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Child mortality in Eastern Ethiopia: acceptability of Postmortem minimally invasive tissue sampling in a predominantly muslim community

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Abstract

Background It is crucial to consider cultural, religious, and socio-behavioural factors that may influence the acceptability of Minimally Invasive Tissues Sampling (MITS). MITS is being used to understand the causes of child death and conducted in nine countries within Africa and South Asia with the highest child mortality. Progress has been made in the development of laboratory infrastructures and training for physicians to do MITS, but many communities are concerned about the religious acceptability of taking samples from deceased children. This paper explores the acceptability of MITS in a predominantly Muslim community.

Methods A qualitative study was conducted in Kersa and Harar, in Eastern Ethiopia between April 23, 2018 and April 21, 2019 where high child mortality rates have been recorded. The study involved interviews and focus groups with 76 participants, including mothers, elders, and religious leaders. In addition, observations were conducted at burial ceremonies and in grieving families' homes. Grounded theory framework is used in this article to understand the acceptability of postmortem MITS.

Results We explore cultural, religious, and socio-behavioural barriers and facilitators that may influence the acceptability of minimally invasive tissue sampling. We identify three themes relating to the acceptability of MITS: (1) Perceptions and rituals related to child death (2), Religious acceptance of post-mortem investigation, and (3) Fears and suspicions of organ theft and body mutilation. Most participants hypothetically accepted MITS, but suggested that the procedure consider religious practices. Religious leaders and parents stated that they would accept the procedure if it would help reduce child deaths. Acceptance is inconsistent and differs across time and place. Some villages accepted the procedure swiftly, only to change their views when they became aware of suspicions from other villages about the procedure disfiguring the body. Parents of deceased children were concerned that taking samples from the children's bodies would delay the burial.

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Conclusions Mortality surveillance requires a thorough understanding of the cultural, religious, and sociocultural aspects that may affect the acceptability of MITS. MITS research should be conducted close to communities, involving community members, incorporating religious perspectives, and promoting health outreach campaigns to facilitate sociocultural perceptions of the research activities.

Keywords Religion, body, Minimal invasive tissue sampling, Child death, Burial ceremonies, Acceptability

Background

In low-income countries, many children die without being seen by qualified medical personnel. Most die without a documented medical history and are often buried before a cause of death has been determined. In addition, under-five deaths that occur in rural areas are often not tracked, and most children die at home before visiting health facilities. The WHO recommends verbal autopsy for identifying causes of death in areas without other systems, but its efficacy is limited by recall bias and difficulty distinguishing diseases with similar clinical presentations [1]. Complete diagnostic autopsies are the gold standard method of determining the cause of death, but it is challenging to undertake these due to a lack of resources in low-income countries [2]. Another concern is that acceptance of complete diagnostic autopsy is low in many parts of the world due to socio-religious practices of burial delay [3].

The preparation of bodies for burial ceremonies is significantly influenced by religious practices. Among many Muslims, ritual washing, cleaning, and prayer must be done within 24 h following a person's death [4]. This will allow the soul to enter paradise in a blessed and pure state [5]. Moreover, according to the Hadith (words of the prophet Mohammed), "to break the bone of a dead person is like breaking the bone of a living person" [6]. One study identified the influence of religion and culture on continuing bonds in a sample of British Muslims of Pakistani origin, which showed that religion strongly influences actions thought to help the deceased, and cultural mores and collectivist ethos have tremendous implications around the time of death [7]. Furthermore, a study conducted about MITS acceptance in North India among Muslims suggested that parents would accept MITS provided they were given the proper attention, communication, counselling of the benefits, and reassurance that there would be no bodily harm during the procedure [8].

This paper emerges from the Child Health and Mortality Prevention Surveillance (CHAMPS) program, part of a nine-country network. It was established by the Bill & Melinda Gates Foundation to identify the causes of death in children among communities with high rates of under-five child deaths [9]. The program carries out both mortality and pregnancy surveillance. Minimally invasive

tissue sampling (MITS) is a method to gather small samples of body fluids and tissue from the bodies of children who have died. It uses a unique instrument with a spring-loaded needle mechanism without any incisions on the body [10]. MITS is less invasive than complete diagnostic autopsies, quicker to perform, and often more acceptable as it is considered not to mutilate the body [11]. The mortality surveillance findings from the sites (between February 4, 2019, and February 3, 2021) indicate that perinatal asphyxia or hypoxia and birth defects were the underlying causes of stillbirths [12]. Among neonatal deaths, perinatal asphyxia or hypoxia was the most common underlying cause, while neonatal sepsis was the most common immediate cause of death [12]. For deaths in children aged 28 days to 59 months, malnutrition was the primary underlying cause, and infections were common immediate and comorbid causes [12]. Although the MITS procedure is less invasive and quicker than other autopsy techniques, communities in eastern Ethiopia are not necessarily ready to accept it. In an area where autopsies are far from common, it was expected that MITS would be contentious because of concerns about mutilation, delays to burials and reduced body purity. Perceptions about child death, delay of burial time, and doubt about the procedure may influence the acceptability of MITS. The aim of this paper is to understand the various factors that impact acceptability and what is needed to accommodate families of children in this context. The MITS procedure may be acceptable in places where it satisfies social and religious rituals, but acceptance is a continuous process.

