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RESEARCH

Exploring treatment decision-making at diagnosis for children with advanced cancer in low- and middle-income countries

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Abstract

Purpose Global childhood cancer survival outcomes correlate with regional contextual factors, yet upfront treatment decision-making for children with advanced or poor prognosis cancer in low- and middle-income countries (LMICs) is not well understood. This study aimed to (1) characterize the landscape of contextual factors that shape physician decision-making at diagnosis for these children in LMICs and (2) describe physician rationales for if/when to offer treatment with non-curative intent, including how they define "poor prognosis" during treatment decision-making.

Methods An international panel of pediatric oncologists practicing in LMICs participated in two focus groups structured for the collaborative generation of factors influencing treatment decision-making, including consideration of non-curative treatment pathways at diagnosis. Thematic analysis of qualitative data was conducted, followed by member checking.

Results Eleven pediatric oncologists participated, representing all global regions defined by the World Health Organization. Participants identified a broad range of factors influencing decision-making across multiple levels, including the individual, hospital, health system, community, and country levels. All participants agreed that treatment with non-curative intent could be offered at diagnosis in certain contexts, and diverse definitions for poor prognosis were described.

Conclusions Upfront treatment decision-making for children with advanced or poor prognosis cancer in LMICs is variable and challenging. Difficulties with decision-making in LMICs may be amplified by inconsistent definitions of poor prognosis and underrepresentation of the factors that influence treatment decision-making within existing decision-making frameworks or childhood cancer treatment guidelines. Future research should explore decision-making approaches, preferences, and challenges in depth from the perspectives of pediatric cancer patients, families, and multidisciplinary clinicians.

Keywords Pediatric cancer · Decision-making · Global health · Poor prognosis · Low- and middle-income countries

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Introduction

In high-income countries (HICs), more than 80% of children diagnosed with cancer survive their illness, and cure-directed therapy is routinely offered at the time of diagnosis to most patients and families. However, the global burden of pediatric cancer is not distributed equitably, with an estimated 90% of diagnoses occurring in low- and middle-income countries (LMICs). Many of these children face barriers to receiving high-quality cancer therapy due to inadequate healthcare infrastructure, limited access to quality therapy, and significant financial hardship, each adversely impacting patient survival outcomes [1, 2].

A significant contributor to poorer survival outcomes for children with cancer in LMICs is delayed diagnosis resulting in an advanced stage of disease at diagnosis [1, 3]. As children with advanced disease can require more intensive therapies and/or have a poorer prognosis, defining treatment goals in resource-limited contexts is challenging. However, an understanding of the components of upfront treatment decision-making (or decision-making at diagnosis) that physicians consider for children with advanced or poor prognosis cancer in LMICs remains incomplete [4, 5]. Specifically, there is a lack of empirical data to explain why, when, and how physicians in LMICs approach decision-making at diagnosis for these children, including navigation of the branchpoint for offering treatment with curative versus non-curative intent [4, 5].

To address this gap, we conducted an exploratory study to identify and characterize (a) the factors that influence physician treatment decision-making at diagnosis for children who present with advanced or poor prognosis cancer and (b) the rationale for if and/or when physicians in LMICs might offer non-curative treatment options for children with poor prognosis cancer at the time of diagnosis.

Methods

This study was reviewed by the Institutional Review Board at St. Jude Children's Research Hospital (SJCRH) and deemed exempt. We describe the methods and subsequent study findings in accordance with the Consolidated Criteria for Reporting Qualitative (COREQ) checklist to ensure rigor [6].

Settings and participants

Faculty and staff in the Department of Global Pediatric Medicine at SJCRH assisted with recruitment by identifying potential participants from the St. Jude Global Alliance community, representing each World Health Organization (WHO)-designated region [7]. Participants were eligible if they were pediatric oncologists or pediatricians who routinely made treatment decisions for children diagnosed with pediatric cancer, had more than 5 years of clinical cancer care experience or had completed a certified hematology/oncology fellowship, practiced in a LMIC as defined by the World Bank, and spoke English [8]. A purposeful sample was selected to represent distinct and varied world regions and country income levels [8, 9]. A member of the study team contacted potential participants via e-mail to recruit and enroll physicians [8].

Study and design

The study protocol was developed by a research team comprising experts in pediatric oncology, hospice and palliative medicine, and global health. The team collaboratively developed a focus group guide designed to elicit the experiences, perspectives, and beliefs of physicians in LMICs around treatment decision-making for children presenting with advanced cancer at diagnosis. A previously published conceptual model [10], grounded in HIC data, was referenced a priori to provide initial scaffolding to categorize decision-making criteria by the decision-maker, disease, and context. Focus group prompts and probes were iteratively revised by the research team and then pilot-tested, integrating feedback to improve the face and content validity of the guide.

Two independent focus groups were coordinated with the goal of promoting dialogue and collaborative generativity while also following established standards for achieving thematic saturation through focus group methods [11]. Due to the exploratory nature of this study, the research team anticipated that the findings generated in focus groups would inform the development of formal semi-structured interview guides to explore treatment decision-making practices in greater depth and nuance with clinicians across LMICs [11].

