THESIS TITLE

Diagnostic Delay and Initial Healthcare-Seeking Pathways in Childhood Cancer: A Cross-Sectional Study at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh

Submitted by:

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Declaration

I, Siddhartha Sankar Das, hereby declare that this thesis entitled “Diagnostic Delay and Initial Healthcare-Seeking Pathways in Childhood Cancer: A Cross-Sectional Study at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh” is an original work submitted in partial fulfilment of the requirements for the degree of Master of Public Health (MPH) at the James P. Grant School of Public Health (JPGSPH), BRAC University, Dhaka, Bangladesh.

I further declare that this work has not been submitted previously, in whole or in part, for any other degree or examination at this or any other university or institution.

All sources used in this thesis have been duly acknowledged and cited. Any assistance received has been mentioned in the acknowledgements section.

I have also added a separate declaration on GenAI use at the end of this work.

Siddhartha Sankar Das
Date: 01/06/2026

Approval

The thesis titled "Diagnostic Delay and Initial Healthcare-Seeking Pathways in Childhood Cancer: A Cross-Sectional Study at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh" submitted by -

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Of 2025-2026 has been accepted as satisfactory in partial fulfilment of the requirements for the degree of Master of Public Health.

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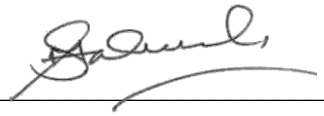

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Ethics Statement

Ethical approval for this study was obtained from the Institutional Review Board of BRAC James P Grant School of Public Health, BRAC University (IRB Ref: MPH-2025-009). Written informed consent was obtained from all participants prior to data collection. All procedures conducted in this study involving human participants were in accordance with the ethical standards of the Institutional Review Board and the 1975 Helsinki Declaration.

Abstract

Background: In Bangladesh approximate 9000 cases of childhood cancer are diagnosed each year; however, however, only 5% of them receive treatment. Over 80% of children with cancer are not diagnosed or appropriately treated in Bangladesh, highlighting the need to investigate diagnostic delays and health-seeking pathways.

Objectives: To identify the factors associated with diagnostic delay among childhood cancer patients in Bangladesh and to assess how caregiver's initial healthcare-seeking pathways influence the time to diagnosis.

Methods: A cross-sectional quantitative study was conducted from January, 2026 to June, 2026. Face-to-face interviews were done with the primary caregivers of childhood cancer patients admitted at the in-patient department of the pediatric hematology and oncology, National Institute of Cancer Research and Hospital, using Kobo Toolbox and 152 data were collected. Non-parametric tests (Mann-Whitney U and Kruskal-Wallis tests) were used to test and find association between independent variables and outcome variable (total interval) while the data was summarized by descriptive statistics. Data analysis was performed using STATA version 17

software, and p-values <0.05 were considered statistically significant. Institutional Review Board of BRAC James P Grant School of Public Health, BRAC University (IRB Ref: MPH-2025-009) approved the study and written informed consent was obtained from all participants.

Results: The median total interval (time from symptom recognition to confirmed diagnosis) was 91 days (IQR: 52.5-188.5 days). The diagnostic interval was the major component of delay (median: 82.5 days, IQR: 44.2-149.7), while the patient interval was short (median: 2 days, IQR:1-7 days). Significant difference in diagnostic delay was observed across cancer types, with longer intervals for retinoblastoma (234 days), CNS tumors (145 days) and bone tumors (121 days), compared to renal tumors (35 days) and leukemia (65 days). There was a significant relationship between the total interval and family income, with the lowest income group having a median interval of 105 days and the highest income group having a median interval of 23 days ($p = 0.030$). Longer intervals were significantly associated prolonged time interval between first and subsequent healthcare visits ($p = 0.0001$), multiple healthcare facility visits ($p= 0.002$), and higher pre-diagnostic expenditure ($p=0.002$) Higher proportions of delay was associated with care pathways, where informal sector providers were the first point of contact.

Conclusions: Diagnostic delay in childhood cancer patients is primarily influenced by health-system barriers, alongside socio-demographic and clinical factors. The findings suggest the need to strengthen referral system across care continuum that will allow early recognition of symptoms and timely diagnosis of cancer. Integrating referral support, reducing financial obstacles, training of frontline healthcare providers, decentralizing pediatric oncology services may help to reduce the diagnostic delay.

Keywords: Childhood cancer, diagnostic delay, healthcare-seeking pathways, care transitions, total interval, Bangladesh.

Acknowledgements

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List of Acronyms

Acronyms	Full Form
ASHIC	A Shelter for Helpless Ill Children
GLOBOCAN	Global Cancer Observatory
HCP	Healthcare Provider
IRB	Institutional Review Board
IQR	Interquartile Range
LMICs	Low-and Middle-Income Countries
NGO	Non-Governmental Organization
NICRH	National Institute of Cancer Research and Hospital
SAARC	South Asian Association for Regional Cooperation
WHO	World Health Organization

Chapter 1: Introduction

1.1 Background and Rationale

Background:

Uncontrolled growth of transformed cells which are subject to evolutionary changes under natural selection is known as cancer (Brown et al., 2023). According to GLOBOCAN 2022, globally approximate 20 million new cases of cancer were diagnosed including 9.7 million deaths (Bray et al., 2024). Of these, it's estimated that 400,00 are childhood and adolescent cancer cases (World Health Organization, 2025). In high income countries about 80% of children with cancer survive, whereas in most low and-middle income countries less than 30% of children survive. (World Health Organization, 2025). Much of this survival gap is due to late diagnosis and delayed treatment.

Every year about 9000 children get diagnosed with cancer in Bangladesh but only 5% receive treatment (Rahman et al., 2023). The childhood malignancies account for 0.5% - 4.6% of all cancer cases in the country (Begum et al., 2016).

One recent survey shows that approximately 1/3 of all cancer patients are children and adolescents, of which the highest number are in the age range 15-19 years in Bangladesh and 13% of childhood cancers occurs before 4 years of age (The Business Standard, 2025). Leukemia (31%), brain and spinal tumors (26%) and lymphoma (10%) are the most common childhood cancers, and are reported more often in urban areas than rural areas; and are more common among males. (The Business Standard, 2025).

Another study of Bangladesh reported that the age-standardized incidence rate of 0-14 years age group was 7.8 per million person-years during 2011 – 2014 where retinoblastoma and leukemia were the most common childhood malignancies (Sorowar Hossain et al., 2016). The incidence rate was 2.1 per million person-years for those between 15-19 years of age, predominantly malignant

bone tumours, germ cell and gonadal tumors and epithelial tumors, and was prevalent in males in both age groups (Sorowar Hossain et al., 2016).

Specialized treatment of pediatric oncology is provided in – National Institute of Cancer Research and Hospital, Bangladesh Medical University, Dhaka Medical College Hospital, Ahsania Mission Cancer & General Hospital, specialized private hospitals like Evercare Hospital, Labaid Cancer Hospital & Super Speciality Centre etc. – in Dhaka in Bangladesh (Rahman et al., 2023). The World Child Cancer-UK project has established a number of regional centers such as M.A.G Osmani Medical College Hospital, Sylhet; Chittagong Medical College Hospital; Mitford Hospital, Dhaka and Shaheed Suhrawardy Medical College Hospital. (Joarder et al., 2024). Non-medical assistance is also provided by NGOs such as the ASHIC Foundation, which houses people for treatment, palliative care and psychological counselling (Sorowar Hossain et al., 2016).

In Model of Pathways to treatment, these delays are defined by several intervals. This includes - appraisal interval (first noticing bodily changes to recognizing the need to seek care), help-seeking interval (decision-making of seeking care to first health-care consultation), diagnostic interval (first consultation to confirmed cancer diagnosis), pre-treatment interval (diagnosis to treatment initiation) (Walter et al., 2012).

Prompt diagnosis of childhood cancer is a crucial factor in determining the success of treatment and survival rates, and contributes to the likelihood of treatment success with minimal side effects (Dang-Tan & Franco, 2007). More than 80% of children with cancer in Bangladesh die from lack of diagnosis and inadequate treatment, thus highlighting the need to study the diagnostic delays and health-seeking pathways (Rahman et al., 2023). In the same study, it has been found that approximately 65% children have been diagnosed after being sick for more than 12 months and more than 70% have to wait over 90 days for treatment to begin (Rahman et al., 2023). An Ethiopian study reported that rural residence, no referral and non-insurance were factors of long diagnostic intervals (Gardie et al., 2023). In a study of Pakistan, it has been observed that provider and health system delays contributed for a significant portion of total delay in pediatric cancer care with significant association with factors as gender, age, and cancer and the efficient referral process and no. of facilities visited were more influencing factors of delay than the distance

travelled (Ul Ain et al., 2025). These results emphasize the multifactorial aspects of the 'diagnostic delay', encompassing both caregiver and health system side.

In Tanzania, children whose caregivers visited a traditional healer first, faced a median delay of 236 days to reach specialized cancer center and diagnostic delay was observed among families of childhood cancer patients who navigated multiple providers and were delayed from lower-level providers to reach the specialized cancer center (Maillie et al., 2020). Every extra transition usually had an extra month of delay, and particularly if the transition was not to a higher center (Maillie et al., 2020).

Rationale:

Childhood cancer in Bangladesh has been relatively under-researched and there is little published research and limited epidemiologic data (Britto et al., 2023). Research has mainly focused on epidemiological patterns and clinical characteristics, diagnostic and treatment delays, socioeconomic impacts on families, health system gaps, and program evaluation (Ahmed & Islam, 2015; Begum et al., 2016; M. R. Islam et al., 2025; Joarder et al., 2024; Rahman et al., 2023; Sorowar Hossain et al., 2016). The evidence available is generally descriptive; there have been few quantitative studies that systematically explore the effect of above factors on time to diagnosis. Thus, these determinants should be measured and figured out which of these are significantly associated with delay in diagnosis and how caregivers' initial choice affects the diagnosis among childhood cancer patients in Bangladesh. The findings will produce evidence that will be used to plan targeted interventions, enhance the referral systems, and design policy interventions for the elimination of diagnostic delays and the improvement of outcomes for patients.

1.2 Problem statement:

Bangladesh studies showed that often repeated treatment cycles before a definitive diagnosis of childhood cancer result from common childhood diseases like infections and anaemia being confused for childhood cancer (Sorowar Hossain et al., 2016). Research across LMICs has identified multiple factors associated with delayed diagnosis including socio-demographic factors

such as low parental education, limited household income, and rural residence; health-system barriers as flawed referral system, provider knowledge gaps, and limited diagnostic capacity and caregiver behaviors such as more reliance on informal providers, multiple care transitions before reaching definitive diagnosis (Nakabiri et al., 2025; Cotache-Condor et al., 2023). These delays have been linked to higher death rates from childhood cancer (Mowla et al., 2025).

In Bangladesh, significant numbers of children are diagnosed late with evidence of long delays in accessing diagnosis (Rahman et al., 2023). Even so, provision for children's cancer is very centralised in Dhaka and families can sometimes be required to visit several centres before they can access specialised services. These fragmented pathways contribute to further delays in diagnosis and treatment.

Caregiver's initial healthcare-seeking pathways also significantly impacts the delay. There is a tendency in SAARC region to go to many centers before arriving to a specialized center, and cancer signs and symptoms are sometimes mistakenly diagnosed during the initial stages, thereby adding to the overall delay (Huq et al., 2024). Likewise, research in other resource-poor health systems has revealed that the delay to diagnosis is significant and is compounded by initial contact with informal health care providers as well as multiple transitions between health care providers (Maillie et al., 2020).

While existing literature shows that diagnostic delay is multifactorial, with some delay attributed to caregiver and others to health system, there is less evidence in the context of Bangladesh that specifically considers total interval, and how caregiver's initial pathways to care affect the delay to confirmed diagnosis for childhood cancer patients. This lack of evidence in the context-specific area is a restraint in developing intervention programs to decrease diagnostic delay.

1.3 Research Questions

What factors are associated with diagnostic delay among childhood cancer patients in Bangladesh, and how do caregivers' initial healthcare-seeking pathways (first point of care and number of care transitions) influence time to diagnosis?

1.4 Study Objectives

1.4.1 General Objective

To identify the factors associated with diagnostic delay among childhood cancer patients in Bangladesh and to assess how caregiver's initial healthcare-seeking pathways influence the time to diagnosis.

1.4.2 Specific Objectives

The specific objectives of this study are:

- To measure the patient interval (appraisal and help-seeking interval), time from symptom recognition to first HCP visit; diagnostic interval, time from first HCP visit to confirmed diagnosis and total interval, time from symptom recognition to confirmed diagnosis - among childhood cancer patients of Bangladesh (Walter et al., 2012).
- To identify socio-demographic, clinical, and health-system factors associated with delays across the diagnostic pathway (patient interval, diagnostic interval, and total interval) among childhood cancer patients in Bangladesh.
- To examine the association between time to diagnosis and caregiver's initial healthcare-seeking events and processes (first point of care, number of care transitions).

1.5 Structure of the Thesis

This thesis is organized into six chapters. Chapter 1 provides the introduction, background, and study objectives; Chapter 2 presents a comprehensive review of existing literature; Chapter 3 outlines the methodology used in this study; Chapter 4 presents the findings; Chapter 5 provides a discussion and interpretation of the results in light of existing evidence; Chapter 6 concludes the thesis with key conclusions, recommendations, and limitations.

