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Willingness to accept paediatric blood sample collection for clinical research purposes in Nepal: a qualitative study

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ABSTRACT

Blood sample collection is essential for clinical research but can be challenging due to cultural beliefs, emotional responses, and misconceptions. This can escalate in paediatric settings. Despite the growing landscape of clinical research, evidence from South Asia remains limited. This study explores the factors influencing willingness to accept paediatric blood sample collection for clinical research in Nepal, drawing on experiences from a clinical research cohort. A qualitative study grounded in a constructivist-interpretivist paradigm, using semi-structured interviews, was conducted with 38 parents/guardians of sick children attending a study fever clinic. A purposive sampling technique was used to recruit participants attending the study fever clinic at Patan Hospital, Nepal. Additionally, interviews were conducted with six research clinicians and nurses. Interviews were conducted between May 2022 and August 2023. The six-step thematic analysis process described by Braun and Clarke was used to identify key themes and subthemes related to blood collection experiences for research purposes. Willingness to provide consent for paediatric blood sampling was shaped by three inter-related factors: personal, behavioural and environmental. Personal beliefs about blood and blood volume, its replenishment and contribution to public health encouraged participation, while fears of harm and lack of personal benefit deterred consent. Behavioural factors included prior experience of blood collection, professional background and perceived necessity of the test. Environmental influences such as trust in the hospital and research staff, effective communication and family decision-making dynamics, were also critical. Some participants equated research blood collection with altruistic donation, while others expressed concerns about misuse or wastage. Our findings underscore the need to engage with the community regarding beliefs about blood in research, transparent communication and trust-building strategies in paediatric clinical research. These findings offer practical guidance for improving participant recruitment and retention in future clinical research in similar settings.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Studies conducted in Africa show that high attrition rates and refusal to participate in clinical research involving blood collection were largely influenced by community perceptions and beliefs regarding blood and blood draw.

WHAT THIS STUDY ADDS

⇒ With the growing landscape of clinical research in South Asia, this qualitative study is among the few studies that explore the perceptions and beliefs regarding paediatric blood collection for clinical research in this region.
⇒ Additionally, the responses are directly from the parents/guardians of the children who have participated in clinical research.
⇒ We found that willingness for paediatric blood sample collection is a complex interplay between individuals' beliefs and knowledge (personal factors); individuals' ability and confidence to undertake the procedures (behavioural factors) and external factors such as social norms, communication by the research staff and trust in the institution conducting the clinical research (environmental factors).

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The study provides valuable insights for future clinical research in low- and middle-income country settings like Nepal, and highlights the importance of considering community beliefs regarding blood prior to implementing any clinical research.
⇒ The study also highlights the importance of designing culturally sensitive engagement and transparent communication with the study participants to help participants trust the research procedures and make informed decisions.

INTRODUCTION

The past few decades have seen a significant rise in clinical research involving human participants.[1] Over time, research is increasingly focused on low- and middle-income countries, driven by the high burden of

disease relevant to research questions, lower operational costs compared with high-income countries and the need to generate evidence applicable to the affected populations.[1 2] Health research in Nepal is also developing, beginning with a 1989 community-based study examining the efficacy of vitamin A supplementation in reducing preschool child mortality.[2 3]

Clinical research often requires the collection of specific biological samples, with blood being the most common, primarily to support current and future research.[4] Despite recognition of the importance of collecting and storing samples for research, accessing human blood samples remains difficult.[5] This becomes more tedious in paediatric research. Aversion to needles, pain, or discomfort may instil fear in children, and a single negative experience of blood sampling can have long-term consequences for the child or their family's attitudes towards clinical settings .[6–8]

Volunteers are often reluctant to participate in clinical research due to misconceptions and fears regarding the use of their blood samples.[9] Hesitancy or refusal to consent for blood samples can significantly impact research success by leading to poor adherence and inadequate sample size for evaluation.[1 10] The symbolic resonance of blood continues to shape public perceptions and behaviours, thereby influencing willingness to provide blood for research.

Blood has long held a dual role in human societies, serving both as a vital biological substance and as a symbol deeply embedded in cultural and spiritual beliefs. Across time and civilisations, blood has been represented as a symbol of life and death, purity and impurity, sacrifice and salvation. Religious textbooks also regard blood to be invaluable as the source of the body and the essence of life.[11] It was only in the late 19th century that scientific discoveries using blood helped shift the paradigm of it from a sacred and mysterious fluid to one with recognised scientific and therapeutic value.[12] During the Medieval period, blood-letting was commonly practised to remove impure or bad blood, a concept that aligns with Ayurvedic scriptures, which also recommend bleeding for healing.[11 12] However, there remains a deep-rooted reluctance to give blood for research due to enduring fears, mistrust and cultural beliefs surrounding blood.