These focus groups were conducted in August 2021 through a virtual online platform, accommodating participant schedules and global time zones. Each focus group was led by trained expert facilitators (M.S., A.P., E.C.K.), lasted 60–90 min, and was audio-recorded. Verbal informed consent was obtained for all participants. Confidentiality was emphasized, no identifying information was collected, and participants were instructed to avoid discussing any patient health information.

Each session began with a brainstorming activity, where participants divided a sheet of paper into sections for decision-maker, disease, and context, and they independently wrote down every factor they could think of that might influence a physician's upfront treatment decision-making within each of the categories. Then, the facilitator led a group discussion to review, affirm, and/or debate the factors generated during initial brainstorming. Participants were asked to share their thoughts about offering therapy with non-curative intent at diagnosis for children presenting with advanced cancer, whether this could or could not be appropriate in a given context, and how they would define “poor prognosis” in the setting of making treatment decisions. Trained facilitators moderated the discussion, eliciting responses from each participant to ensure relatively equivalent contributions in the group discourse. Sociodemographic data were collected from participants, including gender, age, country of practice, years of clinical practice, prior training in pediatric hematology/oncology and/or palliative care, and practice setting.

Data analysis

Demographic characteristics were summarized descriptively. Focus group recordings were transcribed verbatim by trained medical transcriptionists. Two researchers (M.S., A.P.) reviewed transcripts, conducted memo-writing, and conducted a broad thematic analysis to identify high-level themes [12]. Any discrepancies in thematic characterization were reconciled through third-party adjudication (E.C.K) to achieve consensus. The research team identified a broad and comprehensive spectrum of multifaceted and multi-level themes suggesting saturation specific to the targeted inquiry [11].

The research team summarized and organized the factors described by participants using the updated consolidated framework for implementation research (CFIR) [13], anticipating its relevance in the context of future intervention design rooted in this exploratory, pre-implementation qualitative investigation. Formal member checking was conducted, with analyzed data presented back to study participants for review and feedback in a meeting in November 2021 [14]. Participants who were unable to join the scheduled meeting were given an opportunity to provide feedback via e-mail. Participants who engaged in member checking were invited to join the research team to honor their investment in the data synthesis process and elevate the voices of global participants at the authorship level. Analyzed data were reviewed by the interdisciplinary research team as well, and all feedback was appraised and integrated into the final analysis.

Results

A total of 11 physicians participated in two focus groups. Demographic characteristics are listed in Table 1. The group was relatively evenly distributed by gender, and most participants were aged 36 to 50 ($n = 10$, 91%). Participants had at least 11 years of experience; the majority had completed formal fellowship training in pediatric hematology/oncology ($n = 10$, 91%), and more than one-third had completed training in hospice and palliative medicine ($n = 4$, 36%). Most participants worked in publicly funded hospitals ($n = 7$, 64%), and all participants practiced at centers with more than 100 new pediatric cancer cases per year. One participant (9%) practiced in a low-income setting, with the remainder practicing in a low-middle-income country ($n = 7$, 64%) or upper-middle-income country ($n = 3$, 27%). Participants worked in countries representing all WHO-defined regions (Supplemental Fig. 1).

Factors influencing treatment decision-making for advanced cancer

During the focus groups, physicians independently listed and then collaboratively discussed numerous factors impacting decision-making at diagnosis for children with advanced or poor prognosis cancer. Figure 1 stratifies factors by individual (patient, family, physician), hospital, health system, community, and country levels. Participant quotations are presented for factors influencing decision-making at each level, including factors related to prognostication (disease determinant), decision-making challenges (individual–physician determinant), resource limitations (hospital-level determinant), delayed diagnosis (health system determinant), influence of religion (community-level determinant), and geopolitical conflict (country-level determinant) (Figs. 1 and 2, Supplemental Table 1).

Overall, participants described 44 factors influencing treatment decision-making at five health system levels, presented in Fig. 3. Participants described physicians (i.e., themselves) and families as the key decision-makers for children presenting with advanced or poor prognosis cancer in LMIC settings.

Individual-level factors

Individual-level factors were reported from the perspective of the physician participants. Physician-related factors encompassed the physician’s professional background, including prior training in palliative care, clinical experience, and individual beliefs. Participants suggested that junior and senior physicians may approach decision-making differently, with junior physicians more often recommending intensive therapy and senior physicians more likely to consider factors such as cost. Access to malpractice insurance was also noted as a variable that may enhance physician flexibility and proactivity in decision-making.

Patient and family factors influencing decision-making included health literacy, such as the family’s understanding or perceptions of cancer and cancer treatment. Physicians described how families may refuse treatment or express preference for traditional medicine due

Table 1 Demographic characteristics of study participants

Characteristic		*n* (%)
Age	36 to 50	10 (91)
	51 to 64	1 (9)
Gender	Female	6 (55)
	Male	5 (45)
Income level of country where participant practices	LIC	1 (9)
	LMIC	7 (64)
	UMIC	3 (27)
Years of clinical practice since completion of medical school	11–15 years	7 (64)
	16–20 years	1 (9)
	21 + years	3 (27)
Completion of fellowship in pediatric hematology and oncology	Yes	10 (91)
	No	1 (9)
Exposure to pediatric hematology and oncology training in a high-income country	Yes*	5 (45)
	No	6 (55)
Hospital/clinic funding	Public	7 (64)
	Public and private	3 (27)
	Philanthropic	1 (9)
Yearly average of new childhood cancer cases at hospital/clinic	100–299	5 (45)
	> 300	6 (55)
Completion of training in palliative care	Yes**	4 (36)
	No	7 (64)