Chapter 2: Literature Review

2.1 Diagnostic delay in childhood cancer: Global and regional evidence

Childhood cancer is a major health problem; each year, some 280,000 to 300,000 children and adolescents are diagnosed with cancer (Nakata et al., 2025). There is a huge gap in survival between economic settings (M. Z. Islam et al., 2021) . This inequity is especially troubling because almost 90% of the world's children with cancer reside in LMICs, where they encounter systemic inequities such as misdiagnosis, treatment abandonment, and limited access to essential medicines (Ismail et al., 2023). In response, the WHO Global Initiative for Childhood Cancer (GICC) has been launched with the goal of achieving a 60% global survival rate by 2030 (Nakata et al., 2025).

Delay in diagnosis of childhood cancer is heterogenous for different cancer types and health care contexts. One international systematic review paper has found a median interval between 2-260 weeks (Brasme et al., 2012). Evidence from South Asia also show considerable delays. One study from South India reported median interval as 41 days, while in a tertiary hospital study of India found 59 days as median interval (Lashkari et al., 2021; Sampagar et al., 2023).

Research in various contexts has led to the identification of various factors in diagnostic delay. Parent-related factors, physician-related factors and system-level barriers have been identified by global evidence. Parents do not always identify non-specific signs and symptoms, causing delay in seeking care and extended diagnostic pathways (Brasme et al., 2012). Physician also sometime fail to recognize atypical presentations and delay in referral, where system-level barriers of delay include geographical position, referral pathways and inadequacy of tertiary centres (Brasme et al., 2012; Fern et al., 2013).
These determinants are also found in South Asian countries.Though socioeconomic and health system barriers play more prominent role here. Low parental education, low family income, informal provider as first point of contact, inefficient referral system, limited awareness about childhood cancer, inadequate diagnostic facility – have been found as predicators of delay in

studies from India and Bangladesh (Ghosh et al., 2021; Lashkari et al., 2021;Sampagar et al., 2023). Though there are similarities, there are differences, too. In papers it has been reported that; high-income countries focus on the biology of the tumor and symptom recognition, LMIC emphasis is on economic barriers, capacity of primary-care and referral pathways as delays which are modifiable (Brasme et al., 2012; Howard & Wilimas, 2005; Sampagar et al., 2023;).

In the South Asian Association for Regional Cooperation (SAARC) region, countries carry a significant burden of cancer including a significant proportion of cancer-related mortality (Huq et al., 2024). Regional evidence has pointed towards a complex and fragmented referral system, often resulting in delayed presentation to specialised tertiary centres and late diagnoses due to caregivers accessing informal providers, rural practitioners and traditional healers before arriving at a specialised tertiary centre (Faruqui et al., 2019). There are also differences at the epidemiological level: leukemia in the South Asia has a higher mean age at diagnosis (6 - 7 years) than in high-income countries, where the peak age of diagnosis is earlier in childhood (0 - 4 years) (Sorowar Hossain et al., 2016).

Childhood cancers account for approximately 2.8% of all cancers, where the most common types are leukemia (36%), blastoma (18.2%), sarcoma (14.9%) and lymphoma (12.4%) in the country of Bangladesh (Rahman et al., 2023). There is also considerable burden on the caregiver such as financial stress and psychosocial strain arising from childhood cancer (M. Z. Islam et al., 2021). Delayed diagnosis is frequently cited and is closely associated with poor health systems integrity and financial barriers (Ahmed & Islam, 2015). Recent initiatives in Bangladesh are aimed at decentralizing cancer services and implementing digital solutions for early detection and accessibility (M. Z. Islam et al., 2021).

2.2 Conceptual Framework

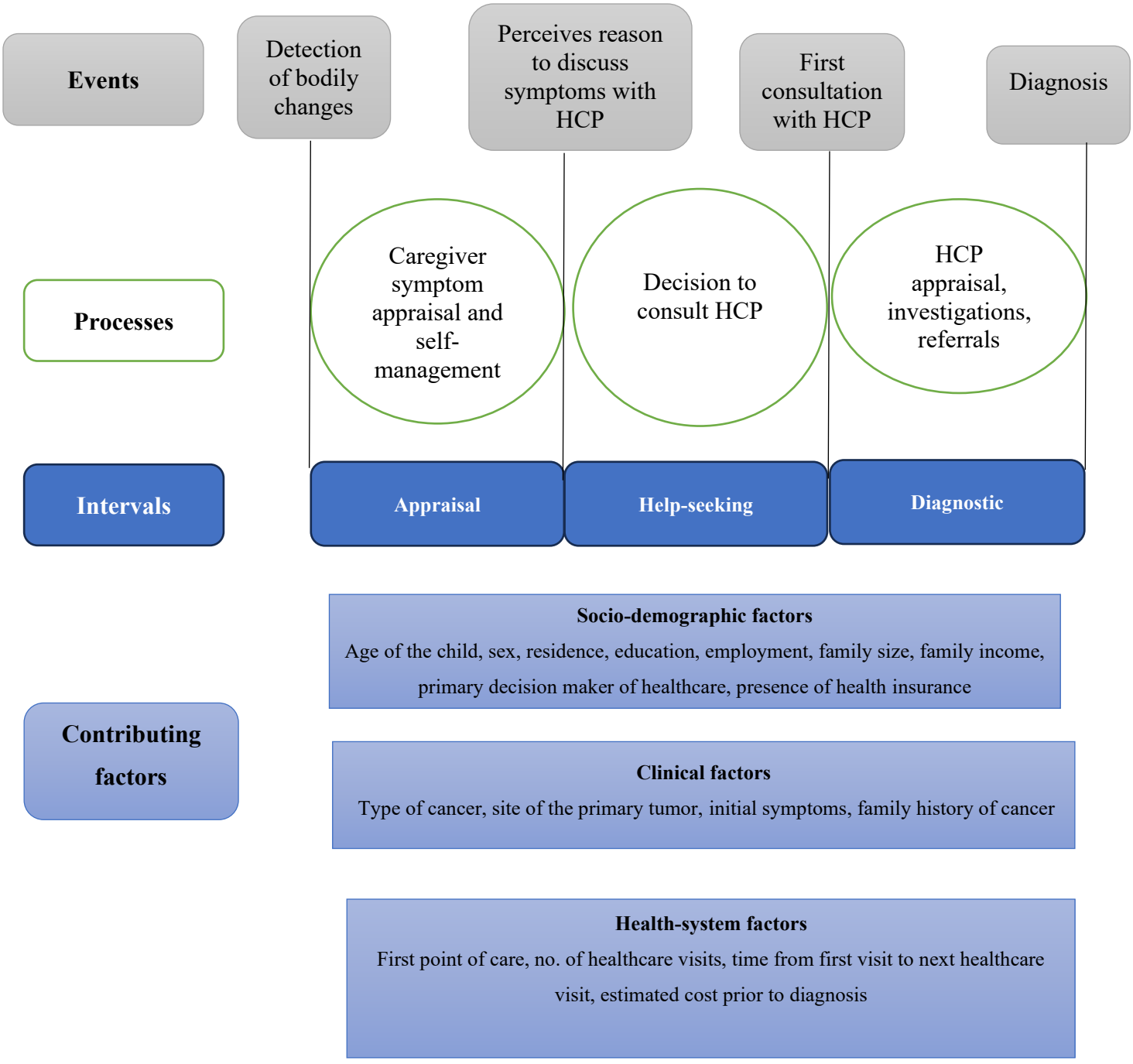

Figure 1: Conceptual framework of diagnostic delay among childhood cancer patients in Bangladesh

The model of pathways to treatment from Walter et al (2012) has been adopted as the conceptual model for this study. The model is based on four components – events, processes, intervals, and contributing factors. The model has four intervals – appraisal, help-seeking, diagnostic and pre-treatment interval. The adapted framework (Figure – 1) is oriented towards the appraisal, help-seeking, and diagnostic intervals pertinent to the study objectives. The pre-treatment interval was therefore not included in the study, as it does not measure the time to treatment and treatment outcomes.

The framework depicts the process of delay between the onset of symptom and diagnosis of childhood cancer. Initially, child's body changes are noted, such as persistent fever, swelling and pain. The caregiver first assumes that they are some sort of general sickness and attempts to treat them alone, perhaps with traditional medicine. The caregiver's knowledge, beliefs, and previous experience affect this appraisal phase in influenced. When the child doesn't get cured, then the caregiver moves on to the help-seeking phase. The initial first point of care (informal provider, pharmacists, primary health care, private practitioners or tertiary level hospital) is a pivotal point in this as misinterpretation of symptoms could result in delay in seeking professional care. Diagnostic interval is the period that starts after the initial consultation with the health care provider. In this stage children undergo numerous transitions between providers and facilities before being transferred to a specialized hospital or being diagnosed. And here each transition may lead to additional delay.

Three factors - socio-demographic, clinical and health-system level factors - influence these intervals. All these play a part in the delay. This conceptual framework enables a broad evaluation of the points in the pathway where delays might happen, and identifies modifiable points that could be targeted to enhance the timely diagnosis of childhood cancer in Bangladesh.

Chapter 3: Methods

3.1 Study Design

This study employed a facility-based, cross-sectional quantitative study design. A cross-sectional study design was considered the most suitable design because it enables simultaneous assessment of dependent variable and independent variables in a specified population at a time.

3.2 Study Area and Setting

The study was conducted in in-patient department of pediatric hematology and oncology department of National Institute of Cancer Research and Hospital, Dhaka, Bangladesh.

NICRH is the nation's leading tertiary level hospital that takes care of patients of all types of cancers with multidisciplinary approach. It is 500 bedded-hospital with all cancer diagnostics and treatment facilities along with 23 departments. Among the departments, the pediatric hematology and oncology department of NICRH provides services to the childhood cancer patients coming from all over Bangladesh. It offers outdoor services, indoor services, daycare chemotherapy and palliative treatment and social support for the paediatric cancer patients.

More specifically, data collection was restricted to paediatric oncology and haematology in-patient wards where childhood cancer patients are actively managed in three wards. In those three wards combined, there were 40 beds allocated for childhood cancer patients. These wards were the main ones in which caregiver interviews were conducted during the specified data collection period.

3.3 Study Period

The study was conducted over a period of six months from January, 2026 to June, 2026. The data was collected from March, 2026 to April, 2026.

3.4 Study Population

3.4.1 Study Population

The study population comprised of primary caregivers of children (<18 years) who had a confirmed cancer diagnosis and were receiving care at NICRH during the data collection period.

3.4.2 Inclusion and Exclusion Criteria

Inclusion criteria:

- Caregivers of childhood cancer patients (<18 years of age) enrolled at NICRH pediatric hematology and oncology in-patient department with available medical records during data collection period.
- Primary care-givers (mother, father or legal guardian) who were present during the initial health-seeking pathways and can provide details about the treatment
- Caregivers who gave informed written consent.

Exclusion criteria:

- Caregivers of adult patients (≥18 years)
- Caregivers aged under 18 years
- Caregiver unwilling to participate or unable to provide relevant information

3.5 Sample Size Calculation

In Bangladesh, the absence of centralized, population-based cancer registry limits the country's capacity to fully understand and address disparities in cancer care (Iqbal, 2025). Also, in other SAARC countries due to the lack of national cancer registry, the prevalence of childhood cancer is not available (Nakata et al., 2025). Hence, the sample size calculation of this study was not possible based on prevalence. All eligible participants (N = 152) who presented to the pediatric hematology and oncology department during the data collection period were included.

3.6 Sampling Technique

Consecutive sampling method was used to select caregivers of children under 18 years who were diagnosed with the cancer during data collection period (Berhane et al., 2019). Here, Consecutive sampling is a non-probability sampling method in which researchers take all the subjects who are considered eligible during a specified period of time (Arrogante, 2022).

3.7 Variables

3.7.1 Dependent Variable

The dependent variable of this study was the total interval (days), time from the first symptom recognition to the date of definitive diagnosis.

3.7.2 Independent Variables

The independent variables included socio-demographic, clinical, patient pathway and caregiver's healthcare seeking characteristics that may impact time to diagnosis in childhood cancer patients. The variables were grouped into the following domains –

1. Socio-demographic characteristics: Age of the patient, sex of the patient, place of residence, religion of caregivers, education level of caregivers, employment status of caregivers, family size, family income, primary decision maker for healthcare, presence of health insurance.
2. Clinical characteristics: Type of cancers, primary tumor site, first symptom noticed, family history of cancer.
3. Patient pathway and caregiver's healthcare seeking characteristics: Caregiver's perceived severity of the first symptom, caregiver's initial thought regarding the cause of symptoms, first action taken after noticing symptoms, first point of care visited, time from first visit to next healthcare contacts, delay in seeking care, number of healthcare facility visits prior to

diagnosis, estimated cost prior to diagnosis, belief about cancer curability, previous knowledge of childhood cancer.

The selection of these variables was guided by the literature and contextuality to the healthcare access and referral system of Bangladesh.