The public are generally unaware of clinical research and about their contribution in advancing science by participating in it.[13] Studies from sub-Saharan Africa have cited common community concerns of blood collection for research purposes as the volume of blood taken, its usage and the potential impact on the individual's health.[1 14–17] This research has highlighted the issue to be particularly relevant in contexts where blood is believed to carry power and hold spiritual significance.[10 17] Rumours of blood theft or selling, negative perceptions of blood draws and magico-religious beliefs like sorcery have hindered recruitment in these settings.[1 15 16 18 19] However, evidence about factors influencing blood collection for research among South Asian participants remains scarce. Often, blood given for medical research is confused with blood donation, which has been promoted by religious organisations as good karma, and more so when it is donated to save the lives of family and friends.[11 20–25] Blood has been regarded as an odd kind of gift characterising blood donation as a pure form of altruism, and often without a tangible reward.[26]

As clinical research continues to grow in Nepal, insights into community perceptions towards blood sample collection for research can strengthen recruitment and retention strategies. A community-based randomised controlled typhoid vaccine trial (TyVAC Nepal) was conducted in Nepal to assess the efficacy of a typhoid conjugate vaccine (Vi-TCV) among 20 000 Nepali children.[27] A cohort study following TyVAC Nepal to assess the medium-term efficacy of Vi-TCV was conducted from 2021 to 2024 (TyVOID Nepal). Both of the clinical studies involved paediatric blood collection for confirmatory diagnosis including genetic analysis and immunogenicity of typhoid infections. In this context, failure to understand the contextual factors surrounding blood collection for research can adversely impact research that requires blood samples.[9] Understanding what influences willingness to provide blood for clinical studies is crucial to minimise dropouts from the studies and ensure valid and reliable results.[28 29] Addressing cultural concerns and building trust are key to overcoming social barriers.[15] Drawing on the experiences with blood sample collection for clinical research, this study aims to explore willingness or hesitation towards paediatric blood sample collection for clinical research among the parents/guardians of children who participated in TyVOID Nepal.

MATERIALS AND METHODS

Study design and setting

We conducted a qualitative study grounded in a constructivist-interpretivist paradigm. The study followed the Consolidated criteria for Reporting Qualitative research (COREQ) (online supplemental annex 1) checklist for reporting.[30]

The study was conducted at the TyVOID Nepal study fever clinic at Patan Hospital, which is one of the largest hospitals in Nepal, providing care to approximately 320 000 outpatients and 20 000 inpatients annually.[31] For the community surveillance of TyVOID Nepal, there was a study fever clinic established at Patan Hospital and there were 17 study fever clinics in the community. Children presenting at the study fever clinic at Patan Hospital and community-based study fever clinics with persistent fever (lasting >2 days and/or a fever of >38°C) were asked for consent, from their parents/legal guardians, to collect ~5 mL blood. This blood sample was used for the confirmation of diagnosis of typhoid fever and DNA from blood sample was stored, again with consent, for genetic analysis.[32]

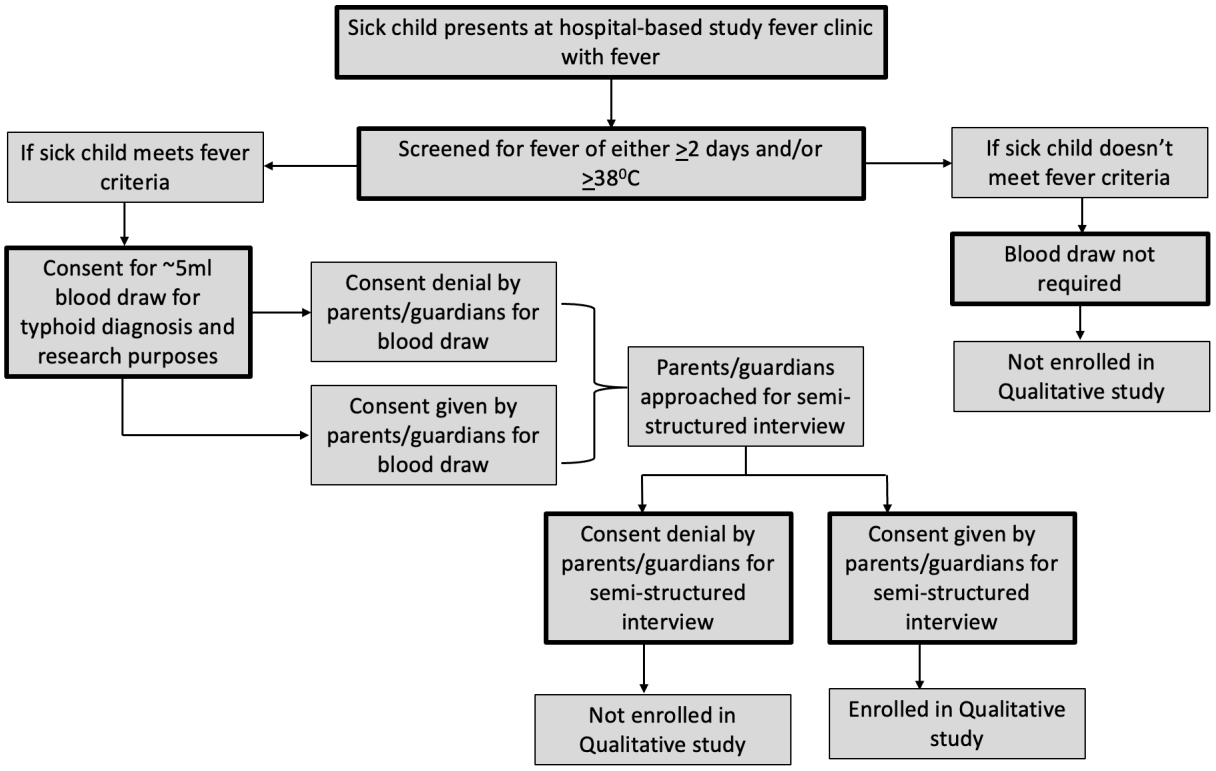

Figure 1 Recruitment flow for qualitative study from the TyVOID Nepal study participants.

