

Caregivers and community perceptions of blood transfusion for children with severe anaemia in Uganda

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Short title: Perceptions of blood transfusion in Uganda

Abstract

Background: Blood transfusion is a common emergency treatment for children with severe anaemia and saves millions of lives of African children. However, the perceptions of transfusion recipients have not been well studied. A better understanding of the perceived risk may improve transfusion care.

Objective: To describe local perceptions of blood transfusion for children with severe anaemia in Uganda.

Methods: A qualitative study based on 16 in-depth interviews of caregivers of transfused children, and six focus group discussions with community members was conducted in three regions of Uganda between October and November 2017.

Results: Caregivers of children and community members held blood transfusion in high regard and valued it as life-saving. However, there were widespread perceived transfusion risks, including: Human immunodeficiency virus (HIV) transmission, too rapid blood infusion, and blood incompatibility. Other concerns were: fatality, changes in behaviour, donor blood being ‘too strong’, and use of animal blood. In contrast, recent transfusion, older age, knowledge of HIV screening of blood for transfusion, faith in God and having a critically ill child, were associated with less fear about transfusion. Respondents also emphasized challenges to transfusion services access including distance to hospitals, scarcity of blood and health workers’ attitudes.

Conclusion: Perceptions of the community and caregivers of transfused children in Uganda about blood transfusion were complex: transfusion is considered life-saving but there were strong perceived transfusion risks of HIV transmission and blood incompatibility. Addressing

community perceptions and facilitating access to blood transfusion represent important strategies to improve paediatric transfusion care.

Key words: Blood transfusion; perceived risk; fear; caregivers; children; community members

Introduction

Since its first application as an emergency treatment in the mid-17th century (Marinozzi *et al.* 2018), blood transfusion has greatly evolved over the years with concomitant advances in screening and technology aimed at making blood transfusion safe (WHO 2017). Nevertheless, its risk as perceived by recipients as well as health workers remains a public health concern (Abdul-Aziz *et al.* 2018). In developing countries, children under five years are the most transfused age group, accounting for 65% of all blood transfusions (WHO 2017). There is substantial literature on the knowledge, attitudes and fears hindering blood donors (Ahmed *et al.* 2006, Mishra *et al.* 2016, Raghuwanshi *et al.* 2016, and France 2018), than about the perceptions of recipients of blood. Knowledge and beliefs of transfusion recipients and their caregivers from sub-Saharan Africa in particular have not been well studied. To-date, with the exception of two studies that reported widespread concerns about consent deviations and the quality of blood prior to receiving blood transfusion (Kajja *et al.* 2011, and Barrett *et al.* 2014), and another that investigated pregnant women's perceptions, there has been limited research on this subject. Pregnant Burkina-Faso women believed that blood transfusion was required for the management of severe anaemia while 'eating well' could resolve moderate anaemia (Compaore *et al.* 2014). In Uganda, blood recipients were concerned about the safety and quality of the blood, and that these concerns were also not adequately addressed during the consent process by the health

workers, who were accused of being ‘too busy’ to do so (Kajja *et al.* 2011). It is not clear what concerns are held by caregivers of children who receive blood transfusion. In this paper, we describe the community perceptions of blood transfusion for paediatric severe anaemia in Uganda.

Materials and methods

Study design: This qualitative study of caregivers’ perceptions of blood transfusion for paediatric severe anaemia in Uganda, conducted between October and November 2017, employed in-depth interviews (IDIs) to collect data, and complemented it with focus group discussions (FGDs). The study was nested in an on-going clinical trial on post-discharge malaria chemoprevention among children recently transfused for severe anaemia (Kwambai *et al.* 2018).

Study area: Data were collected from three regional referral hospitals and surrounding communities to represent three of the ten regions in Uganda: Masaka regional referral hospital, Jinja regional referral hospital and Hoima regional referral hospital in *Buganda (central-), Busoga (eastern-)* and *Bunyoro (mid-western-Uganda)*, respectively.