3.7.3 Operational Definitions

- **Childhood** cancer in this study is defined as any type of malignant tumor detected in a child under 18 years of age, recorded in the medical records of the National Institute of Cancer Research and Hospital (NICRH), Dhaka, Bangladesh (Bandyopadhyay et al., 2022;Ahmed & Islam, 2015).
- **Diagnostic delay** is the time exceeding 91 days from the caregiver's initial recognition of illness-related symptoms to the time the illness is diagnosed as cancer by a qualified health care provider. Any delay that is more than this 91day cut-off is operationally considered as a diagnostic delay. The 91-days cut off was obtained from the median of the total interval of the study population.
- **Appraisal interval** is defined as the time from first noticing bodily changes to recognizing the need to seek care (Walter et al., 2012)
- **Help-seeking interval** is the time from decision making to seek care to the first health-care consultation (Walter et al., 2012).
- **Diagnostic interval** is the time between the initial consultation and diagnosis of cancer (Walter et al., 2012).
- **Patient interval** is the duration between the onset of the first symptom and health-care consultation (Moodley et al., 2026).
- **Healthcare-seeking pathways** are the specific actions and measurable steps that are taken from the onset of symptoms to care-seeking to one or more healthcare providers to final healthcare diagnosis, treatment or management of the illness (Mpimbaza et al., 2018).

3.8 Data Collection

3.8.1 Data Collection Tools

Data were collected using a structured questionnaire in the Kobo Toolbox. The questionnaire was designed based on the study goals, literature and conceptual frameworks referring to the healthcare seeking pathways in childhood cancer and diagnostic delay. The tool comprised of socio-demographic characteristics, clinical information, caregiver knowledge and perceptions of childhood cancer, healthcare seeking behaviours and diagnostic pathway.
Key time intervals were obtained: date of onset of symptoms, date of the first healthcare provider contact, date of diagnosis. sing these dates, patient interval (PI), diagnostic interval (DI) and total interval (TI) were calculated, according to a proposed framework by Walter et al. (2012).

The questionnaire was initially prepared in English and later translated into Bengali. Skip patterns, response validation checks, mandatory response options were incorporated to reduce data entry errors and improve data completeness during interviews.

A structured medical record extraction checklist was also used to gather and verify the clinical and diagnostic information from hospital records in addition to the interview questionnaire. The checklist consisted of data from treatment sheets, investigation reports, histopathology reports, prescriptions and discharge certificates (if available).

3.8.2 Pretesting

The questionnaire on kobo Toolbox form was pretested before data collection was done to test the clarity of the questions asked, sequencing of the questions and operational functionality. The pretesting was done during two days in March 2026 in NICRH in-patient department of Pediatric Hematology and Oncology.
In the pre-test phase 9 interviews were conducted. Time of day for interviews was between 2.00 PM and 6.00 PM taking into account the availability of the carer and activities within the ward.

Pre testing revealed some practical and methodological issues in the questionnaire. Question wording was adjusted based on participant responses and observations during interviews to improve the clarity of the questions. Some answer types were changed, skip logic and flow of the Kobo Toolbox form were changed. Several questions were eliminated due to a lack of clarity and/or the inability to accurately answer. Some questions were added to facilitate the interview in smoother process. These 9 responses were omitted during analysis.

The pretest also provided important practical learning experiences regarding participant approach, rapport building and interview timing. These experiences helped to enhance the technical quality of the questionnaire, as well as the general data collection strategy before implementation.

3.8.3 Data Collection Procedure

The data was collected from March- April 2026 using a structured questionnaire in Kobo Toolbox through face-to-face interview with the caregivers of childhood cancer patients admitted in the in-patient department of Pediatric Haematology and oncology at NICRH. The interviews took place inside the wards in the convenience of the respondents' time without affecting the provision of patient care and participant comfort. The average length of each interview was 40-60 minutes.

After obtaining written informed consent, the interviews were conducted in the local language (Bengali). Caregivers were asked to report key dates related to the child's illness, the date of symptom onset, date of first HCP visit, date of confirmed diagnosis. Information on socio-demographic characteristics, clinical factors, caregiver's knowledge and perception of cancer, initial health-seeking pathways were collected according to the kobo Toolbox questionnaire.

After the interview, patient's medical records in the hospital were reviewed with a structured data extraction checklist. Dates were checked with the caregivers reports and medical records if available. Eligible documents for review included hospital treatment sheet, investigation reports, histopathology reports, doctor's prescription, discharge certificates. In case of discrepancy, medical record data was considered the reference source. Medical records were designated as

complete, partially complete or unavailable based upon presence of key diagnostic information. As a whole, 161 interviews were conducted over two months period.

3.9 Data Management and Quality Assurance

Data collected through kobo Toolbox were reviewed regularly to ensure completeness, consistency and accuracy. Completed interviews and data entries were periodically spot checked to ensure consistency between interview responses and electronic records. Completed questionnaires were stored in draft and checked daily following the data collection for missing answers, inconsistencies in the answers, and duplicate enrolments. Required response field in the kobo Toolbox helped to minimize entry errors during data collection. As a result, no variables in the final dataset were missing. Some answers were sometimes not clear or consistent when they reviewed the data. Where this occurred, the respondents were followed up via telephone to clarify and verify. In this way, the completeness and reliability of the dataset was enhanced. Data was downloaded on a regular basis from Kobo Toolbox to a password protected computer for back-up and analysis. Only supervisory team had the access to the dataset. To ensure confidentiality of participants, identifiable data were removed from data sets used for analysis.

Also to reduce recall bias, calendar landmarking techniques were used. During interviews, caregivers were encouraged to relate events to local festivals, holidays or significant occasions to improve recall of timelines. Caregiver reported information was also verified with available medical records, if available. Use of both interview data and review of medical records enhanced the validity of the information gathered.

3.10 Data Analysis

STATA statistical software (version 17) was used for data analysis. Prior to analysis, the dataset was checked for completeness, consistency, duplicate entries and missing values. Descriptive and bivariate analysis were performed according to the nature and distribution of the variables.

Using graphical methods, continuous variable related to interval were first examined for normality. Since the total interval showed a positively skewed distribution, non-parametric statistical tests were used **(Annex 3).**

Categorical variables were analysed descriptively and presented in frequencies and percentages. Median and interquartile range (IQR) were used to present continuous variables such as patient interval, diagnostic interval, and total interval. The mean, standard deviation, mode and range were computed to provide a description of the overall distribution of the intervals.

The outcome variable, the total interval was categorized into a binary outcome to describe the burden of delay in the study population. As there is no universal, widely accepted definition of what constitutes delayed vs timely diagnosis in childhood cancer, in literatures data driven cutoff like median has been used (Ul Ain et al., 2025b; Nakabiri et al., 2025). That's why a cut-off value of 91 days, derived from the median value of total interval, was used to classify participants into –

- Diagnostic delay (Yes): total interval > 91 days
- Diagnostic delay (No): total interval ≤ 91 days

This categorization allowed estimation of the proportion of patients experiencing delayed diagnosis in the study population.

Socio-demographic, clinical characteristics, patient pathway and healthcare seeking characteristics were summarized using descriptive analyses by diagnostic delay status.

In bivariate analysis, the total interval was considered a continuous variable and presented as a median with an interquartile range (IQR). Since the data were not normally distributed, non-parametric statistical tests were used to analyse the relationship between independent variables and total interval (days).

- Mann-Whitney U test was used for comparisons between two groups.
- Kruskal-Wallis test was used for comparisons between more than two groups

Median and interquartile ranges (IQRs) of the total interval were reported across categories of independent variables along with corresponding p-value.

Distributions of diagnostic delay on selected variables were displayed graphically as bar charts including cancer type, administrative areas, first point of care and time from first to next health care visits. Statistically significant results were considered as $P<0.05$ at all the levels of analysis.

3.11 Ethical Considerations

Multi-step institutional process was used to obtain ethical approval for the study. The study protocol, questionnaire, participant information sheet, consent forms and other necessary documents were initially prepared and submitted to the Institutional Review Board (IRB) of BRAC James P Grant School of Public Health. Then, BRAC JPGSPH IRB review and defence was faced formally. After the review process, Ethical approval from BRAC JPGSPH was obtained. Ethical approval letter with IRB protocol number: MPH-2025-009 dated 22nd February, 2026 was issued. This letter will be valid until 21st February, 2027.

To start the fieldwork, a meeting was held with the head of the NICRH department of pediatric hematology and oncology where the objectives of the study, methodology and ethical considerations were presented. Following queries, the department gave permission to collect data. Subsequently a permission letter to the Director of NICRH seeking institutional approval to conduct the study at the facility was written. Coordination meeting with hospital staffs were held after official approval, to understand patient flow, to identify suitable timings for interviews and to ensure that research activities did not interfere with routine clinical services.

Informed voluntary written consent, including consent of taking photos, were obtained from the respondents before conducting interview. The written informed consent form had the study goals, nature of participation of the participants, risks and benefits, confidentiality, and anonymity of the participants' identity. It was assured that the responses would be taken upon the participants' full consent, if the participant would want to withdraw within the interview, he/she had the right to do so without any concern.

All information obtained were de-identified by a unique participant ID to maintain their confidentiality and anonymity. The final data set contained no personally identifiable information. All files were maintained in a computer accessed by the research team only, and with a password. All interview and medical record information was collected for study purpose only.

As the study involved caregivers of children with cancer, it was tough for some participants to discuss illness experiences and healthcare-seeking journey of their children. To minimize distress, interviews were conducted sensitively and flexibly according to participant's comfort and the patient's clinical condition. Interviews were halted or terminated as felt appropriate. And participants didn't receive any financial benefits from the study. There weren't any conflicts of interest either.

Chapter 4: Results

4.1 Socio-demographic characteristics

Most of the childhood cancer cases were in the age group 10 - <18 years (42%) of which 47% were diagnosed late. There were 62% male and 38% female patients. There was no difference in the distribution of delayed and non-delayed between male and female. Most of the patients were from rural area (85%). In the delayed diagnosis group 82% were rural and 18% were urban.

Among caregivers of childhood cancer patients, 43% were of 30 – 39 years of age and 62% were female. 55% of the families had family size of more than five members. Only 7 people of the respondents were Hindu who were in the non-delayed group. Of caregivers of childhood cancer patients who were diagnosed late, 71% had primary education or below and 70% were not employed. Fathers were the primary healthcare decision makers in 43% of cases followed by mothers (25%). In almost all cases, health insurance was not covered. Only one person reported positive.

Table 1 shows the socio-demographic characteristics of childhood cancer patients and their caregivers according to diagnostic delay.

Table 1: Socio-demographic characteristics of childhood cancer patients & caregivers by diagnostic delay status

Characteristics	Category	Delayed diagnosis		Total (n = 152)
		Yes (n=76)	No (n=76)	
Age of the patient (years)	Less than 5 years	13 (17%)	20 (26%)	33 (22%)
	5 -10 years	27 (36%)	28 (37%)	55 (36%)
	10 - <18 years	36 (47%)	28 (37%)	64 (42%)
Sex of the patient	Male	48 (63%)	46 (61%)	94 (62%)
	Female	28 (37%)	30 (39%)	58 (38%)
Residence	Urban	14 (18%)	9 (12%)	23 (15%)
	Rural	62 (82%)	67 (88%)	129 (85%)
Family size	≤ 5	33 (43%)	35 (46%)	68 (45%)
	>5	43 (57%)	41 (54%)	84 (55%)
Age of caregivers	<30	20 (26%)	22 (29%)	42 (28%)
	30–39	31 (41%)	35 (46%)	66 (43%)
	≥40	25 (33%)	19 (25%)	44 (29%)
Sex of caregivers	Male	28 (37%)	30 (39%)	58 (38%)
	Female	48 (63%)	46 (61%)	94 (62%)
Religion of caregivers	Islam	76 (100%)	69 (91%)	145 (95%)
	Hinduism	0 (0%)	7 (9%)	7 (5%)
Education of caregivers	Primary or below	54 (71%)	54 (71%)	108 (71%)
	Above primary	22 (29%)	22 (29%)	44 (29%)
Employment status of caregivers	Employed	23 (30%)	30 (39%)	53 (35%)
	Not employed	53 (70%)	46 (61%)	99 (65%)

Characteristics	Category	Delayed diagnosis		Total (n = 152)
		Yes (n=76)	No (n=76)	
Primary decision-maker for healthcare	Father	32 (42%)	33 (43%)	65 (43%)
	Mother	23 (30%)	15 (20%)	38 (25%)
	Both	14 (18%)	22 (29%)	36 (24%)
	Other	7 (9%)	6 (8%)	13 (8%)
Presence of health insurance	Yes	0 (0%)	1 (1%)	1 (1%)
	No	76 (100%)	75 (99%)	151 (99%)

**Values are presented as frequency (percentage). Percentages may not sum to 100 or exceeds 100 due to rounding.*

Diagnostic delay status by administrative division

The administrative divisions of Bangladesh are shown in the distribution of diagnostic delay in **Figure 2**. Barishal division had the highest percentage of diagnostic delay with 75% of people experiencing a delay in diagnosis. The percentage of cases that were delayed was also relatively high in Dhaka division (67%). No delays were seen in Sylhet division, on the other hand.