Legend: all participants provide cancer care for children under the age of 18

LIC low-income country, *LMIC* low-middle-income country, *UMIC* upper-middle-income country

*For participants who had prior exposure to pediatric hematology and/or oncology training in a high-income country, two completed 1–6 months of training and three completed over 7 months of training in a high-income country

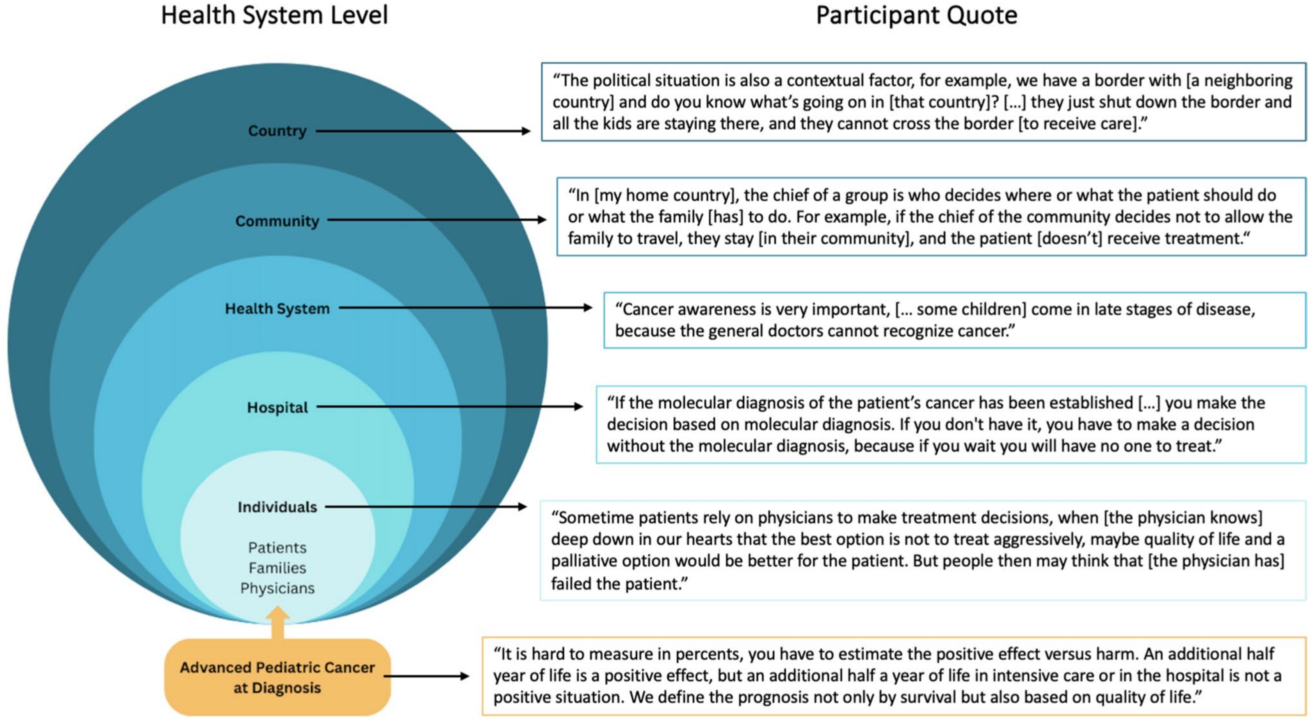
**For participants who completed training in palliative care, 1 completed an undergraduate/medical school course, 2 completed a thematic or postgraduate course without official certification, and 2 completed a certificate course

to lower cost, less toxicity, or cultural norms. Families may request intensive cure-oriented treatment even when discouraged by the physician, in part because the effort and cost of seeking care underpin their expectations for receiving treatment with curative intent. The financial capabilities of the family to support treatment costs were noted as an important factor, regardless of a family's access to health insurance. A family's health insurance could influence treatment decision-making if a specific center was not covered, or an in-network center did not have capacity to provide a given therapy. Additionally, physicians identified religious beliefs as an influence on treatment decision-making (e.g., attitudes and acceptance related to amputation, blood product transfusions, or burial processes).

Participants described examples of shared decision-making strategies when choosing treatment for children with advanced or poor prognosis cancer in partnership with the patient's family. In some settings and cultures, however, they expected the physician to drive decision-making. Participants shared that older children and adolescents sometimes participated in decision-making, although this was influenced by local culture and practice and generally directed by the family.

Disease-related factors

Participants described disease-related factors considered in decision-making including the child's diagnosis, disease stage, prognosis, comorbidities, treatment urgency, and quality of life. Notably, perceptions of prognosis and quality of life also influenced decision-making, with physicians balancing the likelihood of cure and disease-related toxicities without local data to guide decision-making. Comorbidities factored into treatment decision-making, including co-existing congenital syndromes or malnutrition that may increase the risk of the child experiencing treatment-related toxicities or infection. Physicians also described how they may initiate therapy due to poor clinical status or rapidly growing disease without completion of diagnostic work-up.