Study participants

We purposively selected parents/guardians of sick children (<18 years) attending the study fever clinic at Patan Hospital between May 2022 and August 2023. Interviewers rotated visits to the study fever clinic throughout the day to maximise recruitment. Regardless of blood sample consent for TyVOID Nepal, verbal agreement for interviews was sought immediately after participants exited the study fever clinic. Those who declined blood samples often refused interviews, citing the child's illness and time constraints as reasons for refusal. Most interviews were conducted on the same day in a designated hospital room, with some scheduled for the following day when participants returned to collect sample reports. Only one interview was conducted at a community-based clinic (figure 1).

Before interviews, the interviewer explained to the participants about the qualitative study and a written informed consent was signed for audio-recording. When both parents were present, either both stayed in the interview room or one stayed while the other cared for the child. If a single parent attended, the child remained in the interview room. Respondents were compensated US$2.15 (NPR 300) for their time for the interview.

To provide an additional insight on parental decision-making and procedural experiences, interviews with research clinicians and nurses were also conducted. Clinicians and nurses were recruited via verbal agreement, with information sheets sent by email, followed by written consent on the interview day. These interviews took place at the community-based study fever clinics during off-duty hours to maintain confidentiality and minimise patient disruptions.

Patient and public involvement

Patients or public were not involved in the study design. However, the preliminary findings on factors affecting paediatric blood sample collection were shared with community health volunteers (CHVs) during a public engagement event. These CHVs were mobilised for the typhoid vaccine study and had personal experience of their children's blood collection at the study fever clinic. Their feedback supported and validated the study's interpretations, reinforcing the relevance of the findings to community perspectives.

Staff training

Four female interviewers (AD, PO, MP and CA) from the public engagement department, experienced in conducting interviews, were trained on the interview guide. JVN (MA, PhD) and BA (MD, PhD) provided training on conducting interviews before data collection and on the interview guide. AD attended additional qualitative health research training and trained the other interviewers.

Data collection

Data collection method

AD, PO, MP and CA conducted semi-structured interviews (SSIs) with parents/guardians of sick children

until no substantially new ideas emerged from subsequent interviews.[33] We assessed data adequacy during the interviews through regular debrief sessions, based on the diversity of the responses relevant to the research question. When no novel responses were identified in further interviews conducted independently by four interviewers, researchers deemed the study achieved its information power with 38 SSIs and thus no more interviews were conducted. In-depth interviews (IDIs) with research clinicians and nurses were conducted based on the responses obtained from SSI responses.

Each interviewer conducted at least two pilot interviews before the interviews, refining the topic guide. Before formally starting the interviews, the interviewers asked several general questions to provide a more comfortable environment. This lasted around 10–15 min. They then turned on the audio-recorder when beginning the study-related questions. The SSIs following the guide lasted around 30–45 min on average, while IDIs with research clinicians and nurses lasted around 40–60 min. The emic and etic perspectives of the researchers have been described in detail in online supplemental annex 6.

Data collection tool

We conducted all the interviews in Nepali as the participants were comfortable with communicating in it, although they may have spoken additional first languages. A topic guide (online supplemental annex 2 and online supplemental annex 3) was used that was developed by AD based on prior literature[1 14–16 18 19 34 35] and community engagement experience. JVN, BA, MS (MBBS, MPH, PhD) and DP (MBBS, MD) reviewed the guide. The SSI guide covered five key themes with probes in the following topics: importance of blood and its cultural significance, perceptions regarding paediatric blood collection for research, experiences with blood draw from a child with fever at the study fever clinic, participating in clinical studies and family health-seeking behaviours.

Analysis

Following data collection, interview recordings were transcribed verbatim by the interviewers and translated into English by an external translator, with AD reviewing the translations for accuracy and contextual meaning. The translated transcripts were then imported to NVivo software (V.14, QSR International) for analysis.

Data analysis adopted the six-step approach to reflexive thematic analysis by Braun and Clarke to identify, analyse and report patterns within the interview transcripts.[36 37] Consistent with this framework, analysis was carried out iteratively using an interpretative process grounded in a constructivist-interpretivist paradigm.[38]

AD led the coding process through repeated engagement with the transcripts for data familiarisation.[36 38] Initial codes were inductively developed, while remaining aware of the study objectives, relevant literature and public engagement experiences.[37 39] Coding was an active and reflexive process and it was recognised that codes were generated through analytic engagement rather than being inherently present within the data.[37 39] Regular discussions within the interview team supported ongoing reflexive engagement and ensured careful attention to the nuances of participants' responses.