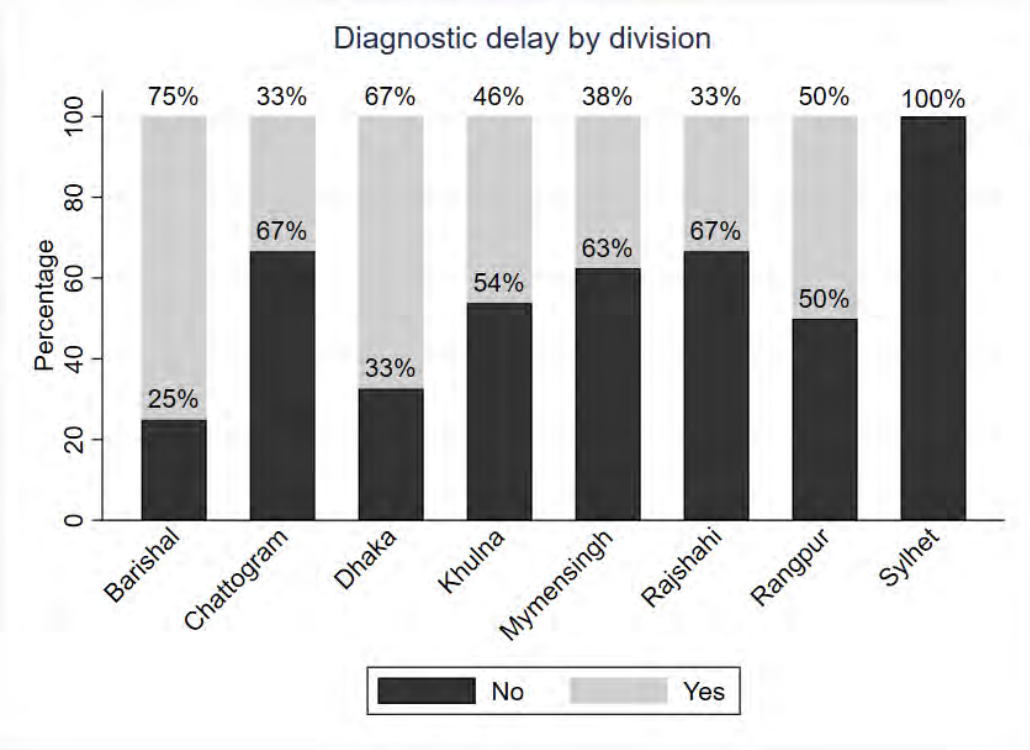

Figure 2: Diagnostic delay status by division

(Total N = 152; Barishal, n = 12; Chattogram, n = 27; Dhaka, n = 52; Khulna, n = 13; Mymensingh, n = 16; Rajshahi, n = 15; Rangpur, n = 12; Sylhet, n = 5)

4.2 Clinical characteristics

Table 2 shows the clinical features of children with cancer according to the diagnostic delay status.

Concerning the primary tumor site, blood was the most common (22%) and then bone tumors (21%). In the delayed diagnosis group bone was frequent tumor site (26%). The primary site of diagnostic delay was lymph nodes in 20% of the cases. In the non-delayed group, blood was the dominant site accounting for 33% of all cases. Pain and swelling were the most frequently reported initial symptoms, each of them comprising 38% of total sample. Of these delayed cases, 41% reported pain and 39% reported swelling. Eye symptom (3%), bleeding (4%), weight loss (5%) and respiratory symptom (5%) were less reported symptoms.

80% of the respondents reported negative family history of cancer, 20% reported positive. No difference in distribution was seen between delayed and non-delayed group.

Table 2: Clinical characteristics of childhood cancer patients by diagnostic delay status

Characteristics	Category	Delayed diagnosis		Total
		Yes (n=76)	No (n=76)	(n = 152)
Primary tumor site	Blood	9 (12%)	25 (33%)	34 (22%)
	Bone	20 (26%)	12 (16%)	32 (21%)
	Lymph nodes	15 (20%)	7 (9%)	22 (14%)
	Brain/CNS	8 (11%)	3 (4%)	11 (7%)
	Eye	4 (5%)	2 (3%)	6 (4%)
	Kidney	0 (0%)	7 (9%)	7 (5%)
	Gonads	2 (3%)	4 (5%)	6 (4%)
	GI tract	2 (3%)	4 (5%)	6 (4%)
	Soft tissues/ muscle	11 (14%)	10 (13%)	21 (14%)
	Others	5 (7%)	2 (3%)	7 (5%)
First symptom noticed*	Fever	15 (20%)	21 (28%)	36 (24%)
	Pain	31 (41%)	27 (36%)	58 (38%)
	Swelling	30 (39%)	28 (37%)	58 (38%)
	Bleeding	3 (4%)	3 (4%)	6 (4%)
	Weight Loss	2 (3%)	5 (7%)	7 (5%)
	Eye symptom	3 (4%)	2 (3%)	5 (3%)
	Neurological symptom	6 (8%)	3 (4%)	9 (6%)
	Gastrointestinal symptom	5 (7%)	8 (11%)	13 (9%)
	Respiratory symptom	3 (4%)	5 (6%)	8 (5%)
	Other	3 (4%)	2 (3%)	5 (3%)
Family history of cancer	Yes	14 (18%)	16 (21%)	30 (20%)
	No	62 (82%)	60 (79%)	122 (80%)

**Note: First symptom noticed is a multi-response variable, summation of total percentage exceeds 100. Values are presented as frequency (percentage). Percentages may not sum to 100 or exceeds 100 due to rounding.*

Diagnostic delay status by types of cancer

The delay in diagnosis in the different types of cancers is shown in percentage in figure 3. The highest percentage of diagnostic delay of 73% was observed in CNS tumors, followed by bone tumors at 68%, retinoblastoma 67% and lymphoma at 61%. On the contrary, in the renal tumor, no patients experienced delay whereas, leukemia had 24% of diagnostic delay.

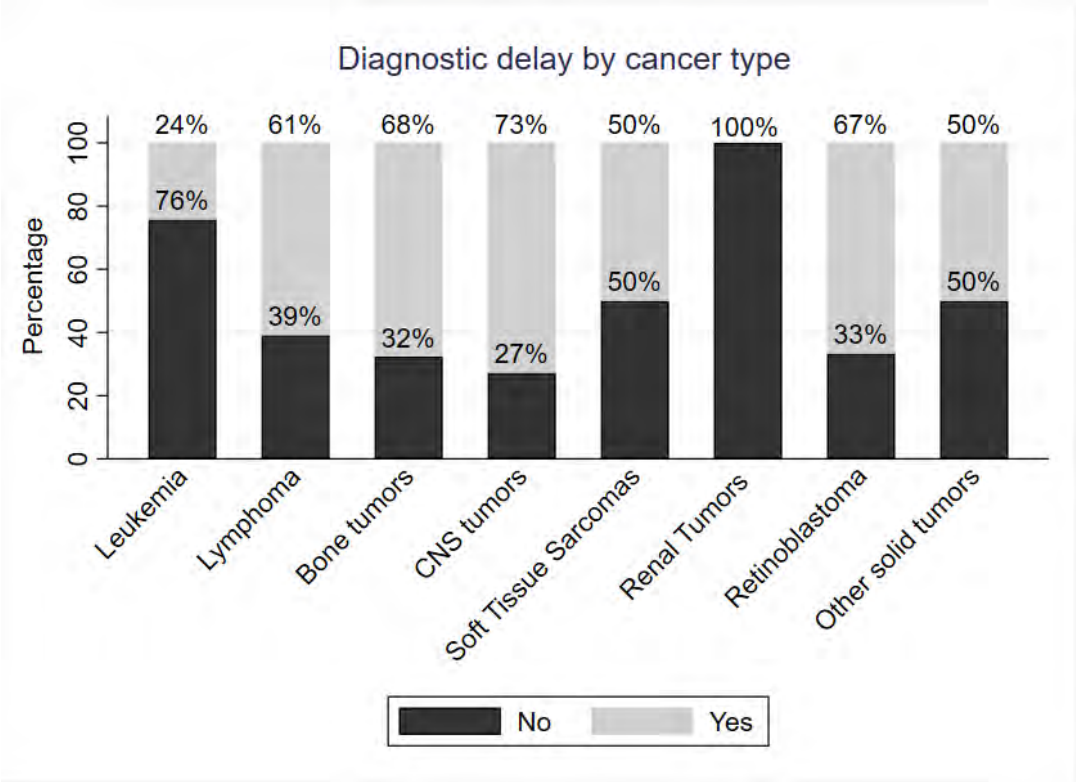

Figure 3: Diagnostic delay status according to cancer types

(Total N = 152; Bone tumors, n = 34; Leukemia, n = 33; Other solid tumors, n = 26; Lymphoma, n = 23, Soft tissue sarcomas, n = 12; CNS tumors, n = 11; Renal tumors, n = 7; Retinoblastoma, n = 6)*

**Note: Other solid tumors include Germ cell tumor, GI carcinomas, Neuroblastomas, Round cell tumors and other tumors*

4.3 Patient pathway and healthcare-seeking characteristics

The patient pathway and healthcare-seeking characteristics of the childhood cancer patients are shown in **Table 3**.

The majority of the caregivers in both groups, both with and without delay, indicated that the first symptom was mild. In delayed group the percentage was 67% while in non-delayed group it was 71%. In more than half cases (53%) they thought that common illness was the cause of the initial symptoms. This was reported in 43% of delayed and 62% of non-delayed cases.

The most common first action after noticing symptoms was buying medicine from pharmacy. More people who experienced delays reported the purchase of traditional medicine (16%) than the non-delayed group (3%). 43% of caregivers were not sure whether cancer is cured or not. 42% believed so, among them 38% were from delayed group and 46% were from non-delayed group.

52% of caregivers went to health care facilities 3-5 times before diagnosis. However, a greater portion of delayed cases reported 6-9 visits (36% vs. 25%) and ≥10 visits (16% vs. 4%) compared to non-delayed cases. There was also a difference in the groups in terms of the estimated cost before diagnosis. In the delayed cases, 45% said that they had spent from 50K to 150K BDT. 80% of caregivers reported that there was no delay in seeking care from their side.

Also, most of the caregivers said they were non-familiar with Cancer in children before their child's diagnosis.

Table 3: Patient pathway and healthcare-seeking characteristics by diagnostic delay status

Characteristics	Category	Delayed diagnosis		Total
		Yes (n=76)	No (n=76)	(n = 152)
Caregiver's perceived severity about first symptom	Not serious	12 (16%)	8 (11%)	20 (13%)
	Mild	51 (67%)	54 (71%)	105 (69%)
	Serious	12 (16%)	11 (14%)	23 (15%)
	Very serious	1 (1%)	3 (4%)	4 (3%)

Characteristics	Category	Delayed diagnosis		Total
		Yes (n=76)	No (n=76)	(n = 152)
Caregiver's initial thought about cause of the symptom	Common illness	33 (43%)	47 (62%)	80 (53%)
	Infection	12 (16%)	6 (8%)	18 (12%)
	Injury	4 (5%)	6 (8%)	10 (7%)
	Supernatural Cause	3 (4%)	2 (3%)	5 (3%)
	Others	5 (7%)	1 (1%)	6 (4%)
	Didn't know	19 (25%)	14 (18%)	33 (22%)
First action taken after noticing symptom	Waited/observed	7 (9%)	1 (1%)	8 (5%)
	Home remedy	2 (3%)	2 (3%)	4 (3%)
	Bought traditional medicine	12 (16%)	2 (3%)	14 (9%)
	Bought medicine from pharmacy	31 (41%)	39 (51%)	70 (46%)
	Visited healthcare facility	24 (32%)	32 (42%)	56 (37%)
Belief about cancer curability	Yes	29 (38%)	35 (46%)	64 (42%)
	No	12 (16%)	10 (13%)	22 (14%)
	Not sure	35 (46%)	31 (41%)	66 (43%)
Number of healthcare visits prior to diagnosis	1–2 visits	5 (7%)	7 (9%)	12 (8%)
	3–5 visits	32 (42%)	47 (62%)	79 (52%)
	6–9 visits	27 (36%)	19 (25%)	46 (30%)
	≥10 visits	12 (16%)	3 (4%)	15 (10%)
Estimated cost prior to diagnosis	≤50k	7 (9%)	25 (33%)	32 (21%)
	50k–150k	34 (45%)	25 (33%)	59 (39%)
	150k–300k	26 (34%)	18 (24%)	44 (29%)
	>300k	9 (12%)	8 (11%)	17 (11%)
Delay in seeking care	Yes	24 (32%)	6 (8%)	30 (20%)
	No	52 (68%)	70 (92%)	122 (80%)
Heard of childhood cancer before	Yes	11 (14%)	8 (11%)	19 (12%)
	No	65 (86%)	68 (89%)	133 (88%)

**Note: Values are presented as frequency (percentage). Percentages may not sum to 100 or exceeds 100 due to rounding.*

Diagnostic delay status by first point of care

Figure 4 demonstrates the percentage of diagnostic delay against the first point of care. In this group, the greatest delay was seen in patients using the services of traditional or spiritual healer. 89% of them experienced diagnostic delay. Also, high delays were observed whose initial contact was a homeopath (75% delayed, 25% non-delayed) or a village doctor (67% delayed, 33% non-delayed). On the other hand, who visited community clinic at the first place, none experienced delay.

