=11, 20.40%).

There were no teaching facilities for children in the hospitals, so "stopping going to school" (n=25, 46.30%) was a main problem faced by participants during their child's treatment. Participants also mentioned issues related to the health system, such as "rude and unskilled" doctors and nurses who "behaved badly" (n=14, 25.90%) and the "dirty environment" in some hospitals (n=8, 14.80%). The main areas of improvement in the health system from participants' perspectives included improving healthcare professionals' behavior (n=22, 40.70%) improving the physical facilities of the treatment facility and accommodation for parents (n=14, 25.90%), upgrading equipment (n=18, 33.30%), providing free medicine (n=4, 7.40%), and creating financial support schemes. Participants from remote areas requested that health facilities "provide treatment at low cost" (n=18, 33.30%). They also wanted "financial help from the government" (n=16, 29.60%), "education and awareness programs" (n=12, 22.20%), and "treatment facilities located close to their residential areas" (n=8, 14.80%).

## **Discussion**

This study found that most children had delayed cancer diagnosis and had been sick for more than 12 months before their cancer diagnosis. However, once the diagnosis was established, the treatment started immediately for most of the children.

Around 15% of participants reported having reduced social support and visits from their social network after the diagnosis. Further, most participants reported receiving unwanted comments when visiting outside the house with their children.

For many of the participants, the economic burden was the worst; many participants could not work because of their child's cancer and lost a good portion of their family income. Further, despite their high total expenditure on treatment, most participants received no financial help from any sources. Over half of the participants were forced to sell some of their property to support their income.

The main health system difficulties encountered by participants included long travel distances to reach treatment centres and find accommodation, high transport fares, low guidance during treatment, and healthcare professionals being unavailable and rude and unprofessional. One of the main issues reported is the effect of treatment on their child's schooling; 20% of children dropped from school due to reasons related to the illness.

Cancer is a leading cause of death for children and adolescents worldwide and approximately 300,000 children aged 0–19 years are diagnosed with cancer each year (Steliarova-Foucher et al., 2017). Avoidable deaths from childhood cancers in LMICs are attributable to lack of diagnosis, misdiagnosis/delayed diagnosis, obstacles to accessing care, treatment abandonment, death from toxicity, and high rates of relapse (World Health Organization, 2021). In high income countries, more than 80% of children with cancer are cured, compared with around 20% in many LMICs (Sumit et al., 2015). However, limited information is available about the socioeconomic burden faced by parents in Bangladesh who have children with cancer. Our study provided useful insights to help address this research gap.

Our findings revealed issues related to the high cost and diagnosis/identification of the problem were two reported reasons for delayed treatment. During the open-ended questions, when asked about suggestions for the health system, the participants stated, "Provide treatment at a low cost". A prior study conducted in Bangladesh indicated a 16 percent treatment abandonment rate at BSMMU, with 62 percent of such untimely stoppage of treatment being directly related to families' inability to fund the charges (Islam et al., 2015). Many children experienced symptoms such as fever, toothache, vomiting, and stomach pain before their diagnosis. However, as many participants were from rural areas where there are no treatment accessible facilities and had low awareness of this issue, they might not have been initially concerned about the symptoms experienced by their children, leading to delays in identification. Late diagnosis means that the cancer may move quickly from early to advanced stages, especially if treatment is delayed. A previous study in Bangladesh confirmed that more than one-third of pediatric patients had to wait  $\geq 3$  months to start treatment because the child's age, the family's economic status, and parental education and awareness about malignancy (Begum et al., 2016). That

study also found that female children had to wait longer to consult a doctor than male children, although parents who had previously heard about childhood malignancy were more prompt in seeking treatment for their child (Begum et al., 2016).