Participants and procedures

In-depth interviews: Sixteen (16) in-depth interviews were held with parents or guardians (caregivers) of children either recently transfused (within three months) or who were at the time still admitted in hospital and been transfused for severe anaemia. The interviewees were purposively selected and included men, women, grandparents, caregivers of children who had received repeat transfusions or who had died following blood transfusion. Of the 16 interviewees,

five were from Masaka, six from Jinja, and five were from Hoima regional referral hospitals, and by the end of this number at each site, saturation was achieved and no new information was gained. Participants were identified from the records of the on-going clinical trial and invited by phone call to come for the interview at the hospital or recruited from the ward. Caregivers of children who received transfusions for chronic diseases, such as sickle cell anaemia or cancer, were excluded. The interview guide covered knowledge about blood transfusion, alternative remedies, fears about blood transfusion, challenges accessing transfusion care, and peri- and post-transfusion care and practices. Interviews were audio-recorded and lasted between 40 to 50 minutes.

Focus group discussions: Six (two per district) focus group discussions (FGDs) of six to eight participants each were conducted. Participants of FGDs included only mothers of children from local communities surrounding (within 20km radius) the respective regional referral hospitals, mobilized by a Village Health Team (VHT) member who also hosted the FGD at their home. The communities (villages) were purposively selected from among those frequently visited by the social workers during follow up of study children on the on-going clinical trial described above. The FGDs were conducted after the IDIs in order to follow up on any emerging themes with community members. Prior to the discussions, formal introductions were made and participants were briefed about the study goals and procedures. A moderator fluent in the respective local languages facilitated the discussions that lasted 50 to 70 minutes each, while an assistant audio-recorded the conversation and noted non-verbal communications.

Data management and analysis: The data were transcribed verbatim and translated into English. The first author (AD), who also attended all IDI and FGD sessions and took field notes, checked the transcripts for completeness before they were uploaded into ATLAS.ti version 7.5.12 software. Code books were developed using deductive codes from the guides as well as inductive codes that

emerged from the data after reading a sample of the transcripts. Four authors (AD, FA, GES, and MBV) contributed to code book development. Once the code books were finalized, coding was undertaken by FA and checked by AD. Code reports were generated centrally and shared with co-authors for review. Code summaries were then developed and the findings were synthesized thematically.

Ethical approval: Ethical clearance was obtained from the Research and Ethics Committee of Makerere University School of Medicine, and the Uganda National Council for Science and Technology. Written informed consents were obtained from all IDIs while FGD participants consented verbally.

Results

Interviewee Characteristics: All of the 16 IDI interviewees were rural individuals with limited formal education but familiar with caring for a child receiving a blood transfusion. All, except one, cared for more than one child. Seven respondents' children had had repeat transfusions. Other characteristics are summarized in table 1.

Blood transfusion, a life-saving treatment

When asked for their opinion about blood transfusion, the parents and caregivers in both IDIs and FGDs expressed overwhelming confidence in blood transfusion as a lifesaving treatment for severe anaemia: *"I expect that when I take my child with severe anaemia to hospital and is considered for blood transfusion then it is automatic that he is going to recover"* (R5_FGD-01_Masaka). In Jinja, the accounts were strikingly similar, further underlining the high regard for and strong belief in transfusion: *"As long as I find blood, I get relieved knowing I have rescued her"* (IDI_01, Jinja).

Participants believed that transfusion restored a child's blood and quickened the recovery process: *"I think blood transfusion helps a child to restore their blood quickly, and recover their health"* (IDI-04, Masaka). *"....home remedies are slow, ...however for blood transfusion, it goes through the blood vessels straight away and in just a few minutes the child would have recovered"* (IDI-02, Masaka).

Compared to alternative remedies for severe anaemia, blood transfusion was perceived to be superior: *"What I believe works is blood transfusion. Because if it didn't, my child would have died"* (IDI-03, Jinja). Respondents appeared to have some insight into how blood transfusion works to correct severe anaemia: *"Doesn't the blood they transfuse into the body first go to the heart which then pumps it to the rest of the body? But remember since this blood doesn't belong to you, the body has to first get used to it"* (R3_FGD-01, Masaka).

Perceived risk and suspicion about blood transfusion

Although blood transfusion was regarded highly for its life-saving potential, participants expressed a diverse range of fears and perceived risk associated with their children receiving blood transfusion. We describe this theme below.

i) Risk of Human Immunodeficiency Virus (HIV) – in both interviews and focus groups, caregivers feared HIV transmission to their child through transfusion, with some questioning the use of blood that health workers routinely drew from HIV-infected persons under treatment, and some concerned about the potential for foul play by a malicious health worker as illustrated in the following quotes:

“I feared that the blood could be infected with the HIV virus” (IDI – 02, Masaka). “What is that blood routinely drawn from HIV+ people in care used for?” ... “I wish they could allow me to donate blood for my child” (R7_FGD-02, Hoima).