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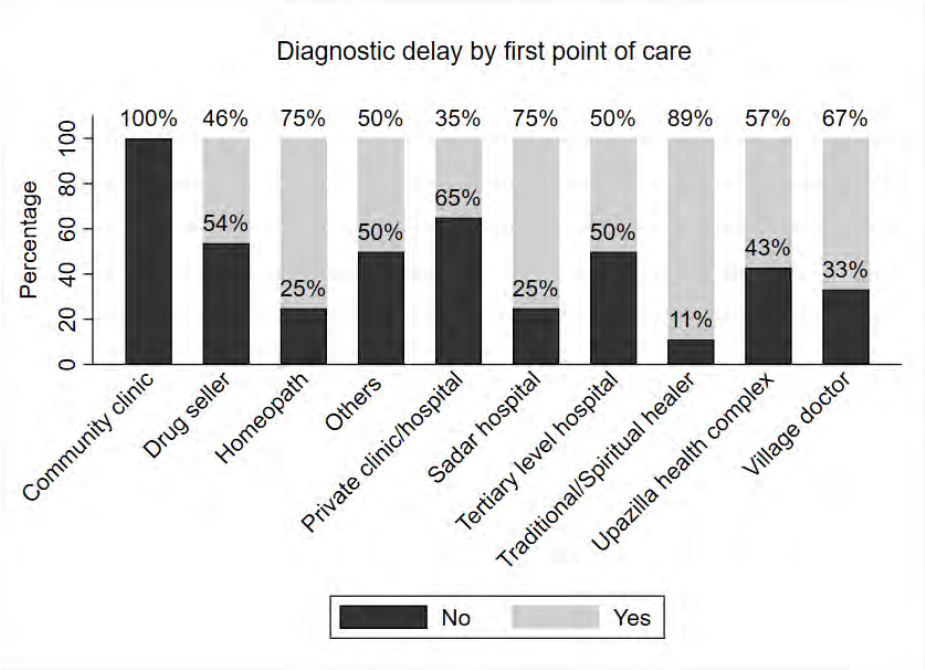

Figure 4: Distribution of diagnostic delay by first point of care

Diagnostic delay status by time from first visit to next healthcare contact

Figure 5 presents diagnostic delay by time from fist healthcare visit to next healthcare contact. Here, a pattern was observed. Patients who visited their next healthcare providers on the same day of the first visit, none experienced diagnostic delay. Subsequently, who visited their next healthcare provider within less than a week of first visit, 77% of them was in non-delayed group, In the third category, who visited after 1-4 weeks, 42% of them experienced delay. The highest percentage of diagnostic delay was observed among patients who had contacted after more than a month of first visit.

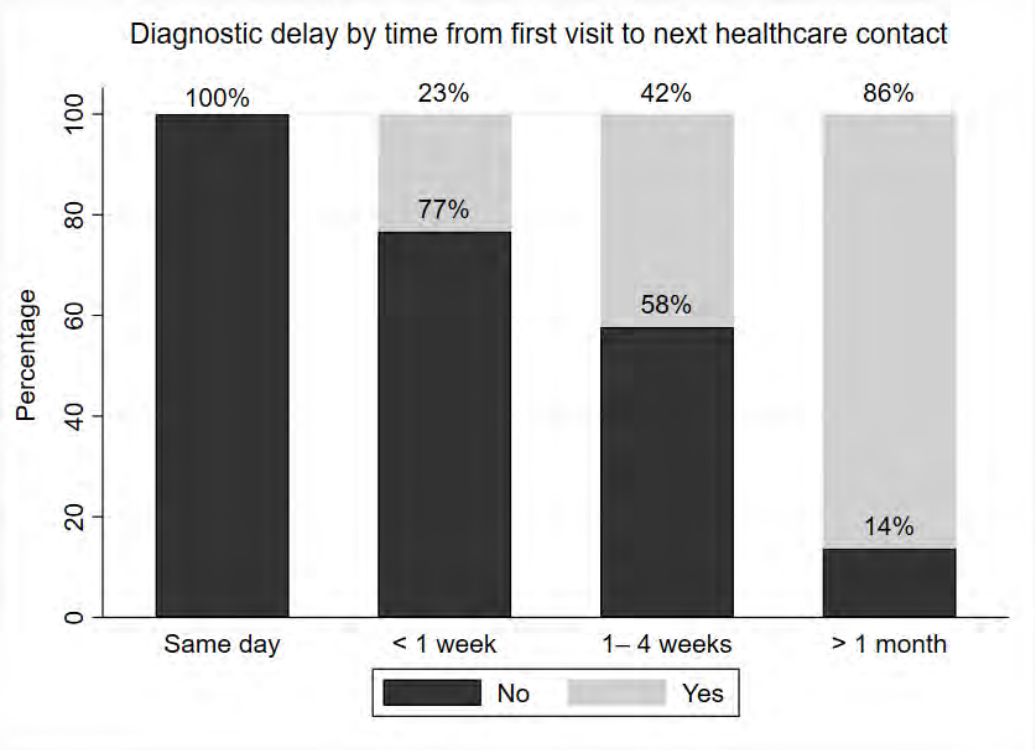

Figure 5: Diagnostic delay status by time from first visit to next healthcare contact

4.4 Distribution of the intervals

The distribution of patient interval, diagnostic interval and total interval within childhood cancer patients is shown in **table 4.**

Data are expressed as means ± S.D., median (IQR), mode and ranges (days). Patient interval was the shortest time here in the pathway. The median patient interval was of 2 days (IQR: 1-7 days). The most frequent time to seek care after symptom appraisal was 1 day.

The diagnostic interval was a major factor in the significant shift in the time interval. The median diagnostic interval was 82.5 days (IQR: 44.2 – 149.7 days).

The total interval (from the time of symptom recognition to confirmed diagnosis) had a mean of 153.4 ± 184.8 days and a median of 91 days. This median was used as cut-off to categorize diagnostic delay.

Table 4: Distribution of patient interval, diagnostic interval and total interval among childhood cancer patients

Interval	Mean ± SD (Days)	Median (IQR) (Days)	Mode (Days)	Range (Days)
Patient Interval	12.8 ± 29.9	2 (1-7)	1	0 - 240
Diagnostic Interval	140.7 ± 182.3	82.5 (44.2 – 149.7)	80	4 - 1170
Total Interval	153.4 ± 184.8	91 (52.5 – 188.5)	120	5 - 1230

4.5 Factors associated with total interval

The bivariate analysis exploring the relationships between socio-demographic, clinical and care-seeking pathway related characteristics and total interval is presented in **table 5**. Non-parametric testing (Mann-Whitney U and Kruskal-Walli's tests) revealed that several factors were associated with prolonged total interval from symptom onset to confirmed diagnosis ($p < 0.05$).

The socio-demographic factors that had a statistically significant relationship with the total interval were family income ($p = 0.030$). Families with income of >30,000 BDT had the shortest median interval of 23 days (IQR: 15 – 116 days) and the lowest income group (≤15,000 BDT) had the longest interval of 105 days (IQR: 50 – 190 days). There was a significant relationship ($p = 0.006$) between the religion of the caregiver: Muslim caregivers had a higher median total interval (96 days, IQR: 60-195 days) than Hindu caregivers (48 days, IQR: 30-50 days).

In clinical characteristics, there were some significant factors. Total interval was related to type of malignancy ($p = 0.0003$). The longest median interval was observed in patients with Retinoblastoma, 234 days (IQR: 88-388 days), followed by CNS tumors (145 days), Bone tumors (121 days) and Lymphoma (114 days). On the contrary, shortest median interval was observed in Renal tumors (35 days) and Leukemia (65 days).

Care-seeking pathway characteristics also had some significant associations. The time from first visit to next healthcare contact was associated with total interval ($p = 0.0001$). Patients who visited subsequent healthcare providers on the same day of their first visit had a median total interval of 35.5 days (IQR: 16-52 days). If it was more than 1 month, it was 195 days.

In addition, the number of health care facilities visited before the confirmed diagnosis was associated with prolonged interval ($p = 0.002$). The median total interval was 71 days for patients with 1-2 visits, while who visited ≥10 healthcare facilities the median total interval was 240 days. The estimated cost before diagnosis was also an important factor ($p = 0.002$). The lowest expense

category had the shortest median interval of 60 days (IQR: 33.5 – 87.5 days), the category 150k–300k BDT had total median interval of 115.5 days.

Table 5: Bivariate analysis of factors associated with total interval among childhood cancer patients

Characteristics	Category	Median (IQR) (Days)	p-value
Age of the patient (years)	Less than 5 years	85 (51-150)	0.265
	5 -10 years	87 (47-131)	
	10 - <18 years	108 (65-225)	
Residence	Urban	122 (39-231)	0.627
	Rural	90 (56-170)	
Religion of the caregivers	Islam	96 (60-195)	**0.006***
	Hinduism*	48 (30-50)	
Education of caregivers	Primary or below	92.5 (50.5-196.5)	0.7390
	Above primary	90 (60-147.5)	
Employment status of caregivers	Employed	88 (50-180)	0.516
	Not employed	96 (56-201)	
Family size	≤ 5	89 (49-198)	0.885
	>5	97.5 (56.5-165)	
Family income	≤15,000 BDT	105 (66-210)	**0.030***
	15,001–30,000 BDT	80 (52-175)	
	>30,000 BDT	23 (15-116)	
Presence of health insurance	Yes	21 (21-21)	0.151
	No	92 (54-189)	
Family history of cancer	Yes	87 (43-126)	0.259
	No	93.5 (60-206)	

Characteristics	Category	Median (IQR) (Days)	p-value
Cancer type	Leukemia	65 (39-90)	
	Lymphoma	114 (60-350)	
	Bone tumors	121 (75-239)	
	CNS tumors	145 (67-219)	
	Soft tissue sarcomas	89 (79.5-131)	**0.0003***
	Renal tumors	35 (20-61)	
	Retinoblastoma	234 (88-388)	
	Other solid tumors*	96.5 (34-189)	
Belief about cancer curability	Yes	83.5 (44-177.5)	
	No	107 (60-262)	0.569
	Not sure	94.5 (54-189)	
Time from first visit to next healthcare contact	Same day	35.5 (16-52)	
	< 1 week	66 (35-88)	**0.0001***
	1–4 weeks	79 (56.5-120)	
	> 1 month	195 (120-367)	
Number of facilities visited before diagnosis	1–2 visits	71 (45.5-134.5)	
	3–5 visits	80 (45-133)	**0.002***
	6–9 visits	111 (69-219)	
	≥10 visits	240 (117-404)	
Estimated cost prior to diagnosis	≤50k	60 (33.5-87.5)	
	50k–150k	108 (60-189)	**0.002***
	150k–300k	115.5 (71-225)	
	>300k	95 (52-257)	

**Note:*

Hinduism, n = 7

Other solid tumors include Germ cell tumor, GI carcinomas, Neuroblastomas, Round cell tumors and other tumors.

Data are analyzed using non-parametric test (Mann-Whitney U test for two-category variables; Kruskal-Wallis test for variables with three or more categories. Here, statistical significance is indicated by $p < 0.05$.

Chapter 5: Discussion

5.1 Summary of key findings

Table 6: Summary of key findings on diagnostic delay in childhood cancer patients attending NICRH, Dhaka

Domain	Key Findings	Statistical/Descriptive summary
Care-seeking pathway intervals	Patient interval was short, but diagnostic interval made the largest contribution to delay	Patient interval: median 2 days (IQR: 1-7) Diagnostic interval: median 82.5 days (IQR: 44.2 – 149.7) Total interval: median 91 days (IQR: 52.5 – 188.5)
Socio-demographic factors	Longer interval related to lower family income	p = 0.030
	Higher income families had shorter intervals	≤ 15,000 BDT: median 105 days vs > 30,000 BDT: median 23 days
	Religion showed statistical association (exploratory finding)	p = 0.006
Clinical factors	Cancer type significantly influenced total interval	p = 0.0003
	Retinoblastoma, CNS and bone tumors had longest interval	Retinoblastoma: median 234 days CNS: median 145 days Bone tumor: median 121 days
	Leukemia and renal tumors had shorter delays	Renal: 35 days, Leukemia: 65 days

Domain	Key Findings	Statistical/Descriptive summary
Health-system factors	The first point of care had a strong influence on delay	Traditional/spiritual healers: 89% delayed
	Multiple healthcare visits increased delay	>10 visits: median 240 days vs 1-2 visits: median 71 days
	Delayed referral increased total interval	Time to next healthcare visit: same day – 35.5 days >1 month – 195 days
	Higher pre-diagnostic expenditure associate with longer interval	p = 0.002

5.2 Discussion of Findings

In this study, diagnostic delay for childhood cancer patients attending NICRH was studied and factors relating to diagnostic delay explored. Findings indicated that the diagnostic interval was the largest among the total interval. Socio-demographic factors, particularly family income; clinical characteristics such as cancer type, healthcare transitions, number facilities visited prior to diagnosis, pre-diagnostic expenditure were associated with longer interval. These findings are discussed in relation to existing literature and context of Bangladesh in the following sections.

The intervals along the care-seeking pathway:

The results provide insight into the days journey of childhood cancer patients. The median patient interval is remarkably short, 2 days (IQR: 1-7 days), with the most frequent time to seek care only 1 day (mode: 1).

This patient interval reflects that the parents of the children seek medical care immediately when the child shows signs of illness. This rapid parental response matches with regional South Asian context-based findings from the Children's Hospital, Lahore, Pakistan where Ul Ain et al., 2025b it was similarly reported that patient delay was negligible as parents seek care immediately (Ul Ain et al., 2025b). It also comes in line with a study performed in Israel in which the delay was brief since acute presentations in children evoke immediate family concern (Haimi et al., 2004).

However, this stands in sharp contrast to a study from Bangladesh by Begum et al., 2016 and African regional studies in Ethiopia by Berhane et al., 2019b where parental socio-demographic barriers, lower education and initial symptom negligence caused prolonged patient interval several weeks (Begum et al., 2016; Berhane et al., 2019b). This change observed in this study may be indicative of caregiver's changed mindset of prompt response when children are sick.

