











Delays in access to paediatric oncology care: Perspectives from eight partner hospitals

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Background. Most newly diagnosed children with cancer live in low-and middle-income countries (LMIC) where challenges in access to diagnosis and treatment cause low survival rates.

Objective. To explore factors affecting delays in accessing paediatric oncology care at seven partner hospitals in LMIC (Malawi, Kenya, Tanzania and Kosovo) and one partner hospital in a high-income country (the Netherlands). Delays at community, primary/secondary and tertiary care levels are explored.

Methods. Leaders of paediatric oncology units from all eight partner hospitals were interviewed using self-administered structured questionnaires in July and August 2023.

Results. Differences in diagnostics and treatment availability were observed between Dutch and LMIC settings. At the community level, all respondents acknowledged that parents' inability to recognise cancer symptoms can lead to delays. Additional factors in LMICs included financial constraints, health beliefs and traditional medicine usage. At the primary/secondary care levels, all respondents acknowledged that misdiagnosis often delays referrals for children with suspected cancer. LMIC respondents also mentioned staff shortages and lack of health insurance. At the tertiary care level, only LMIC respondents reported delays, citing limited diagnostic or treatment modalities and a shortage of experienced staff. Across all settings, diagnosis delays were longer than treatment delays, with patient delays exceeding doctor delays, as noted by seven respondents. These factors contribute to low childhood cancer survival in LMICs.

Conclusion. Delays at all levels hinder prompt access to paediatric oncology care in LMICs. A multi-factorial approach is needed to assure timely access and improve survival.

Keywords. Childhood cancer, access to care, delays, low and middle-income countries, partnership.

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Over 400 000 children are diagnosed with cancer annually. While chances of survival have increased significantly to 80% in high-income countries (HIC), the majority of cases occur in low-and middle-income countries (LMICs), where survival rates remain around 20%.^[1] This disparity stems from challenges in various aspects of access to care for children with cancer in LMICs, such as approachability, acceptability, availability, affordability and the appropriateness of care.^[2] In LMICs, timely access to childhood cancer care is often hindered by significant delays in these five components across three levels: community, primary/secondary care, and tertiary care. These delays can be influenced by patients, healthcare providers and health systems.^[3]

At the community level, families may delay seeking healthcare because of limited medical literacy, inability to recognise cancer

symptoms, alternative health beliefs and a preference for traditional medicine.^[4,5] At the primary/secondary care level, healthcare providers may not recognise early signs and symptoms of cancer in children leading to delays in referrals to specialised centres.^[5] Even when patients are referred, financial hardships (transportation costs or loss of daily wages) may cause further delays.^[6] At the tertiary care level, limited availability of trained staff and high medical bills can delay diagnostics and the start of treatment.

Finally, the health system can also cause delays in accessing healthcare for childhood cancer when universal health coverage is not assured. Klik of tik om tekst in te voeren.^[7] For example, many countries still lack adequate health insurance systems. Klik of tik om tekst in te voeren.^[8] Achieving universal health coverage is recognised as a key factor for enabling access to healthcare for children with cancer in LMICs.

Several studies suggest that paediatric oncology partnerships between HICs and LMICs can help address some of the barriers to childhood cancer care in LMICs. Klik of tik om tekst in te voeren.^[9] The Princess Máxima Center in the Netherlands (HIC) collaborates with seven different hospitals in LMICs through its Outreach Program. These partnerships are defined by long-term collaboration, mutual interest, commitment, equality and local leadership.

There is limited insight into how approachability, acceptability, availability, affordability and appropriateness of care contribute to delays at the various partner sites of the Princess Máxima Center Outreach Program. This study aims to explore delays in access to paediatric oncology care at eight partner hospitals across Malawi, Kenya, Tanzania, Indonesia, Kosovo and the Netherlands.