Some caregivers argued that in their settings, diseases, in particular HIV, were too rampant to be ignored, resulting in a high suspicion index for any blood transfused: *“These days there are so many diseases....so you ask yourself; is the blood being given safe?...because there are those infected with HIV. So as a parent, when they are putting blood on my child, I don’t feel comfortable. And after transfusion, if he gets a simple sickness I rush him to hospital for check-up in fear that they might have transfused him with HIV infected blood” (R4_FGD-01, Hoima).*

ii) *Blood incompatibility-* Many caregivers were aware of donor-recipient blood group incompatibilities, and perceived it to be fatal, while some believed that blood from the donor could be ‘stronger’ than the recipient’s for reasons that the latter (child) was sick:

“We also fear receiving blood that is not in line with our blood group” ...“We fear that the child might be given blood different from his group (R1- FGD-01, Masaka). “Assume you are group-O and they give you A...I feel afraid about that” (R2_FGD-01, Jinja). “Then you cannot recover if that ever happened” (R3- FGD-01, Masaka). “Sometimes we think if they transfuse a child, she might die, because that blood would be incompatible with this existing one” (R2_FGD-02, Hoima).

Human error by negligent health workers was implicated for the risk of blood group incompatibility:

“It is possible [that they can give you wrong blood];...don’t doctors sometimes leave surgical knives in the bodies of those they have operated?” (R5- FGD-01, Masaka). “They will have just

forgotten;...the same can happen - while transfusing the child with a wrong blood group”...“doctors really get tired” (R5 & R3- FGD-01, Masaka).

Furthermore, caregivers described being worried that blood from the donor could be ‘stronger’ and different than the recipient’s on the account that the recipient was younger, and/or sick. The perception that donor blood was stronger and therefore incompatible, was also attributed to temperature differences between the recipient and donor unit, which is obtained from refrigerated storage:

“According to me, the blood of my child has been circulating in the body at a temperature different from that of the blood unit in store. I presume that they usually put it in the fridge. It is therefore difficult for the new one (donor blood) to move at the same speed as the existing one. You imagine how this blood is going to coordinate with the one that has been working and get confused...I wonder how it can be compatible with this existing one” (R6_FGD-02, Hoima).

Similarly, blood incompatibility was also believed to result from the body system initially not being used to the new blood, and requiring time to adjust, while others doubted that all the blood transfused was human blood. Some believed that when the body receives new blood, there was a high risk of the child’s condition worsening as the new blood tends to first interrupt the system:

“I become concerned about his life because he has been given blood which was not created in him” (IDI_03, Hoima). “Sometimes you fear that the blood they are going to put will first disturb her ...because the blood may not be compatible with the existing one” (R1_FGD-02, Hoima). “When they put it, the child will not immediately become fine. It can take some time before it (blood) gets familiar with the existing one so that the child can play, eat, and walk well again” (R7_FGD2, Hoima).

iii) *Negative effects on cognitive abilities and behaviour* - Some respondents believed that transfused blood affected the cognitive abilities and behaviours of the recipient: *“I was told that if they transfuse a child, she can’t live long”... “that the child becomes small and also loses her intelligence”* (IDI- 02 Hoima, a 23 year old single mother). Others reported that they had overheard that a child may be transfused with blood from an animal, and feared that this could result in child’s behaviour becoming ‘wild’:

“Others say that they [health workers] get animal blood and put it into a child. That when they put it into a child he grows wild, becomes heartless...like an animal” (R8- FGD-1, Hoima).

“Another concern is, they transfuse them with blood from animals”....(laughs)....”you can’t see the animal but you can notice that the behaviours of the child are different after blood transfusion; he changes to a wild behavior” (R2 &R6- FGD-2, Hoima).

Some participants appeared to justify their worries about risk of animal blood by claiming that some blood products they sometimes see in hospital were un-familiar and did not look like human blood: *“To me, there are times when you see some types of blood (referring to blood products) at hospital and you also fear...wondering if that were human blood or not?”* (R5- FGD-02, Hoima).

iv) *Once transfused, child will always require transfusion* – some caregivers claimed that children who got transfused would always require transfusion each time they got sick:

“Others say that children who get blood transfusion are very difficult to take care of because once transfused, it means that each time they get sick, they will require a blood transfusion. So if he does not get blood transfusion, he will not survive” (R1_ FGD-01, Masaka).