Codes were subsequently examined and organised using mind maps to explore patterns of shared meaning and relationships within the codes. These patterns were then categorised into potential themes and subthemes that were developed through iterative movement between coded extracts and the full dataset. Study team meetings with BA and JVN facilitated critical reflection on the coherence, conceptual clarity of the themes in relation to the research objectives.

The analysis involved an interplay between inductive engagement with the data and deductive consideration of existing literature and conceptual framings.[37] Themes were reviewed, refined and defined to ensure internal coherence and clear distinction with each other. Finally, themes were synthesised into three overarching domains of personal, behavioural and environmental factors explained in the 'Results' section.

Throughout the analysis and reporting phase, reflexivity was considered integral to interpretation. AD along with other interviewers as Nepali researchers with prior engagement in the typhoid vaccine study brought contextual familiarity with the study setting and participants. This positioned greater understanding of cultural meanings surrounding blood sample collection from children for research purposes. Furthermore, the multidisciplinary backgrounds and contextual perspectives within the study team contributed to greater conceptual clarity and coherence of themes. In line with reflexive thematic analysis, researcher subjectivity was treated as an analytic resource that strengthened the development of meaning-based themes.

RESULTS

The three overarching domains of personal, behavioural and environmental factors collectively shaped the willingness for paediatric blood sample collection for research. Figure 2 illustrates the dynamic relationships among these themes, with supporting final codes presented in online supplemental annex 4. These factors intersected in multiple ways to influence parental decision-making, emerging along a continuum of responses rather than as discrete categories. The socio-demographic characteristics of the study population are given in table 1.

Personal factors

Personal factors include individual beliefs, perceptions, knowledge, and emotions influencing willingness for blood sample collection. However, these factors did not act as discrete barriers or enablers but intertwined with each other as overlapping and often conflicting influences shaping decision-making along a continuum of willingness and hesitation.

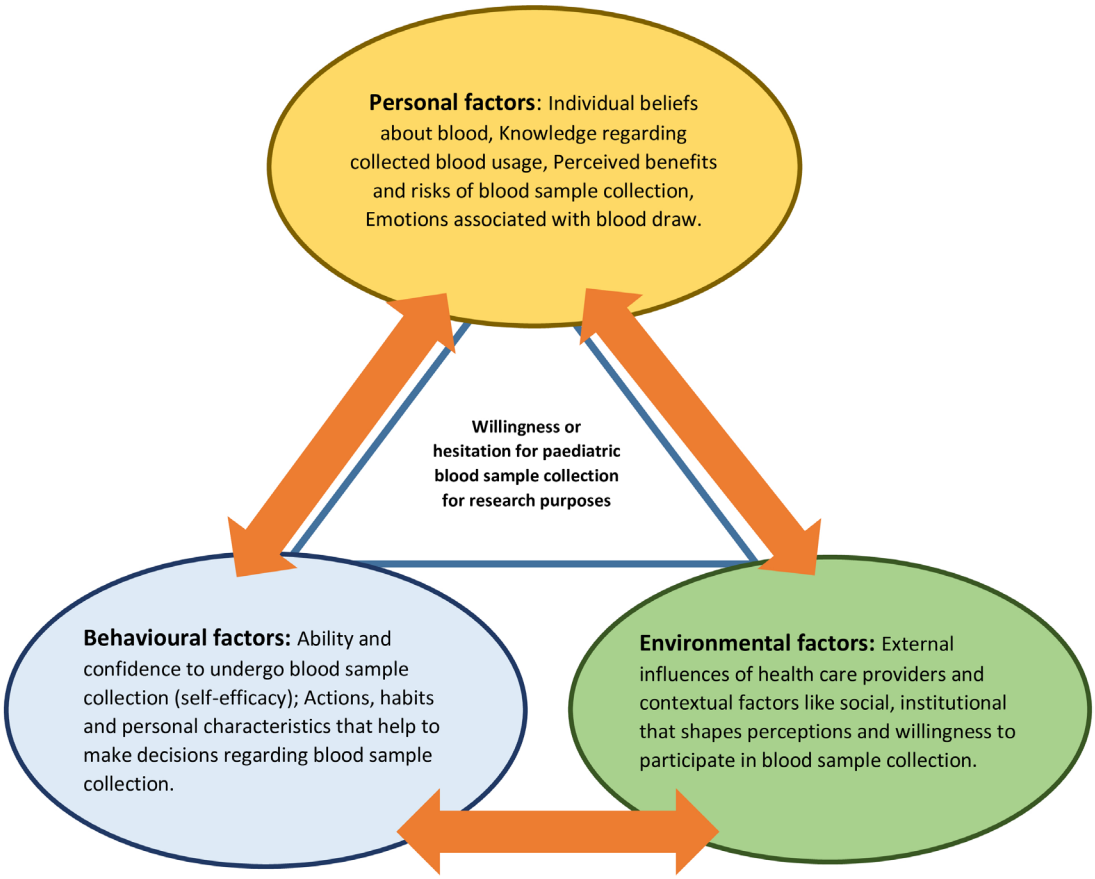

Figure 2 Theme map illustrating interacting personal, behavioural and environmental influences shaping willingness to provide blood sample for research purposes.