"The political situation is also a contextual factor, for example, we have a border with [a neighboring country] and do you know what's going on in [that country]? [...] they just shut down the border and all the kids are staying there, and they cannot cross the border [to receive care]."

"In [my home country], the chief of a group is who decides where or what the patient should do or what the family [has] to do. For example, if the chief of the community decides not to allow the family to travel, they stay [in their community], and the patient [doesn't] receive treatment."

"Cancer awareness is very important, [... some children] come in late stages of disease, because the general doctors cannot recognize cancer."

"If the molecular diagnosis of the patient's cancer has been established [...] you make the decision based on molecular diagnosis. If you don't have it, you have to make a decision without the molecular diagnosis, because if you wait you will have no one to treat."

"Sometime patients rely on physicians to make treatment decisions, when [the physician knows] deep down in our hearts that the best option is not to treat aggressively, maybe quality of life and a palliative option would be better for the patient. But people then may think that [the physician has] failed the patient."

"It is hard to measure in percents, you have to estimate the positive effect versus harm. An additional half year of life is a positive effect, but an additional half a year of life in intensive care or in the hospital is not a positive situation. We define the prognosis not only by survival but also based on quality of life."

Fig. 1 Factors influencing participants' treatment decision-making for children presenting with advanced cancer exist at several health system levels. Participants described factors that influence treatment decision-making at diagnosis for advanced childhood cancer in low- and middle-income countries existing at the level of the individual (patient, family, and physician), hospital, health system, community, and country. Participant quotations illustrate the factors influencing treatment decision-making at each health system level

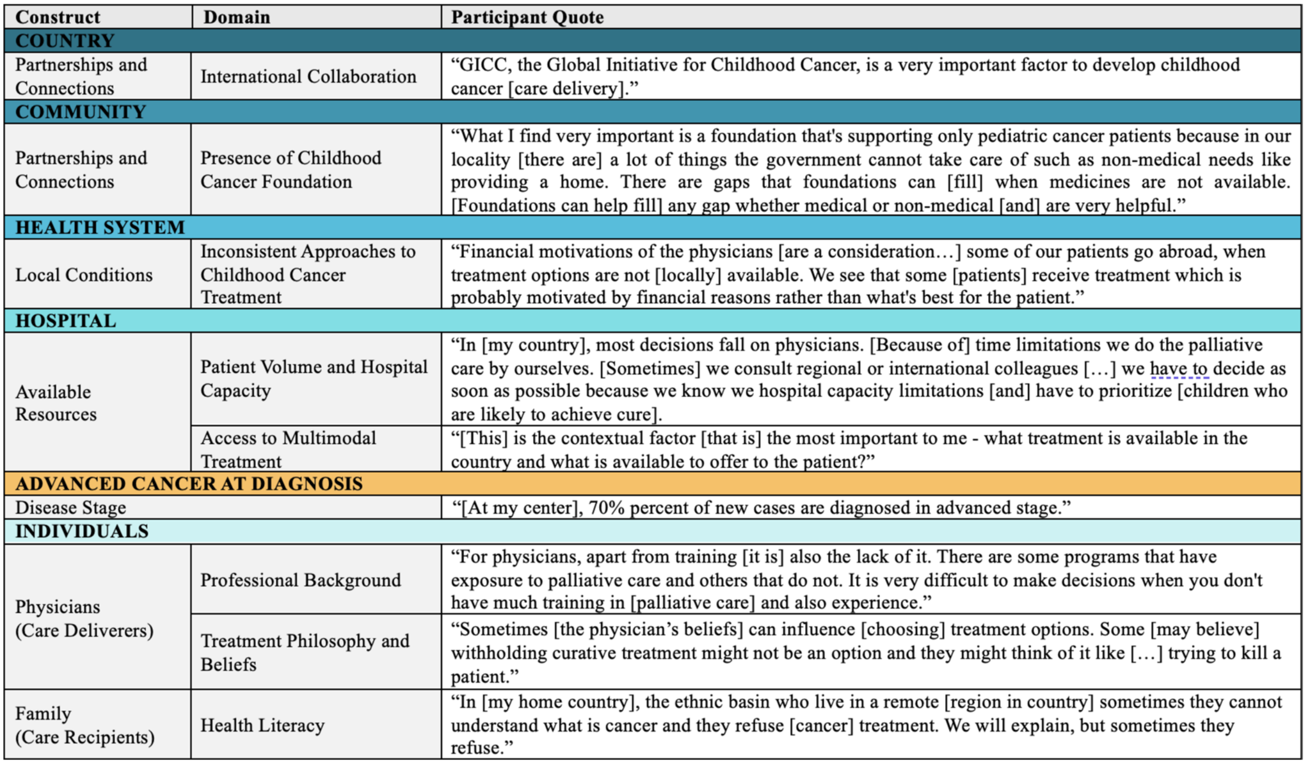
Hospital-level factors

At the hospital level, participants described several factors, including the influence of available resources (i.e., access to diagnostics, multimodal treatment, supportive care, clinical trials, trained personnel, housing, and hospital beds); access to local, regional, and international experts to aid in decision-making; and facilitators and challenges related to communication between the family and healthcare team. For example, physicians described restricting proposed treatments to align with available resources. More specifically, multimodal therapies and supportive care may be constrained by inadequate or inconsistent availability of medications or personnel. At times, physicians questioned medication quality in the context of the patient's lack of expected treatment response. Additional decision-making challenges included a lack of diagnostic modalities that limit accurate diagnoses or delay treatment and, when available, are often cost-prohibitive for families or have suboptimal diagnostic turnaround times.