Although the perceived risks of blood transfusion were widespread, there appeared to be variation in perception, with it tending to be lower among caregivers of recently transfused children. This was probably due to previous experience as well as knowledge of HIV testing for donor blood and pre-transfusion grouping and cross-matching. Other categories of caregivers who expressed less fears of transfusion were the elderly caregivers, and those who expressed much faith in God. Nonetheless, even those who expressed excessive fears of transfusion described exceptional circumstances under which transfusion was acceptable, in particular, the child being critically sick:

“Sometime back I used to fear blood transfusion but when I grew up, I discovered its importance. People used to scare us that some of the blood transfused to children was infected with HIV”.

“But I came to know that every blood unit has to first be tested before being transfused into a person” (IDI-02 Masaka; a 62 year old grand-mum). “Fear?... May be when your child is not sick!.....but when you are sick or in a critical condition....how will you fear a blood transfusion?(R2- FGD-01, Jinja). As long as I know that it is going to save the life of my child then there is nothing to fear because fearing will not bring any solution for my child. When I bring the child to hospital, all I want is his life to be saved” (IDI-04 Masaka, a 37year old born-again Christian).

Challenges in accessing blood for transfusion

Caregivers reported encountering enormous hardships while seeking blood transfusion services in Ugandan health facilities. The most frequently mentioned included scarcity of blood, distant and inaccessible hospitals, and poverty. Health system challenges such as health workers’ attitudes and ‘under the table’ costs were also identified. Reporting about blood scarcity and the need for one to have sufficient money, one caregiver stated:

“.....Blood was scarce and we had to buy it from ‘hospital-one’ (name concealed). Without 20,000 shillings, you could not get blood” (IDI-04 Masaka).

Some participants described feeling extremely frustrated by the complicated, tedious and costly process that often involves back and forth movements between health facilities, in search for blood. Many appeared to resent being referred with the patient to other facilities to obtain a blood transfusion, and appeared to suggest this was the role of the health facilities to find and store blood:

“They refer you to ‘hospital-two’ (name concealed). But a person like me I don't know that place. When you reach ‘hospital-two’; there is no blood and they refer you back to where you came from.....then they tell you to go and buy the blood. I know where to buy it; at ‘Medical Centre-three’(name concealed), (a private health facility in Jinja town). It is at 30,000 shillings a unit. But they may tell you it is out of stock! Then you will have to go to ‘hospital-four’ (name concealed), [another private health facility in Jinja town]. If you find blood there, they may tell you there is only one bottle left, yet your child needs two!” (R4-FGD-01, Jinja).

Reporting about under the table costs, participants decried the tendency by health workers to solicit bribes from the well-to-do patients in exchange for preferential care to the disadvantage of many of them who cannot afford to offer money. They claimed that blood may be hidden away and only given to those who can pay some money:

“Others hide it, and say they don’t have blood when in actual sense they have it but they want some bribe” (R6- FGD-02, Jinja). “We give them money, ‘kintu-kidogo” [literally meaning something small in the swahili language] (R5- FGD-02, Hoima). “You reach hospital; a

government hospital moreover and the health worker asks, 'how much do you have?' before they can treat your baby; and sometimes you don't have even 50 Shillings”(R4- FGD-01, Jinja).

Delays at the hospital facility from overwhelming numbers of patients and weak triage systems were also highlighted as a major bottleneck to accessing transfusion care: *“We delay in the emergency room. You find very many people in the hospital yet your child is badly off. Meanwhile the doctors are doing their own stuff and not minding about you”* (R5_ FGD-02, Masaka). *“You come very early in the morning and line-up; but by the time they reach you, they say they are tired...or tell you that the medicine or blood is out of stock,...or ‘we are going for lunch’.... your child might even die”* (Chorus_ All FGD - 01 women, Jinja).

Distant health facilities appeared to hinder access too, especially when patients were referred: *“Hospitals being very far; by the time you reach there you find that your child is already dead”* (R2_ FGD-02, Masaka).

“That side of Buvuma Islands, there are no boats. So by the time you move from there to reach where you can get blood, it takes long, so even if the child would have survived, they die” (IDI-01_Jinja).