Though the median patient interval is shorter, the median diagnostic interval expands heavily to 82.5 days (IQR: 44.2 – 149.7 days), making up the majority of the median total interval of 91 days (IQR: 52.5 – 188.5 days). This means that out of those three months, a child waits for a diagnosis. Most of that time is spent navigating the healthcare infrastructure after the first healthcare visit. This aligns with the regional findings of Ul Ain et al., 2025b who found that the majority of total lag-times in low-and-middle income countries (LMICs) are attributed to healthcare systems and/or physician delays (Ul Ain et al., 2025b). Also, in a paper from India it was stated that patient face issue due to long waiting time or administrative works of hospitals (Faruqui et al., 2020).

Beyond the statistical distribution of intervals, the clinical consequences of these prolonged intervals were felt during data collection phase of this study. Notably, five pediatric cancer patients whose caregivers gave interview, died in the wards before the two-month data collection period concluded. This tragic inpatient mortality underscores aggressive nature of childhood malignancies and points out towards these delays that allow quick disease progression and early mortality shortly after treatment initiation.

Socio-demographic factors:

The bivariate analysis the association between monthly household income and the total interval (p=0.030). Families in the highest income group of more than 30,000 BDT per month have relatively short median total interval of 23 days. In comparison low-income families (≤15,000 BDT) suffer a median interval of 105 days.

This five-fold difference in diagnostic timeline highlights the financial inequalities in Bangladesh's health system. One possible reason may be that wealthier families can afford private facilities, advance imaging and histopathology test; whereas low-income families have to go through the resource-limited public sector and even they have to delay their diagnostic journey to arrange money for tests and other costs. Low household income was also a main independent predictor of longer time to diagnosis in similar studies conducted in Bangladesh and Ethiopia (Begum et al., 2016; Berhane et al., 2019b).

An unexpected finding in the socio-demographic analysis was the relationship between the caregiver's religion and the total interval (p=0.006). Muslim caregivers had a longer median total interval (96 days) than Hindu caregivers (48 days). But as the sample size was uneven (Hinduism, n = 7), this finding can be treated as an exploratory correlation. Other socio- demographic factors such as child's age, residence, caregiver education, family size showed no statistical association with total interval.

Clinical factors:

The clinical features of a malignancy have association with its time to diagnosis (p = 0.0003). For retinoblastoma, the longest delay is the median total interval of 234 days. As early-stage intraocular tumors are painless in nature, it's often misdiagnosed. Early symptoms like leukocoria (white pupillary reflex) are easily missed by parents. Also, early, quite symptoms do not mimic an acute emergency. This has been reinforced by a study in Kenya that identified retinoblastoma sufferers who had longer interval (Njuguna et al., 2016).

Similarly, hidden solid tumors like CNS tumors (median total interval of 145 days) and bone tumors (121 days) also experience severe delay. These tumors have non-specific symptoms such as vomiting, headache, musculoskeletal pain and are misdiagnosed as common childhood illness resulting in a delay in diagnosis. Renal tumors (median 35 days) and leukemia (65 days) have the shortest total interval on the other side. Fast growing abdominal mass is the classic presentation of renal tumor and leads to shorter time to diagnosis, when it is noticed by parents during bathing or dressing of their children. This was consistent with one study, which showed that the diagnostic delay is longer for brain and bone tumours than for renal tumours (Haimi et al., 2004).

Moreover, diagnosis of a haematological malignancy requires a complete blood count test, which is readily available, easy to perform and inexpensive; thereby, primary healthcare centres may detect abnormalities initially and refer them to the higher centre. If we speak about solid tumor it needs advanced radiological tests. This trend was also consistent with the data from Pakistan and Uganda where the median interval for leukemias and lymphomas were seen to be shorter than the solid neoplasms (Ul Ain et al., 2025; Nakabiri et al., 2025).

Health system factors and healthcare-seeking pathways:

In this study, there were multiple health-system and healthcare-seeking factors that correlated with prolonged interval. One of the factors that was significantly associated ($p=0.002$) was pre-diagnostic expenditure. The median interval was the shortest (60 days) for patients with lowest expenses (< 50k BDT). This group might have two scenarios: either the condition was acute and easily recognizable which caused faster diagnosis, or they were poor and couldn't afford treatment cost, that's why spending was low. In contrast, those earning between 150k and 300k BDT had a longer median total interval (115.5 days). These additional expenses are due to the costs of retesting and switching between clinics during an expensive and repetitive diagnostic process. In Tanzania and India studies, it was discovered that families can end up in poverty by the hidden costs of food, travel and repeated diagnostic testing, before they even receive a final cancer diagnosis (Faruqui et al., 2020;Maillie et al., 2020).

Caregiver's first point of care and subsequent transitions within the healthcare network have given interesting operational insights as well. The level of delay in diagnosis is strongly influenced by the first point of care. Those who sought first opinion from the traditional or spiritual healers have 89% diagnostic delay rate. Likewise, there are high delay rates among people who first visited a homeopath (75% delayed) or a local village doctor (67% delayed).

This is an informal maze that is very common. Buying medicines from pharmacy or using traditional remedies were highly frequent initial action after noticing first symptom. The frontliner in rural areas is village doctors, traditional healer, drug seller, but they lack in specialized training. As a result, they treat early signs of cancer as common illness with repetitive ineffective courses of antibiotics, over the counter drugs or traditional herbs. Study from Tanzania also found informal practitioners as major bottlenecks that trap families in a loop of misdiagnosis, mistreatment which allows the tumor to grow (Maillie et al., 2020).

In formal health care, the results are mixed. The delay rate of caregivers who visited Sadar hospital initially with children was 75% and for Upazila Health Complex the delay rate was 57%. These high percentage show that even in government formal facilities often lack referral guidelines or the diagnostic tools to identify malignancy (Faruqui et al., 2020) .

The severe fragmentation of this pathway is clearly visible by two trends in care transitions –

First, there is a strong relationship between time from first visit to next healthcare contact and total interval ($p = 0.0001$). When a patient visits next healthcare centre on the same day of first visit or is referred on the very first day, median total interval is 35.5 days, resulting in 0% diagnostic delay rate. However, when this care transition to next contact is delayed by over a month, the median total interval reaches to 195 days, which cause 86% delay rate. This indicates that the efficiency of the initial health care contact could impact the course of the whole illness.

Secondly, the number of health care facilities visited before diagnosis was significantly associated with total interval ($p = 0.002$). Families who visited 1-2 facilities faced median total interval of 71 days, but who visited more than 10 facilities, faced 240 days of total interval.

This change is an indicator of a fragmented health system. Every unnecessary care transition adds more sufferings to the families of the childhood cancer patients. The diagnostic loop is the same as found in a study of India, where the lack of a single, fast-tracked referral path from primary to tertiary oncology care centres leaves vulnerable families caught in a ‘Healthcare labyrinth' of repeated referrals (Faruqui et al., 2020).

To summarize, the results of this study have shown the presence of a gap in the journey of diagnosis for childhood cancer patients in Bangladesh. Healthcare is sought almost immediately by caregivers but they are then drawn into the fragmented health care system. This puts families with minimal resources in a multi-layered referral loop that ultimately leads to extended critical periods of delay. Based on the evidence from the literature in the region, mortality from childhood cancers can be reduced through improving referral (Ul Ain et al., 2025b).

5.3 Strengths of the study

The study explores the diagnostic pathway by assessing patient interval, diagnostic interval, and total interval. As the study was conducted at National Institute of Cancer Research and Hospital, the largest tertiary cancer referral centre in Bangladesh, it allowed inclusion of patients from diverse backgrounds and regions. Triangulation was accomplished using caregiver interviews and medical record review to enhance data accuracy. In addition, non-parametric statistical methods were used considering the skewed distribution of interval data during analysis. As there is limited evidence on diagnostic delay and healthcare-seeking pathways, this study may contribute context-specific findings that may help inform future research and planning.

5.4 Limitations of the study

There are several imitations of the study. Data collection time was only for 2 months and sample size was simple small. There was decreased patient flow as well during Ramadan and Eid. Through a cross-sectional study, it’s hard to draw causal inference. As it was a single centre

hospital-based study, findings may not be fully generalizable to all childhood cancer patients in Bangladesh. Some information depended on caregiver recall, particularly dates related to symptom onset, care-seeking – may be subjected to recall bias, though it was cross-checked with medical records. Also, not all pathway events were necessarily recorded and, in particular, visits to informal providers were not always verifiable. The median based cut-off used to define diagnostic delay may limit comparison with studies using different thresholds. Finally, as multivariate analysis was not performed, it limits adjustment for potential confounding factors and identify independent factors of diagnostic delay.

5.5 Implications for Public Health Policy and Practice

The findings of this study highlight important delays within childhood cancer-care seeking pathway in Bangladesh, particularly after the first healthcare contact. This is indicative of a need to reinforce early recognition and referral at primary and secondary health care. There is a need of structured referral policy Furthermore, delays among those caregivers who first came to informal providers show the need to involve on referral networks and train frontline health workers, such as traditional healers, drugs sellers, and village doctors, on the early recognition of danger signs of childhood cancer patients. Caregiver early healthcare seeking behavior may also be improved through public awareness programs on the early signs and symptoms of childhood cancers. The association of prolonged interval with multiple healthcare visits and higher diagnostic costs emphasizes the need for patient navigation support, and financial protection mechanism for affected families as subsidized diagnostic services and cancer care package which aligns with Bangladesh's national commitment to Universal Health Coverage and Sustainable Development Goals (SDG 3.8).

Overall, the study provides evidence that may contribute to national cancer control efforts by informing strategies aimed at improving timely diagnosis, reducing healthcare system delays and strengthening childhood cancer care services and policies in Bangladesh.

Chapter 6: Conclusion and Recommendations

6.1 Conclusion

This study provides a scenario on diagnostic journey of childhood cancer patients. The findings map out all of these steps, identifying areas where the healthcare system may be falling short.

First, the results revealed great vigilance of the caregivers, who promptly find medical help when they notice something is wrong with their child. But the delay started once they got into the health system. This delay reflects problems of the diagnostic and referral process that require greater attention.

Secondly, a child's total interval was linked to family wealth and the characteristics of cancer itself. Longer intervals were observed in families of lower income. And the cancers that mimic common illnesses or develop painless lump like retinoblastoma, bone and brain tumor consistently took the longest to diagnose. These findings suggest that both patient's wealth status and disease presentation may influence the time to diagnosis.

In addition, pathways to accessing health care seemed to be important in the diagnostic process. Families with higher interval were more likely to have first consulted a traditional healer, and then used a variety of healthcare facilities. The results indicated that there could be a link between delays and the referral process and multiple care transitions before arriving at specialized cancer centres. Solving these problems could help reduce the delay in diagnosis and access to the right cancer treatment for children.

6.2 Recommendations

Recommendations for public health policymakers:

To address these challenges discussed so far, targeted interventions can be planned focusing on 1) developing a standardized national referral pathway for suspected childhood cancer patients which will allow children presented with warning signs such as persistent fever, unexplained swelling, prolonged bone pain or abnormal eye symptoms .to refer to higher centres or specialized oncology centres for urgent evaluation, 2) strengthening pediatric oncology diagnostic services outside Dhaka, particularly in divisional medical college hospitals, to reduce geographical barriers and overcrowding in tertiary hospitals; and 3) developing financial support mechanisms for low-income families to reduce the economic burden associated with repeated healthcare visits, investigations and travel during the diagnostic processes. Such initiatives would support Bangladesh's broader goal of achieving Universal Health Coverage (UHC).

Recommendations for program implementers and healthcare managers:

Community-based clinics and primary healthcare providers can be better engaged in the detection and referral of potential cancer cases. Timely transitions to the formal health care system can be facilitated by simple screening tools and referral guidelines. Front-line health-care providers may be targeted for training programs to improve their ability to recognize signs and symptoms and to promptly refer patients to higher health-care facilities. Hospital authority could consider providing separate triage and fast-track diagnostic facilities for paediatric oncology at the tertiary level to reduce waiting time for investigations, pathology reports, specialist consultations, etc.

Recommendations for future research:

Future research should incorporate more healthcare institutions from various parts of the country to enhance the generalizability and reflect the region-specific differences in diagnostic

pathways. Future studies involving prospective follow-up of patients would minimize recall bias and more accurately measure total intervals. Qualitative or mixed methods research with caregivers and health care providers could provide insight into barriers, referral patterns, and decision-making processes to better understand delayed diagnosis. Future researchers may also consider examining children who never reach tertiary care facilities or discontinue treatment early, as these groups may experience even greater delays and barriers within healthcare system.

Declaration of GenAI Use

I, Siddhartha Sankar Das, declare that in preparing this assignment, I used Notebook LM, ChatGPT, Gemini, Quillbot as support tools to assist with brainstorming ideas, to organise the structure of my writing, overcome writer's block, and improve clarity and language in the text that I drafted myself. GenAI was not used to generate original arguments, interpret results, or produce final academic content. All substantive ideas, judgments, references, and conclusions are my own and have been independently verified in line with JPGSPH academic integrity guidelines.