Beliefs about blood

An individual's belief about blood influenced decisions about paediatric blood collection for research. Most participants perceived blood as essential for survival. Those who consented understood its natural replenishment but emphasised the proper diet for its restoration. Many correlated blood collections for research to donation, believing it kept blood fresh and promoted better health.

> It is said to donate blood every 6 months because it is said that our blood gets black [non-functional] if it remains inside. However, if it is given in 6 months then new blood will regenerate and will benefit our health as well. […], so, I am hoping that my child will also become healthy after this blood draw. (IDI37, 25 years, mother)

Participants who refused blood draw perceived blood as vital as air or water, expressing concerns that its use in research was wasteful.

> … without blood, we can't do anything. To make one drop of blood, many meals have to be taken and so blood shouldn't be wasted just like that but I don't consider it bad to draw blood for disease. (IDI25, 54 years, mother)

Knowledge regarding the collected blood usage

Participants' willingness to provide consent for blood samples of their children for research depended on their understanding of sample usage. Those who perceived the 'clinical necessity' and believed their samples aided disease diagnosis or prevention were more likely to consent despite initial discomfort. Some valued blood storage for identifying the causes of infections such as typhoid fever and were reassured that samples could be tested locally or abroad. They were also motivated by a sense of contributing to scientific knowledge and improving public health.

> … how would they do the treatment without testing it? It must be required to do the treatment. Unless blood is tested, they cannot simply assess and finish check-up. Blood is the ultimate test as it is the effect of blood after all. (IDI03, 57 years, grandmother)

Lack of individualised report for the stored blood sample was a barrier for paediatric blood sample collection. Blood sample was collected for diagnostic purpose and the blood DNA would be stored for the study. The participants questioned the value of giving blood for research as they did not receive personal report of their stored samples. This scepticism was echoed by research clinicians who noted that participants often had difficulty understanding how genetic analysis contributes to studying immune responses to vaccines and susceptibility to infectious diseases such as typhoid.

> Why most of them deny is because for them there is no outcome to this. Though we say, DNA test is done to find out the

Table 1 Socio-demographic characteristics of study participants

Socio-demographic characteristics of parents/guardians of the sick children		
Characteristics	**Frequency (n=38)**	**Percentage (%)**
Age of the respondents (years)		
20 to <30	8	21
>30 to ≤40	21	55
>40 to ≤50	4	11
>50	3	8
Unknown*	2	5
Educational status		
Illiterate	2	5
Literate (no formal education—can only read or write)	1	3
Primary (grade 1–8)	4	11
Secondary (grade 9–12)	22	58
Undergraduation	2	5
Postgraduation	2	5
Unknown*	5	13
Relationship with the sick child		
Father	13	34
Mother	19	50
Guardian (other than parents)	6	16
Decision regarding blood collection		
Consent	23	60
Denied	15	40
Socio-demographic characteristics of research clinicians and nurses		
Characteristics	**Frequency (n=5)**	**Percentage (%)**
Research clinician	3	60
Research nurse	2	40
Gender		
Male	2	40
Female	3	60

genetic linkage, people don't buy the fact there will be a cumulative report. (IDIRC01, 30 years, male)

Some respondents considered blood samples collected for research would help in identifying emerging infections and its prevention and provided consent. However, not all shared this view, as a few of them felt its primary purpose should be diagnosing current illness rather than limiting its usage to research only.

> […], blood should not be used solely for study purpose. It will [should] also be used to find out the reason for the illness in children—to find out if the child acquired it from germs or from food. It is not good to draw blood only for study. (IDI20, 42 years, mother)

Perceived benefits and risks of blood sample collection for research purposes

The respondents' perception of the benefits and risks of blood sample collection were closely intertwined rather than mutually exclusive. Those who saw benefits of proactive blood tests to monitor their health status and early detection of illness agreed to it. Few appreciated the research team's efforts and viewed the blood collected from their children would be beneficial for upscaling the researchers' expertise.

> If it is for study purposes, then that is fine. They [research team] also need blood and that can only be known when research is conducted. When they do study then they will be an expert on it. (IDI16, 38 years, father)

However, parents were also hesitant due to concerns about taking extra blood for research as they feared it would cause weakness, dizziness and discomfort in their sick children who they believed already had little blood in their bodies due to their small size and illness.

> Today when they mentioned about storage, I thought they'd do in a big packet. That thought comes to our mind automatically so I denied for it. (IDI23, 35 years, mother)

This concern was also echoed by research clinicians, who noted that many parents associated blood loss with increasing vulnerability. In contrast, those respondents who had no concerns about blood volume were more willing to provide blood samples for the study.