In this study, participants reported they faced many problems in staying with their child in the treatment facility, such as poor accommodation, dirty environments, only one person being allowed to stay in the facility, and high fees. “Rude and unskilled” and “Behaved badly” were among the majority’s remarks. This indicated that the quality of services for children with cancer was lower than expected. We also found that the family usually stay’s with the sick child, similar findings by (A Islam et al., 2015) noted that when a family’s ability to support itself under normal circumstances is severely disrupted because at least one family member (usually the mother or older sister) is required to stay in the hospital with their child, there is often a significant loss of overall family income and undeniable disruption of family life. Families found it difficult and financially straining to rent beds for chemotherapy. This was compounded by the fact that most participants did not receive financial help from any sources, did not take any loans, or sell any property, and that most participants’ monthly income was around 10,000–16,000 Taka. However, participants reported several types of expenditure such as medicine, transport, doctors’ fees, food, and diagnosis, and most spent more than 40,000 Taka every month for their child, which exceeded their monthly income. These families were under constant financial pressure and burden, especially as they did not receive any financial support from external sources. It also suggested the facilities were unable to provide proper care, which increased the burden on families, especially as many families could not afford to pay for full treatment. World Child Cancer, a leading organization that works with government hospitals in Bangladesh, has revealed similar concerns on their online platform, such as a lack of specialist pediatric oncologists, a shortage of trained health care professionals, widespread poverty and inequality, a lack of awareness, and so on (World Child Cancer, n.d.).

A positive finding in this study was that many children did not face significant problems in school and that their schoolmates behaved in a good/supportive manner. However, many participants reported their child’s school attendance was affected because of “infection problems” and “chances of being infected.” In addition, long treatment times may have contributed to the interruption in schooling. This is a major area of service that was stressed by participants as requiring urgent improvement.

Infection risk and having to wear a mask was sometimes misunderstood by other people, especially in rural and remote areas where people are less educated and aware about cancer and its treatment. When children with cancer had to wear masks, people thought that cancer was infectious and contagious, which resulted in reduced social contact and the social stigma. A recent study from Finland found high parental income and high education were associated with lower mortality after childhood cancer, whereas lower health literacy and

financial pressure limited treatment adherence and were associated with higher mortality (Tolkkinen et al., 2018). Therefore, motivation and support during the treatment and follow-up period may be needed for families of children with cancer. Other studies reported similar results (Bonilla et al., 2010; Gupta et al., 2009; Jabeen et al., 2010; Youlden et al., 2011).

Most participants in this study had stopped working because of their child’s cancer diagnosis, although other family members could continue working.

The financial, social, and health system-related challenges identified in the study affected both the adults in the family and the child with cancer. These challenges may create social issues and affect the psychological well-being of the child and their family. A brief report on pediatric oncology in Bangladesh revealed an increasing number of children are being referred for treatment following diagnosis (Afiquel et al., 2013). Although this is positive in terms of the potential progress in identification and diagnosis of cancer, it is also concerning as it may increase the capacity problems within referral units. Late diagnosis and advanced disease at presentation remained issues, as 43% of families refused treatment or stopped treatment prematurely due to cost, family disruption, doubts about curability and after good initial response to treatment (Afiquel et al., 2013). A more recent study revealed similar challenges in pediatric care management in Bangladesh (Khasru, 2017), highlighting that this area needs more attention and interventions.

In conclusion, childhood cancer has a substantial impact on parents’ socioeconomic situation. Most families face financial, social, and psychological difficulties. We found that many families face multiple challenges because of their economic status, parental education and awareness, service accessibility, and service quality. This can be attributed to many reasons, including low staffing in facilities, inadequate equipment, and an increased number of patients. More awareness and education about cancer must be provided for rural communities to prevent social stigma. Facilities need to be more accessible and must provide quality services through proper healthcare financing and strict regulations that hold service provider’s accountable, thereby enhancing service quality. This will also reduce the fees required for cancer treatment. There also needs to be sources to provide financial help to those from rural areas seeking treatment. Proper facilitation of services can directly influence the quality of these services, meaning more children will be able to survive. As children are the next generation for the country, addressing these issues from the root can create a healthy economy.

#### *Study Limitations*

This study used a structured questionnaire to collect data, although some flexibility was given to participants in terms of inclusion of open-ended questions. Therefore, the information generated may be limited; in some areas, more detailed responses could have provided more in-depth insights. Although the results are useful and provided insight into the area of study, further investigation on a larger scale is needed to generate a more robust report about the reality of the cancer care services for children

in Bangladesh.

## Author Contribution Statement

All authors contributed to the study design and implementation and writing of the findings reports.

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### General acknowledgment

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### Ethical declaration

Ethical Approval was obtained from xxxx. Written consent was taken from all the participants.

### Conflict of Interest

No conflict of interest.

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