Methods

Setting

The Princess Máxima Center Outreach Program has established a structure to share expertise with seven hospitals providing paediatric oncology services: Queen Elizabeth Central Hospital (Blantyre, Malawi), Kilimanjaro Christian Medical Center (Moshi, Tanzania), Moi Teaching and Referral Hospital (Eldoret, Kenya), Kenyatta National Hospital (Nairobi, Kenya), Dr. Sardjito General Hospital (Yogyakarta, Indonesia), Dr. Hasan Sadikin Hospital (Bandung, Indonesia) and University Clinical Center of Kosovo (Pristina, Kosovo). These collaborations focus on four pillars: (i) care, (ii) capacity building, (iii) data registries and (iv) research. The Princess Máxima Center is a specialised paediatric oncology centre, while the other seven are general public hospitals with paediatric oncology departments.

The World Bank income classification was used to categorise the countries of participating respondents into low-income, lower-middle-income and upper-middle-income countries (all collectively referred to as LMICs in this manuscript) or HICs.^[10]

Study design

This cross-sectional, exploratory descriptive study examines delays in access to paediatric oncology care across eight partner hospitals in six countries. Paediatric oncology leaders (medical doctors) from each site were interviewed in July and August 2023 using a self-administered structured questionnaire.

The questionnaire was based on a literature review and experience from the research team. This questionnaire focused on challenges in access to care at the community, primary/secondary and tertiary care levels, addressing approachability, acceptability, availability, affordability and appropriateness^[2-4,11,12] Regarding 'approachability' and 'acceptability', we explored factors contributing to late presentation at the community level. For 'availability', we documented the availability of diagnostics, such as ultrasound, CT scan, MRI scan, pathology and laboratory options. Moreover, we examined treatment options, including the presence of chemotherapy, blood products, paediatric surgical team and radiotherapy, following the mapping process outlined by Geel *et al.*^[13] For 'affordability', the presence of an insurance system was documented. 'Appropriateness' was assessed by asking the respondents about the staffing levels employed at their facility.

Four types of delays were explored: patient and parent delay, doctor delay, diagnosis delay and treatment delay. Patient delay refers to the time from the onset of symptoms to the first visit to a conventional healthcare centre. Doctor delay is defined as the time from the first presentation at a conventional healthcare centre to the diagnosis. Diagnosis delay is the interval between the onset of symptoms and the diagnosis. Treatment delay is the period between

diagnosis and the initiation of treatment.^[11] In the questionnaire, these delays were not specified in units such as days or months.

The questionnaire included 115 closed-ended questions that were evaluated on 2 - 4-point rating scales. The questionnaire was pilot-tested on a separate group of respondents for its content and clarity of language. Minor adjustments were made based on the pilot study. Informed consent was obtained from respondents who approved the final report.

Data analysis

All data were collected using the application of Castor version 0.1.45. After finalising data collection and assuring its completeness, data were transferred to SPSS version 26.0 (IBM, USA) for management and analysis. Frequency distributions and proportions were calculated for baseline data.

Results

The questionnaires were distributed to the paediatric oncology leaders at all eight partner hospitals between July and August 2023. All partners participated, achieving a response rate of 100%, and returned the completed questionnaires.

Country and facility characteristics per partner hospital

Table 1 presents the country and facility characteristics for each partner hospital. The partner sites include countries from various income classifications as defined by the World Bank: LMICs ($n=5$) and HIC ($n=1$).^[9] The LMICs can be subclassified into low-income countries ($n=1$), lower-middle-income countries ($n=2$), and upper-middle-income countries ($n=2$).^[10] Most LMIC hospitals ($n=7$) and the HIC hospital ($n=1$) had access to all basic diagnostic equipment. One hospital (LMIC) did not have magnetic resonance imaging (MRI) and two hospitals (LMIC) did not have flow cytometry. Regarding therapeutic modalities, radiotherapy was not directly available at four hospitals (LMIC and HIC), though only one of these hospitals lacked access to radiotherapy at nearby facilities. Additionally, a paediatric neurosurgeon was unavailable at two LMIC hospitals, and universal health coverage (UHC) was not available at three LMIC hospitals.