> … nothing as such happens because of the blood draw. That will be replenished by the amount of food the child has. […] This much blood will come out of the body even when the child gets hurt. (IDI05, 39 years, mother)

These narratives reveal a balancing act between altruism and fear, which was made not through clear acceptance or refusal but through weighing competing concerns.

Emotional reactions

Parents experienced mixed emotions about blood sample collection, with fear and uncertainty causing hesitation, while positive experiences and incentives encouraged participation. Although emotions were not a direct reason for refusal, many feared the process would scare their children and expressed uncertainty about repeated blood draws for research from febrile children. This was also confirmed by a research nurse who observed parents becoming emotional during sample collection, sometimes leading to refusal.

> During blood draw, when the children start crying, I have seen emotional parents who want to discontinue. Sometimes the parents say the syringe is so big which in turn scares the children and we have to counsel the parents instead. (IDIRN02, 30 years, female)

Although fear and uncertainty existed, strategies such as providing small incentives or distraction during the procedure helped to alleviate distress and comforted the children that transformed anxiety into reassurance. Additionally, respondents who experienced hassle-free outpatient services at the study fever clinics, received fever-related free medicines and some free tests (like blood culture, urine/stool routine examination) were more likely to provide consent, highlighting the role of positive healthcare experiences in fostering participation.

> …I easily agreed for blood draw of my child today as I didn't have to queue to get ticket and service was fine the last time I visited here for the check-up. (IDI37, 25 years, mother)

Behavioural factors

Behavioural factors encompass personal characteristics, actions, and habits influencing individuals' ability and confidence to undergo blood sample collection from their children for research purposes. These factors interacted with personal beliefs and emotions and were often shaped by a balance between understanding the research purpose, perceived control over the decision and concerns for their child's well-being.

Self-efficacy regarding blood sample collection for research

Respondents' knowledge, past experiences with blood collection, and perceived control over the process influenced their decisions to provide consent. Those familiar with the typhoid vaccine study and with positive perceptions of research were more willing to consent, while scepticism, particularly concerns about Nepal being used as a testing ground, led to refusals. Yet among the sceptical parents/guardians, a sense of duty that the blood collection would help their children to diagnose their illness coexisted with hesitation, demonstrating that confidence and uncertainty were continuously negotiated rather than oppositional.

> …when you say study, you are doing a trial as my sick child has already given blood 3-4 times. Nepal is a place to conduct test [experiment] by other countries. […] Nepal is a laboratory where every country wants to use. Period! (IDI12, 30 years, mother)

Academic background and professional experience of parents/guardians contributed to their confidence in consenting to paediatric blood collection for research. However, factors such as child's weakness, menstruation or perceived beliefs that the tests were unrelated to their illness led to refusal. The voluntary nature of consent also played a role, as some parents declined blood draws when they felt the research had no immediate benefit for their child's condition.

> In addition to the routine blood tests, the doctor also mentioned about DNA, gene and hereditary linkage to the causation of infection in children and the blood would be stored for a long time. Since those tests were unrelated to sickness and I was given an option to choose whether to store it or not, […] I didn't feel it was necessary to do. (IDI43, 32 years, father)

Decision-making

Many parents decided to agree for blood collection when they felt the child's condition seemed urgent, prioritising immediate care, whereas others declined when they perceived the illness as minor or when the research purpose seemed unrelated to treatment. These choices reflected an ongoing weighing of necessity, benefit and control by the parents.

> I felt like it was unnecessary and something unrelated to my child's illness at that moment. He was brought here because he had fever and we wanted that to be treated. We felt DNA was unnecessary. On top of that, I was told it would take one year for the report to arrive. (IDI45, 40 years, uncle)

Caregiving dynamics within the family also played a key role in decision-making, with mothers typically accompanying children to the fever clinic, but relying on fathers regarding the decisions about research-related blood draws, which was also confirmed by the research nurse involved in the procedure.

> … in this case, I have to ask the child's father to take out more than the needed blood. Only my approval doesn't count. (IDI33, 40 years, mother)

Environmental factors

The environmental factors theme captured broader social and institutional contexts that shaped parental decisions about blood sample collection from their children for research purposes. These factors interacted with parental personal beliefs and behavioural confidence to form a shifting context in which decisions were made.

Influence of research staff

Respondents' willingness to provide blood samples was significantly influenced by the attitudes and communication skills of the research staff. Polite, calm and reassuring tone with clear explanations played a crucial role in decision-making. Participants appreciated when doctors and nurses took their time to explain the study and the intended use of the collected blood, which alleviated their concerns. Additionally, efforts to comfort and distract children from crying, for example, during the procedure reduced parental anxiety, increasing the likelihood of consent.

> I felt easier and happy when the doctor asked politely in soft voice. They explained in detail in a good manner and I agreed. Additionally, they consoled the child and distracted them which made it easier for us. (IDI28, 35 years, sister)

Prior experiences also shaped participants' decisions, with some noting that previous painful draws made them hesitant, while a smooth and professional experience encouraged participation.

Trust

Participants' trust in the organisation's credibility and ethical practices played a crucial role in their willingness to provide blood samples for research. Trust in the hospital where the procedure was carried out, prior positive experiences with its services and familiarity with its healthcare system fostered a sense of security, making individuals more comfortable with consenting for blood draws.