In the context of limited hospital capacity or staffing, physicians reported feeling an obligation to prioritize the care of patients with more favorable prognoses over those who presented with advanced disease. Participants also highlighted the variability of staff training in pediatric oncology or palliative care as a factor influencing their ability to recommend certain treatment options. Participants described the importance and influence of input from multidisciplinary teams locally, regionally, and internationally, especially for physicians with less clinical experience, those lacking formal subspecialty training, or in the setting of rare or complex cases. Time constraints and lack of available communication tools or educational resources in local languages further influenced treatment decision-making processes between physicians, patients, and families.

Health system level

Lack of cancer awareness in the community and fragmentation of the healthcare system were described as factors contributing to the presentation of advanced disease at diagnosis, complicating treatment decision-making. Physicians also described how organizational variance within the healthcare system (i.e., different centers within a city, country, or region that provide different treatment options at varying costs) may influence decision-making. Further, inequities in access to healthcare were perceived to shape treatment decision-making, as physicians felt unable to offer therapies that a family could not reliably or consistently access.



Construct	Domain	Participant Quote
COUNTRY		
Partnerships and Connections	International Collaboration	"GICC, the Global Initiative for Childhood Cancer, is a very important factor to develop childhood cancer [care delivery]."
COMMUNITY		
Partnerships and Connections	Presence of Childhood Cancer Foundation	"What I find very important is a foundation that's supporting only pediatric cancer patients because in our locality [there are] a lot of things the government cannot take care of such as non-medical needs like providing a home. There are gaps that foundations can [fill] when medicines are not available. [Foundations can help fill] any gap whether medical or non-medical [and] are very helpful."
HEALTH SYSTEM		
Local Conditions	Inconsistent Approaches to Childhood Cancer Treatment	"Financial motivations of the physicians [are a consideration…] some of our patients go abroad, when treatment options are not [locally] available. We see that some [patients] receive treatment which is probably motivated by financial reasons rather than what's best for the patient."
HOSPITAL		
Available Resources	Patient Volume and Hospital Capacity	"In [my country], most decisions fall on physicians. [Because of] time limitations we do the palliative care by ourselves. [Sometimes] we consult regional or international colleagues […] we have to decide as soon as possible because we know we hospital capacity limitations [and] have to prioritize [children who are likely to achieve cure].
	Access to Multimodal Treatment	"[This] is the contextual factor [that is] the most important to me - what treatment is available in the country and what is available to offer to the patient?"
ADVANCED CANCER AT DIAGNOSIS		
Disease Stage		"[At my center], 70% percent of new cases are diagnosed in advanced stage."
INDIVIDUALS		
Physicians (Care Deliverers)	Professional Background	"For physicians, apart from training [it is] also the lack of it. There are some programs that have exposure to palliative care and others that do not. It is very difficult to make decisions when you don't have much training in [palliative care] and also experience."
	Treatment Philosophy and Beliefs	"Sometimes [the physician's beliefs] can influence [choosing] treatment options. Some [may believe] withholding curative treatment might not be an option and they might think of it like […] trying to kill a patient."
Family (Care Recipients)	Health Literacy	"In [my home country], the ethnic basin who live in a remote [region in country] sometimes they cannot understand what is cancer and they refuse [cancer] treatment. We will explain, but sometimes they refuse."

Fig. 2 Factors described by participants organized by health system level, construct, and domain related to treatment decision-making at diagnosis for advanced childhood cancer in low- and middle-income countries. Factors described by participants organized by updated consolidated framework for implementation science (CFIR). Further factors are summarized in Supplemental Table 1

Community level

Participants shared that in some circumstances, spiritual leaders or community leaders held decision-making authority for children diagnosed with cancer living within their communities. Physicians also described the influence of non-family community members who may participate in decision-making. Local culture and religion were identified as variables that influenced decision-making in nuanced, varied, and profound ways. Lack of community education was reported as a driver for some families' belief that cancer is incurable. Finally, physicians underscored the importance of local foundations to help subsidize treatment costs.