Delays at community level

Table 2 details the reasons for delays in seeking medical care at the community level as reported by respondents. In all settings ($N=8$), a common delay factor was patients not recognising symptoms of childhood cancer. For the HIC respondent, this was the sole reason for the delay at the community level. Financial reasons for the delay, including medical costs, travel costs and poverty, were reported by partner sites in Africa and Asia ($n=6$). Logistical reasons, such as long distances to clinics and lack of caregivers for land or siblings, are reported in African and Asian partner sites ($n=6$). The European LMIC respondent attributes community delays to patients seeking care in private hospitals or overseas but identifies no other causes. Only African respondents ($n=3$) mentioned alternative health beliefs and perceptions, such as cancer being a curse or childhood cancer being incurable. All African and Asian respondents ($n=6$) recognised the use of traditional medicine as a factor delaying access to conventional healthcare. Finally, African respondents ($n=3$) cited long waiting lists in public hospitals as a cause for delay.

Delays at primary/secondary care level

Table 3 presents the reasons healthcare providers at the primary/secondary care level delay referring children with suspected cancer to tertiary hospitals, as reported by respondents. The most common reasons were difficulty recognising symptoms ($n=7$) and misdiagnosis

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Table 1. Country and facility characteristics per partner hospital

	Queen Elizabeth Central Hospital	Kilimanjaro Christian Medical Center	Moi Teaching and Referral Hospital	Kenya National Hospital	Dr. Sardjito General Hospital	Dr. Hasan Sadikin Hospital	University Clinical Center of Kosovo	Princess Máxima Center
Country	Malawi	Tanzania	Kenya	Kenya	Indonesia	Indonesia	Kosovo	The Netherlands
Continent	Africa	Africa	Africa	Africa	Asia	Asia	Europe	Europe
Population	19 980 000	63 590 000	53 191 654	53 191 654	277 713 268	277 713 268	1 873 000	17 530 000
Population <18 years	10 360 787	33 684 117	24 428 416	24 428 416	82 961 631	82 961 631	429 330	3 280 802
Percentage <18 population	52	53	45	45	30	30	23	19
World Bank Country Income Classification	LIC*	Lower MIC**	Lower MIC**	Lower MIC**	Upper MIC**	Upper MIC**	Upper MIC**	HIC***
Bed capacity								
Beds in total hospital	1 105	1 000	1 000	2 000	850	928	1 807	87
Beds in the paediatric unit	250	175	200	400	101	80	151	87
Beds for paediatric oncology	30	35	35	100	36	33	19	87
Staff								
Paediatric oncologist	1	2	3	3	6	4	6	60
Paediatric oncology nurses	13	10	16	40	39	3	19	240
Diagnostics								
Laboratory	X	X	X	X	X	X	X	X
Pathology	X	X	X	X	X	X	X	X
Flow cytometry	X	X	X	-	X	X	X	X
Ultrasound	X	X	X	X	X	X	X	X
CT scan	X	X	X	X	X	X	X	X
MRI scan	-	X	X	X	X	X	X	X
Treatment								
Paediatric surgery	X	X	X	X	X	X	X	X
Paediatric neurosurgery	X	-	-	X	X	X	X	X
Chemotherapy	X	X	X	X	X	X	X	X
Radiotherapy	-	-	X	X	X	X	-	-
Health insurance								
Universal Health Coverage	Yes	No	No	No	Yes	Yes	Yes	Yes
Health insurance system	Yes	No	Yes	Yes	Yes	Yes	No	Yes
Coverage childhood cancer	No	Partially	Partially	Partially	Yes	Yes	Partially	Yes

X = indicated as influencing delays.