> My family and I have been visiting this hospital for the last 5–6 years and there has been nothing wrong with us. Even for minor illnesses, we come here so when the doctor asked me for blood draw today, I did not feel it was a big issue. Since, this was my first time of signing consent, I felt different, but I felt there could be no harm in such a big hospital. The main reason for giving blood sample is my trust towards the hospital. (IDI32, 54 years, grandmother)

Moreover, participants expressed strong confidence in the expertise and ethical integrity of the research clinicians, often relying on decision-making based on the belief that doctors possess the knowledge to determine what is best. This sentiment was echoed by the research clinicians as well, who noted that many individuals in Nepal rely on medical professionals' guidance rather than making their decisions.

> In Nepal, they transfer the autonomy to the doctors because of the trust they have on us. We get credit for both the good and the ugly. Though it should be their individual decision, people say, I will follow your decision. (IDIRC1, 30 years, male)

Furthermore, the transparency of the consent process, particularly the requirement of a written signature, reassured a few participants about the legitimacy of the research and enhanced their sense of control over their participation. The ability to make an informed choice regarding sample storage further enhanced individuals' trust and impacted their willingness to provide blood samples.

Community norms on blood draw

Few parents reported hearing rumours about research studies, particularly scepticism regarding vaccines being studied for clinical trials in Nepal before being used in other countries. However, these rumours did not seem to influence their decision regarding blood sample collection. While respondents did not report any direct rumours about blood collection in the community, some of them recalled hearing misconceptions, such as hospitals selling collected blood or taking excessive amounts from sick children. These misconceptions, although not widespread, contributed to initial hesitancy among some parents.

> I have heard people saying blood is taken out in hospital and is sold. They are the same people who say too much blood is taken out from the children who are already sick and it will be sold. (IDI40, 35 years, mother)

Aligning with this, the research staff emphasised the critical role of counselling in dispelling doubts, where clear communication and trust-building efforts helped to mitigate fears among the participants leading to willingness for the blood sample collection from sick children.

DISCUSSION

This is one of the few studies exploring willingness of parents/guardians regarding paediatric blood sample collection for clinical research from the South Asian region. Our findings demonstrate a critical interplay of personal, behavioural and environmental factors that shaped the parents'/guardians' willingness to consent to paediatric blood sample collection for research. Synthesising insights across the three themes, our findings revealed six key constructs that collectively shape parental willingness or hesitation to provide paediatric blood samples for clinical research: *trust, perceived benefit*, beliefs regarding blood, *fear of harm, communication clarity* and *behavioural confidence*. These constructs did not function as independent facilitators or barriers but interacted dynamically within a shared socio-cultural environment. *Trust* and *communication clarity* emerged as critical environmental influences that fostered reassurance and understanding. *Perceived benefit* and *fear of harm* reflected competing emotional and cognitive evaluations within the personal domain, while *behavioural confidence* captured parents' sense of control and capacity to engage

with research procedures. *Cultural beliefs* influenced all other constructs, shaping how parents interpreted both the physical and symbolic aspects of blood. Together, these inter-related constructs explain why willingness and hesitation occurred along a continuum, influenced by the ongoing negotiation between belief, emotion and contextual trust.

At the personal level, the key enabler for blood sample collection was the belief that blood is essential for survival and could be safely replenished with a proper diet. This perception led to a sense of confidence among the participants, easing their concerns about physical consequences of blood draw, fostering a willingness to contribute to research, particularly for vaccine development. Their knowledge about the role of blood in the diagnosis and prevention of infection enabled them to consent for blood draw for research. This finding aligns with findings from a qualitative study conducted in Ghana, where individuals recognised the diagnostic value of blood and were more willing to consent.[15]

Participants often associated blood tests with infection screening, aiding in detecting internal infections, a perspective consistent with previous research among South Africans.[40] The findings of this study show that participants with a positive attitude towards research believed the storage of their blood samples would contribute to scientific knowledge and improve public health by identifying emerging infections in the future, thus consented for blood draw from their children. Similar feelings of altruism were demonstrated in a study conducted among the participants in Gaza who were willing to donate blood for medical research, motivated by both societal and personal benefits.[41] The altruistic feeling in this study often stemmed from a misconception equating research blood collection with blood donation that would help the participants in the early detection of illness, a finding consistent with a study in The Gambia.[1]

Studies conducted among Asian nationals also reported philanthropic motive to contribute to science as their reasons to participate in clinical trials and infection research.[29 42 43] A qualitative study conducted among the Ebola survivors in Guinea found moral obligations and social responsibility to do something in return for their survival against a lethal disease motivated them to donate plasma.[44] Conversely, those who refused blood collection perceived it as wasteful and weakening to their health, believing blood was vital for the body and should not be taken for research. This mirrors studies in The Gambia and Ghana, where blood was viewed as a life force and its loss was associated with depletion of body strength and susceptibility to health conditions.[1 19] Concern about the side effects of participating in clinical trials was the most important deterrent among South Asian populations.[42] Fear of needles was a common emotional response expressed at a personal level, echoing prior findings.[34 40 45] However, among those who consented for the blood draw often did so without emotional consideration for the research itself, as their primary concern was on ensuring their children received treatment for the infection. Concerns about blood volume also influenced consent, with some parents fearing excessive blood loss would weaken their sick children, similar to the findings from the Ebola trial in Guinea and the studies in The Gambia and Sierra Leone.[1 16 44] Others worried about dizziness or illness due to blood loss, as reported in Ghana.[15] However, parents who consented did not perceive the volume as excessive, with one even comparing it to a leech bite.