Country level

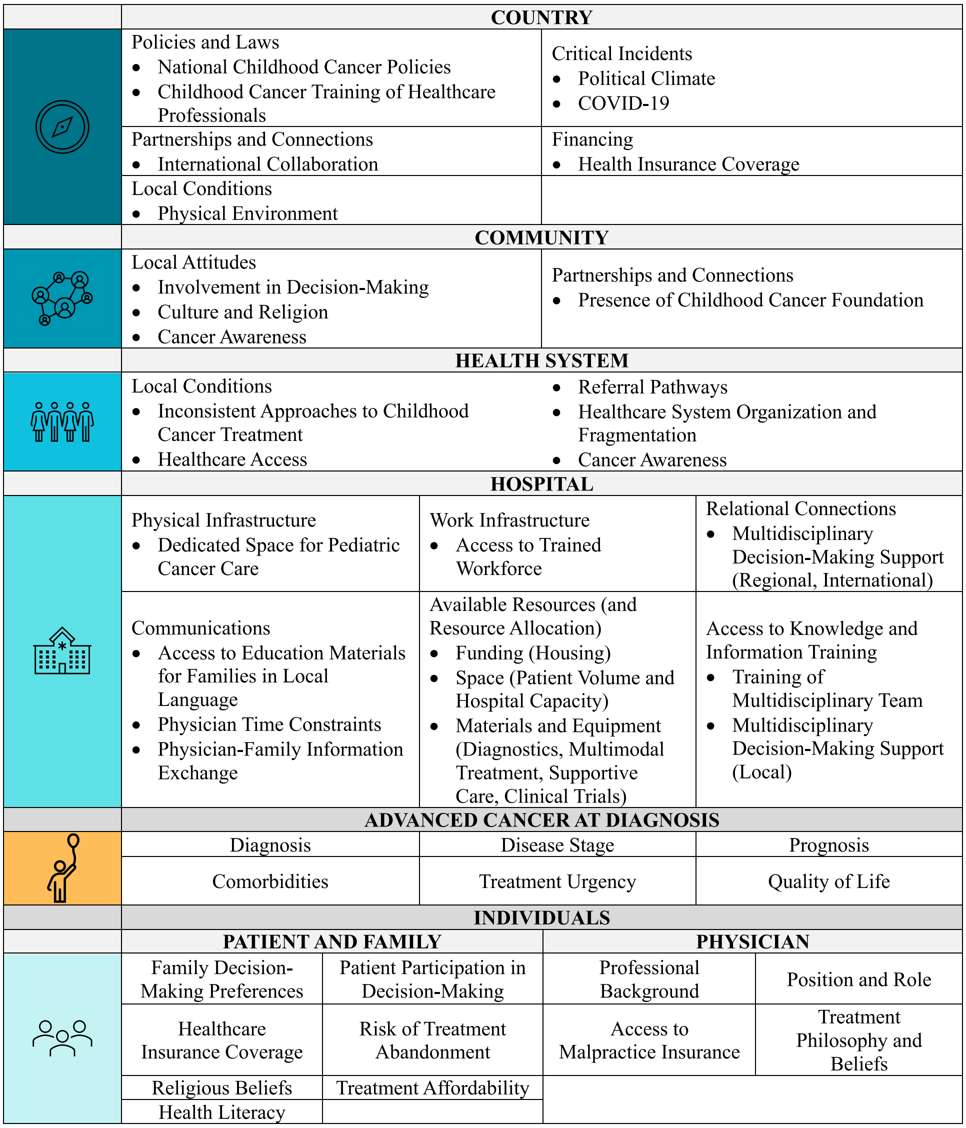
Treatment decisions were exacerbated by inadequate national policies related to treatment payment or delivery for childhood cancer. Participants discussed the importance of international collaboration, including the WHO Global Initiative for Childhood Cancer. Participants also shared the impact of the broader political climate, in particular for children who needed to cross borders to receive necessary care. Participants additionally reflected on the impact of unforeseen international crises, such as the recent COVID-19 pandemic that impacted access to healthcare resources.

Offering treatment with non-curative intent at the time of diagnosis

All participants agreed that it could be appropriate to offer therapy with non-curative intent at diagnosis for certain children presenting with advanced or poor prognosis cancer in LMICs. Participants offered contingencies for when they might consider a non-curative treatment strategy, such as when survival was unlikely or when cure-directed treatment would cause significant toxicities. In this setting, participants stressed the importance of involving families in the decision-making process. Some participants also acknowledged that they rarely offer non-curative therapy at diagnosis of advanced cancer or strive to avoid making this treatment recommendation. Salient themes, supported by participant quotations, are summarized in Table 2.

Characterizing "poor prognosis" cancer

Notably, participants did not endorse a consistent definition of "poor prognosis," and many physicians verbalized difficulty with defining this term. Various descriptions of poor



COUNTRY

Policies and Laws
- National Childhood Cancer Policies
- Childhood Cancer Training of Healthcare Professionals

Critical Incidents
- Political Climate
- COVID-19

Partnerships and Connections
- International Collaboration

Financing
- Health Insurance Coverage

Local Conditions
- Physical Environment

COMMUNITY

Local Attitudes
- Involvement in Decision-Making
- Culture and Religion
- Cancer Awareness

Partnerships and Connections
- Presence of Childhood Cancer Foundation

HEALTH SYSTEM

Local Conditions
- Inconsistent Approaches to Childhood Cancer Treatment
- Healthcare Access
- Referral Pathways
- Healthcare System Organization and Fragmentation
- Cancer Awareness

HOSPITAL

Physical Infrastructure
- Dedicated Space for Pediatric Cancer Care

Work Infrastructure
- Access to Trained Workforce

Relational Connections
- Multidisciplinary Decision-Making Support (Regional, International)

Communications
- Access to Education Materials for Families in Local Language
- Physician Time Constraints
- Physician-Family Information Exchange