($n=8$). Misdiagnosis was the only cause mentioned by the HIC respondent for the primary/secondary level. Concerning responses per continent, the European LMIC respondent identified only three causes: recognised symptoms, misdiagnosis and mistreatment. In contrast, African and Asian respondents reported 6 - 20 reasons for delay. All seven LMIC respondents noted a lack of health insurance as a delaying factor, while challenges with the referral system were reported by African and Asian respondents ($n=5$). The belief that cancer is not curable was only mentioned by African respondents ($n=3$), as was the reputation for long delays in public hospitals ($n=3$). Finally, staff shortages and limited supervision of junior staff were identified as causes of delays by African and Asian respondents ($n=5$).

Delays at tertiary care level

Table 4 presents the reasons for delays in diagnostics and treatment initiation for children with cancer at the tertiary care level, as reported by respondents. The HIC respondent indicated no delays at this level. All seven LMIC respondents attributed delays to the availability of diagnostic services and treatment modalities, particularly citing delays in pathology services. African and Asian

respondents ($n=4$) reported delays owing to families awaiting approval of treatment costs. In addition, staff shortages were noted by African and Asian respondents ($n=5$).

Evaluation

according to most LMIC ($n=6$) and HIC ($n=1$) respondents, 'patient delay' is longer than 'doctor delay'. However, one LMIC respondent indicated that 'doctor delay' contributes more to overall lags than 'patient delay'. All respondents ($N=8$) agreed that 'diagnosis delay' was longer than 'treatment delay' in their settings. Most LMIC respondents ($n=4$) noted that 'diagnosis delay' was longest for solid cancers, while some LMIC and HIC respondents ($n=3$) reported it to be longest for brain tumours. One LMIC respondent observed no difference in 'diagnosis delay' and type of cancer. 'Treatment delay' was reported as longest for brain tumours by most LMIC respondents ($n=4$), while some ($n=2$) indicated it was longest for solid cancers. Two paediatric oncology leaders (HIC and LMIC) perceived no difference in 'treatment delay' by cancer type. 'Diagnosis delay' and 'treatment delay' were not impacted by either early-stage cancer or late-stage cancer according to most LMIC respondents ($n=4$).

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Table 2. Reasons for parental delays in seeking medical care at a community level

Reasons for delay	Queen Elizabeth Central Hospital	Kilimanjaro Christian Medical Center	Moi Teaching and Referral Hospital	Kenyatta National Hospital	Dr. Sardjito General Hospital	Dr. Hasan Sadikin Hospital	University Clinical Center of Kosovo	Princess Máxima Center
	Do not recognise symptoms of cancer	X	X	X	X	X	X	X
Use of traditional medicine	X	X	X	X	X	X	-	-
Poverty	X	X	X	X	-	X	-	-
Medical costs	-	X	X	X	-	X	-	-
Travel costs	X	X	X	X	X	-	-	-
Poor transport facilities	X	X	X	X	X	-	-	-
Long distance to clinic	X	X	X	X	X	-	-	-
No health insurance	X	X	X	X	X	X	-	-
Loss of daily wages	X	X	X	X	X	-	-	-
Nobody to look after other children	X	X	X	X	X	-	-	-
Nobody to look after the land	X	X	X	X	-	-	-	-
Low trust in healthcare providers	-	-	X	X	-	-	-	-
Conventional medicine has an uncertainty of cure	-	X	X	X	-	-	-	-
Belief that cancer is not curable	-	X	X	X	-	-	-	-
Belief that cancer is a curse	-	X	X	X	-	-	-	-
Reputation of long delays in public hospitals	-	X	X	X	-	-	-	-
Reputation of corruption in public hospitals	-	-	-	X	-	-	-	-
Hospital procedure to clear bill	-	X	-	-	-	-	-	-
Detention of child in hospital	-	-	-	-	-	-	-	-
Fear of surgery	-	X	X	X	X	-	-	-
Fear of cancer treatment	-	X	X	X	X	-	-	-
Side effects of cancer treatment	-	X	X	X	-	-	-	-
Pressure from the community to use traditional medicine	X	X	X	X	-	X	-	-
Pressure from the community to not use conventional medicine	-	X	X	X	-	-	-	-
Preference to seek care overseas	-	-	-	-	-	-	X	-
Preference to seek care in a private clinic first	-	-	-	-	-	-	X	-

X = indicated as influencing delays.