Just like distance, poverty among most rural caregivers hinders many from accessing the much needed transfusion services in time:

“After being told that the child has no blood; you start wondering what you are going to do, and contemplating; what should I sell to get money to reach hospital? You may sell a goat or food stuffs that you are harvesting.he rather dies from hospital but when I have reached”. “Sometimes if you have friends, you go to them and borrow...” (IDI_02, Jinja). *“The money that I had couldn’t transport me up to Masaka referral hospital”....(IDI-04, Masaka).*

Potential consequences of blood transfusion fears and challenges

The fear of contracting HIV from donor blood was not without misconceptions; some of which may significantly undermine the use of this service among some caregivers. In addition, concomitant poverty and several other health system challenges together appear to force many to seek alternative local remedies, risking the death of many children, as illustrated below:

“They told us that the blood they get from HIV infected people help to treat people who are also infected. They say there are few people who are free from HIV, yet they keep recruiting many people to donate blood..... so, how safe are we? That out of ten you find only three who are HIV-negative; how will the blood be enough in hospitals? That’s why some people refuse to take their children to hospital and decide to use herbal medicine” (R3_ FGD-02, Hoima). “Where they refer you to go and get blood is far,...and there is no money. In such a case if I had my sister, I would instruct her to go back home and prepare local herbs and give to the child until the doctors bring blood or until we get money for transport” (R3_ FGD-01, Jinja). “For example, right now the doctors are on strike,so you reach hospital and they are on strike. Why wouldn't I go home and boil my herbs” (R4_ FGD-01_ Jinja).

Further more, caregivers of children receiving blood transfusion often encountered discouragements from their communities arising mainly from misperceptions:

“People from the community often say those things;... ‘don’t you know that sometimes they transfuse with bad blood (‘ebisaayi’) that may affect your child and you can even lose him’...but me I told them that if he is to die, that would be God’s will. Even those who do not get blood transfusion die”. “If you listen to them, you may not come to hospital”(IDI-02_ Jinja).

Peri-transfusion and post-transfusion care, beliefs and practices

Besides the fear for a too rapid blood infusion and avoiding feeds while receiving a transfusion, there were no major beliefs held among the community about the transfusion process:

“I have heard that when the transfusion is on, you are not supposed to give the child food to eat..... that you wait until the blood drip is complete....” (IDI-02_ Jinja). *“And when you see that the blood in the tube is flowing very fast into the child, you just know that you have lost that child...”* (R-3_ FGD-01, Masaka).

On the contrary, post-transfusion care views were many and strong. Community members reported that children in the post-transfusion period needed to be cared for well generally.

Proscriptions included avoiding heat including: not bathing in warm water, avoiding the heat of the sun and fire, avoiding rain and heavy covers:

“In that case I have to stay home for some weeks and care for my child because another person would not care; ...they might even say 'go and bring me water to drink'.....” (R5_ FGD-01, Jinja). *“After blood transfusion, we are told not to expose the child to direct sunshine. You have to leave her in the house or under the shed. Failure to do so will lead to too much heating from the sun, yet the child possesses blood that is not theirs”* (IDI-02, Masaka). *“When a child has undergone blood transfusion, it is not good to bathe him with warm water, because it affects the blood flow. It warms the blood, affecting its movement...and it circulates fast. But cold water cools the blood and its movement is regulated”*. *“Yes, with warm water it moves very fast....but when you bathe the child with cold water, it cools the body and there is good circulation of blood”* (R1&R5_ FGD-02, Jinja). *“When it is raining; you do not send that child into the rain,...you do not send*

that child to cook, or to fetch water” (R3_ FGD-01, Jinja). “The heat from the fire should not get near the child.....” (Chorus, All women_ FGD-01, Jinja).

Discussion

The aim of this qualitative study was to describe the local community perceptions of paediatric blood transfusion in Uganda. The study found that both caregivers and community members perceived blood transfusion as an important and life-saving intervention but also found both infectious and non- infectious risk concerns, including the dread for HIV transmission, blood incompatibility and a too rapid blood infusion among others. The perceived benefits correlated with documented evidence in the literature of the indispensable life-saving role of blood transfusion among children with severe anaemia in Africa and the lethal nature of delay in transfusion (Dzik 2015, and Thomas *et al.* 2017). Furthermore, the interviews documented several challenges including the effects of poverty, health systems bottlenecks of blood scarcity, delays in transfusion and disinterested health workers -- all of which undermine access to life-saving transfusion services. The findings of this study are relevant to the African setting and beyond not only because of the sampling approach used that included different categories of caregivers, but also because perceived risk is neither dependant on its severity nor likelihood of occurrence, but rather socially constructed and this being driven by many factors (Hergon *et al.* 2004, and Lee 2006). This particular notion was highlighted by one FGD respondent from Masaka who urged that knowing that the blood is first tested for HIV does take away their fears. Whereas the majority of findings, such as the life-saving benefits of blood transfusion may be generalizable, others such as the dread for HIV transmission and challenges of blood scarcity may be specific to the communities assessed. Further research is required to determine if specific

beliefs and practices are widespread and could therefore be addressed on a national or pan-African level.