Available Resources (and Resource Allocation)
- Funding (Housing)
- Space (Patient Volume and Hospital Capacity)
- Materials and Equipment (Diagnostics, Multimodal Treatment, Supportive Care, Clinical Trials)

Access to Knowledge and Information Training
- Training of Multidisciplinary Team
- Multidisciplinary Decision-Making Support (Local)

ADVANCED CANCER AT DIAGNOSIS

Diagnosis	Disease Stage	Prognosis
Comorbidities	Treatment Urgency	Quality of Life

INDIVIDUALS

PATIENT AND FAMILY		PHYSICIAN	
Family Decision-Making Preferences	Patient Participation in Decision-Making	Professional Background	Position and Role
Healthcare Insurance Coverage	Risk of Treatment Abandonment	Access to Malpractice Insurance	Treatment Philosophy and Beliefs
Religious Beliefs	Treatment Affordability		
Health Literacy			

Fig. 3 Multi-level determinants that influence treatment decision-making at diagnosis for advanced childhood cancer in low- and middle-income countries. Determinants or factors are influenced by the health care system level (i.e., community level) and by the domain (i.e., local conditions). These determinants are organized using a multi-level determinant framework (consolidated framework in implementation research; CFIR) to define, group, and map factors described in the focus groups

prognosis referenced a low chance of cure or survival, physician perceptions of poor quality of life, and fragile patient status (i.e., advanced disease complicated by comorbidities). These concepts supported by participant quotations are summarized in Table 3.

Discussion

We present findings from a qualitative study that explored physicians' decision-making at diagnosis for children presenting with advanced or poor prognosis cancer in LMICs. We found that decision-making from the physicians' perspective is complex and influenced by specific multi-level health system determinants (Figs. 1, 2, and 3). Physicians in this study identified numerous contextual factors that influenced upfront treatment decision-making for these children, including family preferences, available resources, healthcare access, local culture, and/or national payment structure for childhood cancer care delivery (Figs. 1, 2, and 3). Lack of clarity or consensus on the definition of "poor prognosis" or when to recommend therapies with curative versus non-curative intent also emerged as a factor that complicates decision-making.

Our data suggest that decision-making challenges in LMICs may be amplified by diverse, nuanced factors that are not standardly considered in existing decision-making frameworks or childhood cancer treatment guidelines [15–29]. Presently, the bulk of literature describing approaches to treatment decision-making in pediatrics and pediatric oncology has been conducted in HICs [27–30]. Research from HICs supports a shared decision-making (SDM) model, where clinicians and families collaborate, reviewing treatment options, preferences, and priorities

Table 2 Participant's perspectives on offering treatment with non-curative intent at the time of diagnosis

Is it ever appropriate to offer treatment with non-curative intent at the time of diagnosis?	Theme	Participant quote
Yes, …	… AND only when cure is not possible	"It can be appropriate when it is no longer possible to provide curative therapy due to terminal stage of disease."
	… AND I do it to avoid harm	"It is appropriate not to offer curative therapy if you have the evidence that you will not cure the patients but will do the harm. It happens sometimes with [a] small amount of patients, and you have to be wise to really identify that situation, not to do harm for a dying child."
	… AND we always involve the family in decision-making	You know unless in exceptional circumstances we always try to go for curative intent and maybe you know one, two, three cycles… [and when that does not lead to cure,] we always involve the family and the patient if the patient is able to participate
	… BUT I rarely do it because we have curative treatments to try	"I agree, it's okay to not offer curative therapy at all at the time of the diagnosis, but […] you know, we have everything available."
		"I'm really struggling because you know my brain says that is it ever appropriate not to offer, yes. But then I'm really struggling to recall…an instance where I actually practiced that and not offered curative treatment…always with the caveat saying that we can bail out if it seems to be not responding."
	… BUT I do everything to avoid making this recommendation	"[It] is a decision after strong discussion…you know, it is not a pleasant experience to tell that to a family or patient. So you will do everything to avoid that."

Table 3 Participant descriptions of "poor prognosis" at diagnosis for children presenting with advanced cancer in low- and middle-income countries

How do you define poor prognosis?	Theme	Participant quote
	Low chance of cure	"Chances of cure are very little."
	Low chance of survival	"Expected survival rate 20–30%."
		"Child will not likely survive."
	Advanced cancer complicated by comorbidities	"When the status of the patient is critical with minimal chance of recovery."
	Low quality of life	"We try to measure it…not only [based] on survival but [also] quality of life."
	Difficult to define	"There is no specific definition for poor prognosis."
		"I [would define it] when chance of cure is low, but how you define 'low' is very loosely said."

before a treatment approach is determined [28]. SDM typically is relevant when more than one medically reasonable option exists [27, 28]. Notably, most treatment decision-making at diagnosis for children presenting with cancer in HICs does not need SDM, as only one option for first-line therapy is usually recommended [27, 29].

Yet, in LMICs, where many children present with advanced or incurable disease, multiple reasonable treatment options may exist as first-line therapy. When no one option has a clearly superior benefit-to-risk ratio, SDM may serve as a useful model to support decision-making approaches at diagnosis for these children. In this study, physicians acknowledged the importance of including families in treatment decision-making in the setting of advanced disease without curative options, and strategies to support SDM in this context deserve further attention and exploration.