All seven respondents agreed that delays by patients, parents and healthcare providers have serious consequences for childhood cancer care, while the HIC respondent reported no such consequences. These consequences included poor prognosis ($n=7$), reduced quality of care ($n=7$), diagnosis at advanced stages of disease ($n=6$) and increased treatment costs ($n=5$). Delays also lead to adverse outcomes, such as higher death rates during treatment ($n=6$), more cases of progressive or relapsed disease ($n=5$) and increased treatment abandonment ($n=4$). All seven LMIC respondents stated that these delays ultimately contributed to low childhood cancer survival rates in their centres.

Discussion

This study aimed to explore perspectives on delays in accessing paediatric oncology care at eight partner hospitals in Malawi, Kenya, Tanzania, Indonesia, Kosovo and the Netherlands. Our findings suggest that factors contributing to delays at the community, primary/secondary and tertiary care levels are present across all

settings. However, differences in perspectives emerged between LMIC and HIC respondents. The HIC respondent indicated only misdiagnosis and unrecognised symptoms at the community and primary/secondary care levels as causes of delay. In contrast, Kosovo, the European LMIC respondent, reported delays primarily at the tertiary care level, citing challenges with the availability of diagnostics and treatment. This differs significantly from respondents in Africa and Asia, where delays were reported at all three levels. Additionally, alternative health beliefs and perceptions in these regions negatively impacted the approachability and acceptability of childhood cancer care. Financial constraints challenged both acceptability as well as affordability of care. Staffing issues were also mentioned by the respondents as an obstacle to delivering high-quality care, affecting its availability and appropriateness. Differences in delays were observed not only based on income classification but also across and within continents. Our study findings suggest that improving access to childhood cancer care in LMIC requires addressing challenges at every level, from patient to doctor. There is a need to focus on

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Table 3. Reasons for referral delays by healthcare providers at the primary/secondary care level for children with suspected cancer

Reasons for delay	Moi							
	Queen Elizabeth Central Hospital	Kilimanjaro Christian Medical Center	Teaching and Referral Hospital	Kenyatta National Hospital	Dr. Sardjito General Hospital	Dr. Hasan Sadikin Hospital	University Clinical Center of Kosovo	Princess Máxima Center
Do not recognise symptoms of cancer	X	X	X	X	X	X	X	-
Misdiagnosis	X	X	X	X	X	X	X	X
Start mistreatment based on misdiagnosis	X	X	X	X	-	X	X	-
First start cancer treatment at their facility	-	-	-	X	-	-	-	-
Do not know the appropriate referral system	-	-	X	X	-	-	-	-
The referral system does not allow direct referral to tertiary care	X	X	X	-	-	X	-	-
Lack of clarity on cancer care centres								
Belief that cancer is not curable	-	X	X	X	-	X	-	-
Belief that cancer is a curse	-	X	X	X	-	-	-	-
Advise family to use traditional medicine	-	-	-	-	-	-	-	-
Fear of surgery	X	-	-	-	-	-	-	-
Fear of cancer treatment	-	X	-	X	-	X	-	-
Side effects of cancer treatment	-	X	-	X	-	X	-	-
Family is poor and cannot afford treatment	-	-	-	X	-	X	-	-
Family has no health insurance	-	X	X	X	-	X	-	-
Long distance to tertiary care hospital	X	X	X	X	X	X	-	-
Transport difficulties	X	X	X	X	-	X	-	-
Reputation of long delays in public hospitals	X	-	X	X	-	X	-	-
Reputation of corruption in public hospitals	X	X	-	X	-	-	-	-
Hospital procedure to clear bill	-	-	-	X	-	-	-	-
Detention of child in hospital	-	X	-	-	-	-	-	-
Staff shortages in primary/secondary care	-	-	-	-	-	-	-	-
Shortage of experienced doctors in primary/secondary care	-	X	X	X	-	X	-	-
Limited supervision of junior staff at primary/secondary care	-	X	X	X	X	X	-	-
Ill-trained personnel at primary/secondary care	-	X	X	X	X	X	-	-