According to psychometric paradigms of risk perception, the blood transfusion associated safety concerns documents in this study fall in all the three psychological risk dimensions of ‘benefit’, ‘dread’, and ‘unknown risk’. The life-saving role of transfusion fell into the ‘benefit’ domain; the fear for HIV transmission, a too rapid blood infusion and blood incompatibilities belonging to the ‘dread’ domain; while concerns such as reduced life span and being transfused with animal blood to the ‘unknown risk’ domain. This study however found no obvious consequences of risk perceptions such as stigmatization that have been documented to ensue (Slovic 1987, and Ngo *et al.* 2013). Except for the community’s local constructions of blood incompatibilities that went far beyond the blood groups to include donor blood-recipient ‘familiarity’(the body having to first get used to it), ‘possessing blood that was not created in you’, and donor blood-recipient temperature differences which were believed to dysregulate blood flow, the majority of the findings are comparable to blood transfusion risks documented by other studies performed outside sub-Saharan Africa. Even most of the perceived risks such as changes in behaviour and cognition and donor blood being ‘stronger’ were understood in the context of ‘incompatibility’. Indeed, these previously unrecognized views and concerns likely emerged because this study was the first in Sub-saharan Africa to evaluate perceived risk of blood transfusion using focus group discussions and in-depth interviews rather than questionnaires with closed ended questions, or telephone interviews as has been in the case with prior surveys (Ngo *et al.* 2013).

Transfusion safety concerns remain high in the general public, the greatest being the dread of contracting HIV from a blood transfusion, which may be exaggerated sometimes. Other documented blood transfusion risks as perceived by both patients and clinicians include hepatitis,

allergic reactions, fever and dyspnoea, with differences between the two groups (Lee 2006, and Vetter *et al.* 2014). Another public survey still showed fear for HIV/AIDS to be the greatest, with females perceiving higher risks (Finucane *et al.* 2000). However, most of these surveys have been conducted in developed countries, with the current study being the first of its kind to evaluate blood transfusion perceived risks in Africa.

Among caregivers of recently transfused children, the general fear associated with blood transfusion was less compared to community members in FGDs. This is in line with risk judgement analysis, where some scholars have urged that past experience greatly shapes the perception of risk (Lee 2006). A study done in Korea showed similar findings (Whang *et al.* 2009). Another observed trend with the caregivers was that they generally appreciated the benefits of blood transfusion. In contrast, community members in FGDs voiced concerns about challenges of transfusion access such as bribes, delays at health facilities and referral networks more than the caregivers. Apart from these few differences, responses from IDIs and FGDs were similar.

Beliefs that the source of blood for the transfusions could be from animals were an interesting finding in this study, but these are similar to ancient views held by some people during earlier blood transfusion experiments in Europe which involved getting donor blood from animals such as sheep and dogs into humans. At the time, the belief that such animal-human transfusions might transfer wild spirits and change human behaviour into animal behaviour were common and caused opposition against these early scientific developments (Marinozzi *et al.* 2018). These views were expressed by respondents from *Bunyoro* region; and besides this uniqueness, there were no differences in local perceptions of transfusion across the three regions of Uganda.

The perception of blood transfusion by community members and caregivers documented here as being both beneficial and risky with access challenges, bring to light the many knowledge gaps that need to be addressed through patient and community sensitization as well as the ugly health systems bottlenecks that must be overturned to promote access to timely transfusion services in Uganda.

Limitations: The fears and safety concerns documented in the current study emanated from interviews of 75% women caregivers of children. Because the female gender has been associated with an exaggerated risk perception of blood transfusion compared to males (Finucane *et al.*, Lee 2006, and Whang *et al.* 2009), these findings may not be balanced based on gender. Similarly, the views from FGDs of female community members might not be representative of the entire community. The current study also did not evaluate the views of those who avoid or refuse blood transfusion. It was also beyond the scope of this study which employed a qualitative approach to measure risk domains.

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