Currently, the literature on patient or family preferences in decision-making for pediatric cancer in LMICs is sparse [31–36]. However, a recent study conducted in Guatemala revealed that most families (78%) preferred SDM over physician-driven treatment decision-making for their children at diagnosis, regardless of disease stage or prognosis. At the same time, 69% of these families wanted their medical team to guide decision-making rather than provide multiple treatment pathways without a clear recommendation [31]. Further qualitative inquiry anchored in participatory research is needed in diverse healthcare settings to further understand nuances in decision-making preferences, including differences in cultural perceptions around SDM and the perspectives of children diagnosed with cancer and their families. Capturing these variations by generating local knowledge has the potential to develop pragmatic strategies to better support decision-making experiences and patient outcomes.

Study findings should be interpreted in the context of limitations. This exploratory, qualitative study was purposefully limited to a small number of pediatric oncologists practicing in LMICs, with the goal of gaining insights into decision-making approaches, considerations, and challenges. The weight of each identified factor relative to others remains unclear, as does the impact of these considerations on the child's illness course. Collectively, these data will inform future work that probes concepts with greater specificity across diverse pediatric cancer community members. Focus group participants practiced at higher volume medical centers that treat more than 100 childhood cancer cases per year, which may influence physician perspectives on treatment decision-making for children with advanced or poor prognosis cancer at the time of diagnosis. Most physicians represented lower- and upper-middle-income countries, with only one participant from a low-income country [8]. This study was not designed to compare or contrast study findings across regions or by country income level. While focus group methodology encouraged collaborative idea generation, it did not facilitate layered elicitation of private or sensitive information from individuals that may influence decision-making [37]. Participants may not have had the opportunity or felt comfortable disclosing local practices that were discordant with practices followed by other focus group participants. Recognizing this limitation, findings generated in this study will be used to inform the development of a semi-structured interview guide that will allow for the exploration of decision-making practices in greater depth through individual discussion. Importantly, the perspectives of multidisciplinary clinicians and families were not included in this study; future research will elevate child, parent, and multidisciplinary clinician voices reflective of varying resource levels to further clarify and characterize diverse treatment decision-making pathways in LMICs.

In summary, this study demonstrates the unique factors and nuanced challenges that influence treatment decision-making by physicians who care for children with advanced or poor prognosis cancer in LMICs. While pediatric oncologists strive to prioritize treatment recommendations that offer cure, this recommendation may not always be possible for children who present at diagnosis with advanced or poor prognosis cancer globally, given existing limitations in available healthcare infrastructure and therapies. Future qualitative work should focus on understanding upfront treatment decision-making for advanced or poor prognosis cancer from the diverse perspectives of patients, families, and multidisciplinary clinicians. Aggregated, these findings will inform the development of evidence-based interventions, frameworks, and decision aids to support decision-making in these settings, guided by local needs, and priorities to improve patient outcomes and reduce suffering globally.

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Author contribution Marta Salek, Carlos Rodriguez-Galindo, Dylan Graetz, Nickhill Bhakta, Erica Kaye, Justin Baker, Lisa Force, Paola Friedrich, and Jean Hunleth contributed to the study conception and design. Data collection was performed by Marta Salek, Amy Porter, and Erica Kaye. Data analysis was performed by Marta Salek, Amy Porter, Essy Maradiege, Mae Concepcion Dolendo, Diego Figuerdo, Fadhil Geriga, Sanjeeva Gunasekera, Roman Kizyma, Hoa Thi Kim Nguyen, Irene Nzamu, Muhammad Rafie Raza, Khilola Rustamova, Nur Melani Sari, Dylan Graetz, Nickhill Bhakta, and Erica Kaye. The first draft of the manuscript was written by Marta Salek, and all authors (Amy Porter, Essy Maradiege, Mae Concepcion Dolendo, Diego Figuerdo, Fadhil Geriga, Sanjeeva Gunasekera, Roman Kizyma, Hoa Thi Kim Nguyen, Irene Nzamu, Muhammad Rafie Raza, Khilola Rustamova, Nur Melani Sari, Carlos Rodriguez-Galindo, Dylan Graetz, Nickhill Bhakta, Erica Kaye, Justin Baker, Lisa Force, Paola Friedrich, Jean Hunleth, Paul Wise) commented on previous versions of the manuscript. All authors (Marta Salek, Amy Porter, Essy Maradiege, Mae Concepcion Dolendo, Diego Figuerdo, Fadhil Geriga, Sanjeeva Gunasekera, Roman Kizyma, Hoa Thi Kim Nguyen, Irene Nzamu, Muhammad Rafie Raza, Khilola Rustamova, Nur Melani Sari, Carlos Rodriguez-Galindo, Dylan Graetz, Nickhill Bhakta, Erica Kaye, Justin Baker, Lisa Force, Paola Friedrich, Jean Hunleth, Paul Wise) read and approved the final manuscript.

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Data availability All data supporting the findings of this study are available within the paper and its Supplementary Information.

Declarations

Ethics approval This study was reviewed by the Institutional Review Board at St. Jude Children's Research Hospital (SJCRH) and deemed exempt.

Consent to participate Verbal informed consent was obtained for all individual participants included in the study.

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