X = indicated as influencing delays.

specific causes of delays unique to each country and continent. This study suggested that reasons for delay at community level are mainly related to not recognizing the signs and symptoms of the disease, cultural health beliefs and financial challenges. Costs to travel to a health facility, losing daily wages when going to a hospital and not being able to pay for medical costs were confirmed by studies conducted in Kenya and Indonesia that stress the importance of health insurance coverage in reducing delays.^[8,12] Interestingly, alternative health beliefs about childhood cancer were mainly reported by respondents from Africa, while the usage of alternative medicine was reported by all respondents from Africa and Asia but not by European respondents. Literature suggests that cultural beliefs and traditional medicine usage are more common obstacles to timely

paediatric oncology care in Africa and Asia^[3,14,15] Raising awareness within communities about the importance of conventional medicine for treating childhood cancer could help reduce these delays.

At primary/secondary care level, delays were related to healthcare provider's health beliefs and their inability to recognise the disease. Similar to community level delays, issues with approachability and acceptability were major obstacles to accessing care. Previous studies on timely access to childhood cancer care have emphasised the importance of recognising signs and symptoms by both healthcare providers and parents.^[5] Moreover, African and Asian respondents reported delays owing to staff shortages. Absenteeism and staff shortages in LMICs are well-documented threats to medical services, as healthcare workers often face heavy workloads and lack of opportunities for training to

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Table 4. Reasons for diagnostics and treatment initiation delays by healthcare providers at tertiary care level for children with cancer

Reasons for delay	Queen Elizabeth Central Hospital	Kilimanjaro Christian Medical Center	Moi Teaching and Referral Hospital	Kenyatta National Hospital	Dr. Sardjito General Hospital	Dr. Hasan Sadikin Hospital	University Clinical Center of Kosovo	Princess Máxima Center
Do not recognise symptoms of cancer	-	-	X	-	-	-	-	-
Misdiagnosis	-	-	X	-	X	X	-	-
Start mistreatment based on misdiagnosis	-	-	X	-	X	X	-	-
Advise family to use traditional medicine	-	-	-	-	-	-	-	-
Belief that cancer is not curable	-	X	-	-	-	-	-	-
Side effects of cancer treatment	-	X	-	X	-	X	-	-
Family is poor and cannot afford treatment	-	X	-	-	-	X	-	-
Family has no health insurance	-	X	-	-	X	X	-	-
Delays in approval of treatment costs by family	-	X	X	-	X	X	-	-
Hospital procedure to clear bill	-	-	-	-	-	-	-	-
Detention of child in hospital	-	-	-	-	-	-	-	-
Staff shortages in tertiary care	-	X	X	X	X	X	-	-
Waiting time/lists in tertiary care	-	-	X	X	X	X	-	-
Shortage of experienced doctors in tertiary care	X	X	X	-	-	X	-	-
Limited supervision of junior staff at tertiary care	-	-	X	-	-	X	-	-
Ill-trained personnel at tertiary care	-	-	-	-	-	X	-	-
Delays in routine laboratory tests	-	-	X	-	X	-	X	-
Delays in pathology services	-	X	X	X	X	X	X	-
Delays in imaging	-	-	X	X	X	X	-	-
Delays in medical procedures (for example BMA/biopsy)	-	-	X	X	X	X	-	-
Underuse of medical equipment	-	-	-	-	-	-	X	-
Shortage of medical drugs and supplies	X	X	-	X	X	X	X	-
Disabling and breakdown of medical equipment	-	X	-	X	X	X	X	-
Delays in the repair of medical equipment	-	X	-	X	X	X	-	-
Delays in chemotherapy administration	-	-	-	X	X	X	X	-
Postponed radiotherapy	-	-	-	X	X	X	X	-
Postponed surgery	-	-	X	X	X	X	-	-
Delays in blood products administration	X	X	X	X	X	X	-	-

X = indicated as influencing delays.

enhance their knowledge.^[16] Respondents also shared that the absence of health insurance was a major factor in referral delays to tertiary care. These findings highlight the need for training on the signs and symptoms of childhood cancer, strengthening referral systems and expanding health insurance coverage for childhood cancer.