Behavioural influences on consent for the blood collection included confidence in the process, shaped by their academic background, professional values and prior experience of blood draw. Respondents with research or healthcare experience exhibited a positive attitude towards research procedures and were more likely to consent. Parents who agreed to blood collection seemed to be well-informed about sample handling, including storage for future research and possible testing outside Nepal. Unlike studies in sub-Saharan Africa, where rumours of blood theft or selling discouraged participation,[14 18 44] no such instances were reported in this study. However, participants emphasised that blood collection should benefit individuals and should not just be used for research. While the Ebola Tx trial found trust in international teams for plasma donation,[44] a few respondents in this study expressed concerns that researchers from high-income countries targeted populations from low-income countries like Nepal for research, although this did not affect their decision to consent.

Environmental factors, particularly institutional trust, played a critical role—especially trust in Patan Hospital, as participants generally believed the hospital handled samples ethically. Unlike African studies where distrust in government and hospitals hindered participation,[16 18] participants in this study trusted the research institution. Some participants reported signing informed consent as a motivation to participate in research as it gave them a freedom to make an informed choice. Notably, clear and empathetic communication of the research staff (clinicians, nurses and medical assistants) also enhanced willingness to provide consent from their children. This was also reported in a study among the South Asian participants where having a good rapport was identified as an enabler in clinical trial recruitment.[42] External factors like cultural norms led to constrained decision-making, with mothers unable to consent for the extra blood for research without their husbands.[15]

Strengths and limitations

While there is extensive research from sub-Saharan Africa, studies on perceptions of blood sample collection for research in South Asia are limited. Including parents/guardians of children enrolled in clinical research immediately after exiting the study fever clinic also helped to minimise recall bias. Interviews with research clinicians and nurses helped us to validate and contrast the responses from the parents/guardians.

The study has several limitations. First, parents/guardians who declined blood collection also often declined interviews, whose opinions on blood sample collection may have been unexplored. We note that these individuals might hold stronger scepticism or different cultural beliefs regarding

research, which could not be captured in our dataset. Second, only parents/guardians were interviewed, while children whose blood draw was done could have provided different insights into the enablers and barriers based on their personal experience. Not involving the public or patients in the study design during the inception phase is a limitation, as community involvement could have grounded the development of research questions in the community's understanding and experiences. Although interviews were scheduled at participants' convenience, some parents came alone with sick children, which may have limited their response length due to having their child with them. This qualitative study was only conducted using interviews, and future research could benefit from other ethnographic methods such as observation or focus group discussions to gather more diverse perspectives. During analysis, which was conducted with English transcripts, the nuances of the findings may have been lost in translation due to the complexities in language meaning. While AD cross-checked the translated document with the audio recordings and transcripts, meaning still may have been lost.

The enablers and barriers identified in the study should not be taken literally as they are. Since the enablers and barriers can coexist, the enablers can qualify as barriers or may contain the nuances of the barriers that are unexpressed, while some identified barriers may have inherent, unexpressed enablers. Hence, enablers and barriers should not be understood as dichotomy categories.

Lastly, the sample may not represent the general population of Nepal, as interviews were conducted only with a self-selected sample of parents/guardians of the children participating in TyVOID Nepal who were visiting the study fever clinic, and may not capture a wide range of health beliefs in the Nepali population.

CONCLUSION

This study highlights the complex interplay of personal, behavioural and environmental factors that shape parental willingness or hesitation to provide paediatric blood samples for research purposes. Parents' decisions were not determined by simple facilitators or barriers but emerged along a continuum of negotiation between fear, trust, perceived benefit and their beliefs about blood. Synthesising these findings, six key constructs of trust, perceived benefit, cultural beliefs, fear of harm, communication clarity and *behavioural confidence* were identified as central to decision-making.

The conceptual framework developed from this analysis provides a transferable lens to understand how social, emotional and cultural influences shape participation in paediatric clinical research. Practically, these findings can guide researchers and policymakers in designing culturally sensitive communication, community engagement and consent strategies that strengthen trust and promote ethical inclusion. It contributes to global discourse on research participation by offering a contextually grounded yet adaptable model applicable to similar low- and middle-income country settings.

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Ethics approval The qualitative study was reviewed and approved by the Oxford Tropical Research Ethics Committee (11-21) and the Nepal Health Research Council (240/2021 P) and was done in accordance with the principles of the Declaration of Helsinki.

Data availability statement De-identified individual data from this study will be made available to researchers by the corresponding author upon reasonable request.

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