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Appendices:

Appendix A: Data Collection Tool

Diagnostic Delay and Initial Healthcare-Seeking Pathways in Childhood Cancer: A Cross-Sectional Study at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh

Section A: Socio-demographic Information

SL No.	Question	Code	Options	Instruction
A_1	Date of the interview			
A_2	Time of the Interview			
A_3	Data collector's name			
A_4	Name of the patient			
A_5	Age of the patient			
A_6	Sex of the patient	1	☐ Male	
		2	☐ Female	
		96	☐ Others	
A_7	Name of the respondents (parent/primary caregiver)			

A_8	Sex of respondents	1	☐ Male	
		2	☐ Female	
		96	☐ Others	
A_9	Age of respondents (in years)			
A_10	Relationship to the patient	1	☐ Father	
		2	☐ Mother	
		3	☐ Grandparents	
		96	☐ Others	
A_11	Place of residence			
A_12	Religion	1	☐ Islam	
		2	☐ Hinduism	
		3	☐ Buddhism	
		4	☐ Christianity	
		96	☐ Others (specify)	
A_13	Phone No. of the respondent			
A_14	Highest educational qualification of the respondent	1	☐ No formal education	
		2	☐ Below primary education	
		3	☐ Completed primary education (class 5)/ Ebtedayee	
		4	☐ Completed secondary education (SSC /Dakhil)	

		5	☐ Completed higher secondary education (HSC/ Alim)	
		6	☐ Completed Bachelor/Diploma/Fazil	
		7	☐Completed Masters or higher/Kamil	
		96	☐ Others (Specify)	
A_15	Occupation of the respondent	1	☐ Service holder	
		2	☐ Housewife	
		3	☐ Farming and agriculture	
		4	☐ Labor and construction	
		5	☐ Business and trade	
		6	☐ Fisheries	
		7	☐ Informal sector (Rickshaw puller, street vendor)	
		8	☐ Retired	
		9	☐ Unemployed	
		96	☐ Others (Specify)	

A_16	What is the total number of people in your household?			
A_17	Highest educational qualification of the father	1	☐ No formal education	
		2	☐ Below primary education	
		3	☐ Completed primary education (class 5)/ Ebtedayee	
		4	☐ Completed secondary education (SSC) /Dakhil	
		5	☐ Completed higher secondary education (HSC)/ Alim	
		6	☐ Completed Bachelor/Diploma/Fazil	
		7	☐ Completed Masters or higher/Kamil	
		96	☐ Others (Specify)	
A_18	Occupation of the father	1	☐ Service holder	
		2	☐ Housewife	
		3	☐ Farming and agriculture	

		4	☐ Labor and construction	
		5	☐ Business and trade	
		6	☐ Fisheries	
		7	☐ Informal sector (Rickshaw puller, street vendor)	
		8	☐ Retired	
		9	☐ Unemployed	
		96	☐ Others (Specify)	
A_19	Highest educational qualification of the mother	1	☐ No formal education	
		2	☐ Below primary education	
		3	☐ Completed primary education (class 5)/ Ebtedayee	
		4	☐ Completed secondary education (SSC) /Dakhil	
		5	☐ Completed higher secondary education (HSC)/ Alim	
		6	☐ Completed Bachelor/Diploma/Fazil	

		7	☐ Completed Masters or higher/Kamil	
		96	☐ Others (Specify)	
A_20	Occupation of the mother	1	☐ Service holder	
		2	☐ Housewife	
		3	☐ Farming and agriculture	
		4	☐ Labor and construction	
		5	☐ Business and trade	
		6	☐ Fisheries	
		7	☐ Informal sector (Rickshaw puller, street vendor)	
		8	☐ Retired	
		9	☐ Unemployed	
		96	☐ Others (Specify)	
A_21	Primary decision-maker for healthcare	1	☐ Father	
		2	☐ Mother	
		3	☐ Both	
		96	☐ Others	
A_22	Monthly Family Income (in BDT)			

A_23	Do you have any health insurance?	1	☐ Yes	
		2	☐ No	
A_24	Housing condition	1	☐ Pucca	
		2	☐ Semi-pucca	
		3	☐ Katcha	
A_25	Family history of cancer			

Section B: Current Clinical Information

SL No.	Question	Code	Options	Instruction
B_1	Type of cancer	1	☐ Leukemia (ALL)	Need to cross check medical record
		2	☐ Leukemia (AML)	
		3	☐ Leukemia (CML)	
		4	☐ Lymphoma (Hodgkin)	
		5	☐ Lymphoma (Non-Hodgkin	
		6	☐ CNS Neoplasm	
		7	☐ Neuroblastoma	
		8	☐ Retinoblastoma	
		9	☐ Renal Tumors (Wilm's Tumor)	
		10	☐ Bone Tumor (Osteosarcoma)	

		11	☐ Bone Tumor (Ewing sarcoma)	
		12	☐ Soft Tissue Sarcoma (Rhabdomyosarcoma)	
		13	☐ Soft Tissue Sarcoma (Other STS)	
		96	☐ Others	
B_2	Primary tumor site	1	☐ Blood	Need to cross check medical record, Skip the next question if the answer of B_1 is leukemia
		2	☐ Bone marrow	
		3	☐ Lymph nodes	
		4	☐ Brain/CNS	
		5	☐ Eye	
		6	☐ Kidney	
		7	☐ Bone	
		8	☐ Soft tissues/ muscle	
		96	☐ Others (please specify)	
B_3	Stage at diagnosis	1	☐ Stage I	Need to cross check medical record,
		2	☐ Stage II	
		3	☐ Stage III	
		4	☐ Stage IV	
		96	☐ Others (Please specify)	
		99	☐ Not documented	
B_4		1	☐ Standard risk	
		2	☐ High risk	

	Stage at diagnosis (For leukemia)	96	☐ Others (please specify)	
		99	☐ Not documented	
B_5	Current phase of care	1	☐ Newly diagnosed	Need to cross check medical record
		2	☐ On active treatment	
		3	☐ On maintenance therapy	
		4	☐ Treatment completed	
		5	☐ Palliative care	
B_6	Time since confirmed diagnosis	1	☐ <1 month	
		2	☐ 1-3 months	
		3	☐ 3-6 months	
		4	☐ >6 months	
B_7	Current treatment modality	1	☐ Chemotherapy	Need to cross check medical record
		2	☐ Surgery	
		3	☐ Radiotherapy	
		4	☐ Supportive care only	
B_8	Current referral status	1	☐ Directly receiving care at NICRH	
		2	☐ Referred from another facility and continuing care	
		3	☐ Referred for specialized treatment to other hospital	

Section C: Caregiver Symptom Appraisal and Perceptions

SL No.	Question	Code	Options	Instructions
C_1	When did the caregiver first notice symptoms (first bodily change related to the illness)?		☐ Exact date (DD/MM/YYYY)	
			☐ Month/Year only _____	
			☐ Approximate period (e.g., 3 months ago)	
			☐ Don't know/ can't recall	
C_2	Main symptom noticed first	1	☐ Fever	
		2	☐ Pain	
		3	☐ Swelling	
		4	☐ Bleeding	
		5	☐ Vision Problem	
		6	☐ Weight Loss	
		96	☐ Other	
C_3	How serious did you think the first symptom was when you noticed it?	1	☐ Not serious	
		2	☐ Mild	
		3	☐ Serious	
		4	☐ Very serious	
C_4	What did you initially think was	1	☐ Common illness	
		2	☐ Infection	

	the cause of the symptom?	3	☐ Injury	
		4	☐ Supernatural Cause	
		96	☐ Others	
		99	☐ Didn't know	
C_5	What was the first action you took after noticing the symptom?	1	☐ Waited/observed	
		2	☐ Home remedy	
		3	☐ Bought traditional medicine	
		4	☐ Bought medicine from pharmacy	
		5	☐ Visited healthcare facility	
C_6	Did the symptom change before you sought care?	1	☐ Improved	
		2	☐ Stayed the same	
		3	☐ Worsened	
C_7	Was there any delay seeking care after noticing symptoms?	1	☐ Yes	If the answer is No, move to C_9
		2	☐ No	
C_8	If yes, what was the reason you delayed seeking care after noticing symptoms?	1	☐ Thought it would go away	
		2	☐ Cost concerns	
		3	☐Distance/transport	
		4	☐ Family advice	
		96	☐ Other	

C_9	Had you heard of childhood cancer before this illness?	1	☐ Yes	
		2	☐ No	
C_10	When you first heard, from where you came to know first (source of information)? (Open ended)			
C_11	Was it same or different from the perception you have now? (Open ended)			
C_12	Do you believe cancer can be cured?	1	☐ Yes	
		2	☐ No	

Section D: Initial Healthcare-Seeking Events

SL. No.	Question	Code	Options	Instructions
D_1	When did the caregiver seek help? (first visit where medical advice or treatment was sought)		☐ Exact date (DD/MM/YYYY)	
			☐ Month/Year only	
			☐ Approximate period (e.g., 3 months ago)	
			☐ Don't know/ can't recall	
D_2	How long after the symptom did you			

	perceive reason to discuss symptoms with HCP? (days)			
D_3	When did the caregiver seek help? (first visit where medical advice or treatment was sought)		☐ Exact date (DD/MM/YYYY)	
			☐ Month/Year only	
			☐ Approximate period (e.g., 3 months ago)	
			☐ Don't know/ can't recall	
D_4	How long after the symptom did you visit the the first HCP? (days)			
D_5	First point of care visited	1	☐ Traditional/Spiritual healer	
		2	☐ Drug seller	
		3	☐ Village doctor	
		4	☐Community clinic	
		5	☐ Upazila Health Complex	
		6	☐Sadar Hospital	
		7	☐ Tertiary Level Hospital	
		8	☐ Private clinic/hospital	

		9	☐ NICRH	
		96	☐Others (please specify)	
D_6	Main reason for choosing first point of care	1	☐ Close to home	There can be multiple answers
		2	☐ Low cost	
		3	☐ Trust issue	
		4	☐Advice from others	
		5	☐ Previous experience	
		96	☐ Others (please specify)	
D_7	Who decided place of first point of care?	1	☐ Father	
		2	☐ Mother	
		3	☐ Grandparents	
		96	☐ Others (please specify)	
D_8	What was done at first visit?	1	☐ Physical examination	There can be multiple answers
		2	☐ Medicines prescribed	
		3	☐ Tests advised	
		4	☐Reassurance only	
		5	☐ Referred to another facility	
D_9		1	☐ Yes	

	Was cancer mentioned or suspected during the first visit?	2	☐ No	
		99	☐ Not sure	
D_10	Time from first visit to next healthcare contact	1	☐ Same day	
		2	☐ < 1 week	
		3	☐ 1-4 weeks	
		4	☐ >1 month	
D_11	Was there any disagreement about what to do or where to take?	1	☐ Yes	
		2	☐ No	
D_12	If yes, reasons for disagreements/delays (Open ended)			

Section E: Care Transitions and Diagnostic Milestones

SL. No.	Question	Response
E_1	How many different healthcare providers (formal/informal) did you visit before the cancer diagnosis was confirmed?	

SL. No.	**Care Transition Log**									
E_2	Order of visit	Type of healthcare provider	Type of health facility	Name of the facility	Time taken to travel to this facility/provide?	Mode of Transport	Transport cost (BDT)	Was the patient referred to another facility?	If referred, where was the patient referred?	Time spent at this stage before moving to next facility/provider? (days)
	1									
	2									
	3									
	4									

SL. No.	Questions	Code	Options	Instruction
E_3	When was the diagnosis of cancer confirmed?		☐ Exact date (DD/MM/YYYY)	
			☐ Month/Year only:	
			☐ Approximate period (e.g., 3 months ago)	
			☐ Don't know/ can't recall	
E_4	How long after the symptom was the diagnosis confirmed? (days)			
E_5	How long after the first HCP visit was the diagnosis confirmed? (days)			
E_6	At which facility was the diagnosis confirmed?			
E_7	Total number of facilities visited before diagnosis			From E_1, this information will be obtained
E_8	Who decided to move to higher center?	1	☐ Father	
		2	☐ Mother	
		3	☐ Grandparents	
		96	☐ Others (please specify)	

E_9	Estimated total cost (in BDT)			Summation of E_7 to E_10
E_10	Who paid for the cost?			

Medical Record Extraction Checklist

Study Title: Diagnostic Delay and Initial Healthcare-Seeking Pathways in Childhood Cancer: A Cross-Sectional Study at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh

Unique ID of the respondent:

Date of extraction:

Section A: Record availability

SL No.	Question	Options
1	Is medical record available?	☐ Yes ☐ No
2	Types of documents reviewed (tick all that apply)	☐ Hospital treatment sheet ☐ Doctor's prescription ☐ Discharge certificate ☐ Investigation report ☐ Histopathology report ☐ Referral slip ☐ Others (please specify)
3	Record completeness	☐ Complete (key dates available) ☐ Partially complete ☐ Not available

Section B: Clinical characteristics

SL No.	Question	Options
1	Cancer type (as per latest record)	
2	Primary tumor site	
3	Stage at diagnosis	☐ Stage I ☐ Stage II ☐ Stage III ☐ Stage IV ☐ Not documented ☐ Others (please specify)
4	Stages at diagnosis (For leukemia)	☐ Standard risk ☐ High risk ☐ Others (please specify) ☐ Not documented

Section C: Diagnostic milestones

SL No.	Question	Options
1	Date of first presentation to any healthcare provider (if recorded)	___/____/____ ☐ Not documented
2	Date of definitive diagnosis	___/____/____ ☐ Not documented
3	Referral documented before reaching tertiary center	☐ Yes ☐ No ☐ Not documented

Section D: Verification status

SL No.	Question	Options
1	Caregiver-reported dates cross-checked with record	☐ Matched ☐ Discrepancy noted ☐ Record unavailable
2	Is discrepancy present, which source used as final reference?	☐ Medical record ☐ Caregiver report ☐ Others

Appendix B: Informed Consent Form

Information Sheet

Introduction: Greetings! My name is Siddhartha Sankar Das and I come from BRAC James P Grant School of Public Health. I am conducting a study on 'Diagnostic Delay and Initial Healthcare-Seeking Pathways in Childhood Cancer: A Cross-Sectional Study at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh' for my MPH thesis.