At the tertiary care level, LMIC respondents exclusively reported challenges related to the availability of diagnostics and treatment modalities. These findings align with those from a mapping study conducted in Sub-Saharan Africa, where only 9 out of 48 responding

countries had access to all three treatment modalities.^[13] These problems can negatively impact treatment outcomes for children with cancer. Global efforts are therefore needed to improve access to cancer diagnostics and treatment options in LMICs.^[5,13]

Most respondents stated that delays caused by patients and parents are greater than those caused by doctors. However, prior studies in Kenya and Indonesia found that patient delays are generally much shorter than health system delays.^[4,12] Conversely, other studies from LMICs have suggested that patient-related factors contribute

to diagnostic delays.^[17] Since the signs and symptoms of childhood cancer are non-specific, parents may delay seeking care and physicians may not refer immediately.^[5] Moreover, the rarity of childhood cancer means that physicians may not be familiar with its signs and symptoms. Socioeconomic factors also play a significant role, as financial constraints can impact the time to diagnosis.^[6] Even in HICs, failure to recognise the signs and symptoms of childhood cancer is a major contributor to diagnostic delays.^[18] Raising awareness among both the general public and healthcare providers could help reduce diagnosis delays globally.^[5,19]

Diagnosis delays were reported to be longer than treatment delays across all settings. This is consistent with findings from another review, which confirmed that the time to start treatment is generally shorter once a diagnosis is made.^[20] However, our study found that delays in the availability of drugs or obtaining parental consent can still hinder the timely start of treatment. The longer diagnosis delays highlight the need for interventions aimed at improving the detection and appropriate referral of childhood cancer cases.

Both solid and brain cancers are reported to have longer diagnosis and treatment delays compared with haematological cancers. The stage of cancer did not impact either diagnosis or treatment delays according to our respondents. The site of cancer has previously been described to potentially affect delays,^[3] with brain tumour cases often experiencing more significant delays than other cancers.^[21] This is partly because signs of brain tumours can be easily confused with other illnesses or attributed to psychiatric conditions, curses or spells.^[22] Traditional medicine is frequently used as a first recourse for these symptoms.^[14] Moreover, the timely availability of diagnostic imaging, such as MRI or CT scans, is essential for early diagnosis but is often lacking in LMIC.

Limitations

The main limitations of this study include the low number and limited representativeness of participants. Respondents were healthcare professionals at the tertiary care level, thus their insights were primarily based on their experiences with delays at the primary/secondary care and community levels. Further research should explore the perspectives and experiences of primary/secondary care providers and community members to gain a deeper understanding of delays at these levels. Additionally, new studies that include a wide range of healthcare providers at the various participating tertiary care centres could provide valuable insights from different perspectives.

It is important to note that not all participating countries have a single centralised specialised childhood cancer hospital. Most of the included countries have multiple centres where children can receive comprehensive paediatric oncology care, meaning that respondents may not fully represent their entire country's experiences.

Conclusions

This study showed that delays at the community, primary/secondary and tertiary care levels each impact different aspects of access to childhood cancer care. These findings suggest that a multifaceted approach is necessary to address these delays. Cultural health beliefs and perceptions should be addressed through education for both communities and healthcare workers. Early recognition of signs and symptoms can enhance the approachability and acceptability of care, ensuring timely and appropriate referral to comprehensive cancer care centres with health insurance coverage. Finally, there is a need for clinical research on delay in LMICs. Adopting this combined approach could ultimately improve childhood cancer survival rates in these regions.

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Data availability statement. The authors will share data upon reasonable request.

Conflicts of interest. None.

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