Serial no.: MPH – 2025 - 009

Aim: The study aims to understand how long it takes for childhood cancer patients to receive a confirmed diagnosis from symptom onset and how caregiver's initial healthcare-seeking pathways influence the time to diagnosis. The findings will help improve early detection and referral of childhood cancer.

Justification of participation: Your participation is important because you are the primary caregiver of the child with cancer. Your experience will help identify factors that may delay diagnosis and inform improvements in care for children in Bangladesh.

Procedure: If you agree to participate, I will conduct an interview of about 45-60 minutes in a private and calm setting within the hospital. I will ask about your child's illness and treatment history, socio-demographic information, healthcare visits before confirmed diagnosis, and your experiences of seeking care. I will review your child's medical records to collect information related to diagnosis and treatment timelines. No personal identifying information will be collected from the records.No audio or video recordings will be made. You may skip questions if you feel uncomfortable to answer.

Benefits of participation: There will be no direct clinical or financial benefits. However, your insights will help improve services and support for childhood cancer patients.

Compensation: No financial incentives will be provided.

Risk: You don't have any risk of being physically or mentally harmed if you participate in this study. Recalling events related to diagnosis, may make you a bit uncomfortable. However, if you wish not to answer any such sensitive or personal question, please let me know, and I will respect your decision.

Confidentiality and anonymity: All information you provide will be kept confidential. Your data will be stored securely and only accessible to the research team. Your identity will not be revealed in any reports or publications.

Nature of participation: Participation is completely voluntary. You may choose not to participate or withdraw at any time, without any effect on you or your child's care.

Contact information: If you have any further query about the research project, then please contact Siddhartha Sankar Das, through this phone number: +8801864704154 & Email: siddhartha.sankar.das@g.bracu.ac.bd

For ethical concerns, can contact the Institutional Review Board: + 801993379512. Email: irb-jpgsph@bracu.ac.bd)

Consent Form

Title of the study: Diagnostic Delay and Initial Healthcare-Seeking Pathways in Childhood Cancer: A Cross-Sectional Study at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh

If you agree to participate in this study, please confirm by putting your signature/thumbprint.

Thank you for your cordial cooperation.

Do you give permission to review medical records?	☐ Yes	☐ No
Do you give permission to share your findings?	☐ Yes	☐No
Do you give permission to take photos?	☐ Yes	☐ No
Do you give permission to share the photos?	☐ Yes	☐ No
(If I need to contact the/collect data from the respondent again, need to state here and ask permission…)		
Do you have any question?	☐ Yes	☐ No
State the question (If any)		

Interviewer name: **Respondent's name:**

Interviewer signature: **Respondent's signature/thumbprint:**

Date: **Date:**

তথ্য পত্র

ভুমিকা: শুভেচ্ছা। আমার নাম সিদ্ধার্থ শংকর দাশ এবং আমি ব্র্যাক জেমস পি গ্রান্ট স্কুল অফ পাবলিক হেলথ, ব্র্যাক ইউনিভার্সিটি থেকে এসেছি। আমি জনস্বাস্থ্য বিষয়ে আমার স্নাতক থিসিসের অংশ হিসেবে ঢাকা জাতীয় ক্যান্সার গবেষণা ইনস্টিটিউট ও হাসপাতালে 'শিশুদের ক্যান্সার রোগ নির্ণয়ের বিলম্ব ও প্রাথমিক স্বাস্থ্যসেবা গ্রহণের ধাপসমূহ' শীর্ষক একটি গবেষণা পরিচালনা করছি।

ক্রমিক নং: MPH – 2025 - 009

উদ্দেশ্য: এই গবেষণার উদ্দেশ্য হলো - শিশু ক্যান্সার রোগীদের ক্ষেত্রে উপসর্গ শুরু হওয়ার পর নিশ্চিত রোগ নির্ণয় হতে কত সময় লাগে এবং অভিভাবকের প্রাথমিক স্বাস্থ্যসেবা গ্রহণের পথ কীভাবে রোগ নির্ণয়ের সময়কে প্রভাবিত করে তা বোঝা। এই গবেষণার ফলাফল শিশু ক্যান্সার দ্রুত শনাক্তকরণ ও রেফারাল ব্যবস্থার উন্নয়নে সহায়তা করবে।

অংশগ্রহণের যৌক্তিকতা: আপনার অংশগ্রহণ গুরুত্বপূর্ণ, কারণ আপনি ক্যান্সারে আক্রান্ত শিশুটির অভিভাবক। আপনার অভিজ্ঞতা রোগ নির্ণয়ে বিলম্বের কারণগুলো চিহ্নিত করতে এবং বাংলাদেশে শিশু ক্যান্সার চিকিৎসা ব্যবস্থার উন্নয়নে সহায়ক হবে।

পদ্ধতি: আপনি যদি অংশগ্রহণে সম্মত হন, তাহলে হাসপাতালের ভেতরে একটি শান্ত ও নিরাপদ পরিবেশে প্রায় ৪৫ - ৬০ মিনিটের একটি সাক্ষাৎকার নেওয়া হবে। এতে আপনার শিশুর রোগ এবং চিকিৎসার ইতিহাস, বিভিন্ন স্বাস্থ্যসেবা গ্রহণের অভিজ্ঞতা এবং সামাজিক ও অর্থনৈতিক তথ্য সম্পর্কে প্রশ্ন করা হবে। আমি আপনার সন্তানের রোগ নির্ণয় ও চিকিৎসার সময়কাল সম্পর্কিত তথ্য সংগ্রহের জন্য তার মেডিকেল রেকর্ড পর্যালোচনা করব। রেকর্ড থেকে কোনো ব্যক্তিগত পরিচয়সূচক তথ্য সংগ্রহ করা হবে না। কোনো ধরনের অডিও বা ভিডিও রেকর্ডিং করা হবে না। আপনি যেকোন প্রশ্নের উত্তর চাইলে এড়িয়ে যেতে পারেন।

অংশগ্রহণের সুবিধা: এই গবেষণায় অংশগ্রহণের ফলে আপনার কোনো প্রত্যক্ষ চিকিৎসা বা আর্থিক লাভ হবে না। তবে আপনার মতামত ও অভিজ্ঞতা ভবিষ্যতে শিশু ক্যান্সার রোগীদের সেবা ও সহায়তা উন্নত করতে সহায়ক হবে।

ঝুকি: এই গবেষণায় অংশগ্রহণের ফলে আপনার কোনো শারীরিক বা মানসিক ক্ষতির ঝুঁকি নেই। তবে শিশুর রোগ নির্ণয়ের অভিজ্ঞতা স্মরণ করতে গিয়ে আপনি সামান্য মানসিক অস্বস্তি অনুভব করতে পারেন। যদি কোনো প্রশ্ন আপনার

কাছে সংবেদনশীল বা ব্যক্তিগত মনে হয় এবং আপনি উত্তর দিতে না চান, অনুগ্রহ করে জানাবেন - আপনার সিদ্ধান্ত সম্পূর্ণভাবে সম্মান করা হবে।

গোপনীয়তা: আপনার প্রদত্ত সকল তথ্য সম্পূর্ণ গোপন রাখা হবে। তথ্যগুলো নিরাপদভাবে সংরক্ষণ করা হবে এবং শুধুমাত্র গবেষণা দলের সদস্যদের কাছেই থাকবে। কোনো প্রতিবেদন বা প্রকাশনায় আপনার পরিচয় প্রকাশ করা হবে না।

অংশগ্রহণের ধরণ: এই গবেষণায় অংশগ্রহণ সম্পূর্ণ স্বেচ্ছামূলক। আপনি চাইলে অংশগ্রহণ না করতে পারেন বা যেকোনো সময় সরে দাঁড়াতে পারেন। এতে আপনার বা আপনার সন্তানের চিকিৎসা সেবায় কোনো প্রভাব পড়বে না।

যোগাযোগের তথ্য: আমাদের গবেষণার সাথে সম্পর্কিত যেকোনো প্রশ্নের জন্য, আপনি সিদ্ধার্থ শংকর দাশ, ইমেল আইডি: siddhartha.sankar.das@g.bracu.ac.bd, M: +8801864704154-এর সাথে যোগাযোগ করতে পারেন।ব্র্যাক জেপিজিএসপিএইচ ইনস্টিটিউশনাল রিভিউ বোর্ড (আইআরবি) যোগাযোগের বিস্তারিত: আইআরবি প্রশাসক, ফোন: 01993379512। ইমেল: irb-jpgsph@bracu.ac.bd, নিরীক্ষার উদ্দেশ্যে, প্রয়োজন হলে, IRB গবেষণা রেকর্ড অ্যাক্সেস করতে পারে।

অনুমতি ফর্ম

‘শিশুদের ক্যান্সার রোগ নির্ণয়ের বিলম্ব ও প্রাথমিক স্বাস্থ্যসেবা গ্রহণের ধাপসমূহ: ঢাকা জাতীয় ক্যান্সার গবেষণা ইনস্টিটিউট ও হাসপাতালে পরিচালিত একটি ক্রস-সেকশনাল গবেষণা’

আপনি যদি এই গবেষণায় অংশগ্রহণ করতে সম্মত হন, অনুগ্রহ করে আপনার স্বাক্ষর/আঙুলের ছাপ দিয়ে নিশ্চিত করুন।

আপনার আন্তরিক সহযোগিতার জন্য আপনাকে ধন্যবাদ।

আপনি মেডিকেল রেকর্ড পর্যালোচনার অনুমতি দিচ্ছেন?	☐ হ্যাঁ	☐ না
আপনি আপনার তথ্য প্রকাশের অনুমতি দিচ্ছেন (নাম-পরিচয় গোপন রেখে)?	☐ হ্যাঁ	☐ না
আপনি কি ছবি তোলার অনুমতি দিচ্ছেন?	☐ হ্যাঁ	☐ না
আপনি কি ছবি শেয়ার করার অনুমতি দিচ্ছেন?	☐ হ্যাঁ	☐ না
(যদি পুনরায় তথ্যদাতার সাথে যোগাযোগের প্রয়োজন হয়, তখন এখানে তা উল্লেখ করতে হবে এবং পুনরায় অনুমতি নিতে হবে)		
আপনার কি কোন প্রশ্ন আছে?	☐ হ্যাঁ	☐ না
প্রশ্নটি উল্লেখ করুন-		

সাক্ষাৎকার গ্রহণকারীর নাম:	**উত্তরদাতার নাম:**
সাক্ষাৎকার গ্রহণকারীর স্বাক্ষর:	**উত্তরদাতার স্বাক্ষর/আঙুলের ছাপ:**
তারিখ:	**তারিখ:**

Appendix C: Histogram

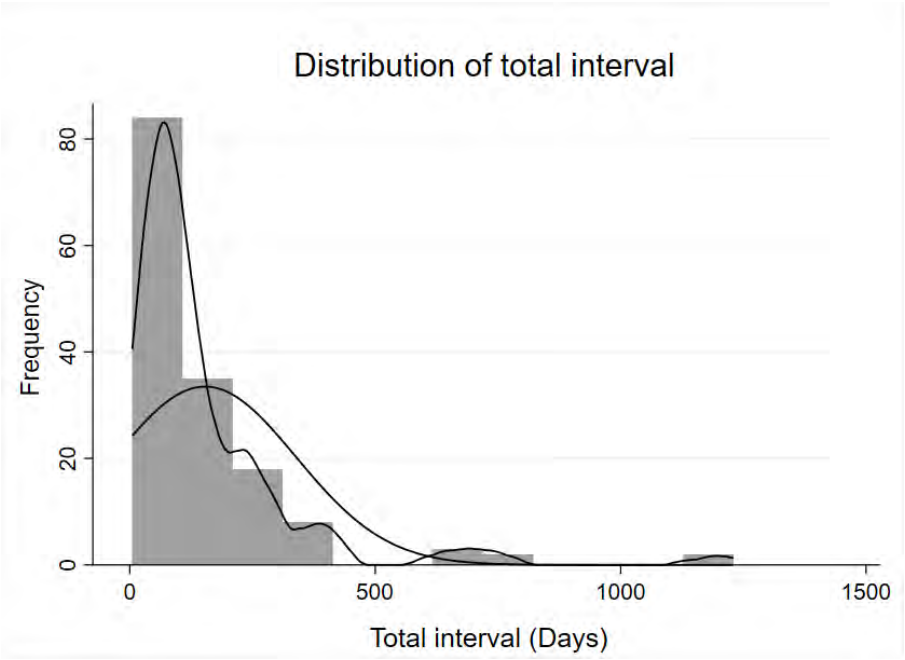

Figure 6: Histogram demonstrating the heavily right-skewed frequency distribution of the total interval (Days) among childhood cancer patients (N = 152)