Methods

Setting

The research was conducted in Ethiopia's Kersa and Harar Health Demographic Surveillance Systems (HDSS). The Kersa HDSS serves 24 of the 38 sub-districts [12]. In Kersa, 93.8% of the study population practice agriculture as their primary means of livelihood, and the remaining 6.2% are urban dwellers. The Harar Urban HDSS was established in six sub-districts among 19 urban sub-districts of the city of Harar [12]. Most of the population in Harar DSS are urban dwellers. Most of the study population was Muslim.

Design

The Child Health and Mortality Prevention Surveillance (CHAMPS) network, with nine sites in Africa and South Asia, aims to identify and track definitive causes of under-five child mortality in regions where it is highest and to generate and share high-quality data to inform policy and public health action. CHAMPS began work in Ethiopia in August 2017, conducting formative research and community engagement activities. The program carries out both mortality and pregnancy surveillance.

The CHAMPS social and behavioural science research used a qualitative design based on sociological and anthropological approaches, including ethnography and phenomenology. This research methodology is significant because it helps us understand behaviours and allows us to interact with community members and leaders. Ethnography helps in understanding local views on child death and burial ceremonies, which can impact the acceptability of child mortality and notification of child deaths. Phenomenology is an approach that seeks to understand first-hand experiences, in this case of families who have lost children under five, including attending grieving ceremonies and understanding ritual practices around stillbirths and child deaths. The study used a multi-method approach, including focus groups, participant observations, semi-structured interviews, and in-depth interviews to gather data on the feasibility of child mortality surveillance among grieving families, religious leaders, and community-based organizations. This multi-method approach facilitated data triangulation to validate data collected across different tools to assess the feasibility of child mortality surveillance. The study aimed to understand the factors affecting the acceptability of Minimally Invasive Tissue Sampling (MITS), a method used to collect small samples of body fluids and tissue from deceased children [10].

Participants and data collection

The social science component of the study was conducted from April 23, 2018 to April 21, 2019 and used qualitative research methods to capture the 'emic' (community) point of view on burial practices of under-five child death. Before conducting qualitative research, we conducted Participatory Inquiry into Community Knowledge of Child Health and Mortality Prevention Surveillance (PICK-CHAMPS) workshops from July to August 2017 [3]. The PICK-CHAMPS workshops included 20 workshops in Kersa and Harar (437 participants) and aimed to develop a social history of the community and to learn about how the community had successfully met earlier challenges; understand community perceptions, beliefs, and practices related to child death, and the MITS procedure [13]. These discussions helped the researchers

form better relationships with study participants and develop community engagement activities [13].

The PICK-CHAMP workshops significantly aided the qualitative research process by facilitating community entry and communication, fostering strong relationships with the study communities. The data from these workshops was integrated into Key Informant Interviews and Focus Group Discussion guides to explore factors affecting child mortality surveillance, explicitly examining the implementation of Minimally Invasive Tissue Sampling (MITS) in healthcare facilities, homes, and communities.

There were 76 participants in the qualitative study, which included focus groups, participant observations, semi-structured interviews, and in-depth interviews. Before data collection, the CHAMPS team underwent training from Emory University's senior scientists on qualitative data collection tools, participant selection, interview guide writing, data transcription techniques, data management, and NVivo qualitative data collection tools. The training helped us adopt a reflective approach, and minimize subjectivity during data collection, coding, and analysis.

The study used purposive sampling techniques to select participants based on their experiences with child death, burial ceremonies, and religious beliefs (Muslim, Orthodox, Protestant). Collaborating with Kersa Health Demographic Surveillance data collectors and supervisors, the study included families who lost children under five, religious leaders, community-based organization leaders, and other community members. To ensure a variety of participant voices were included, the study also involved community leaders and members who could influence the acceptability of MITS, such as traditional birth attendants and healthcare workers.

The study participants were interviewed in person, and their consent was obtained after explaining the objectives of the study. The study aimed to prevent child mortality in the region and inform public health policy for better healthcare and interventions. The authors gathered data through one-on-one interviews in private settings, such as homes, health facilities, or research site offices. The study involved key informant interviews ($n=12$) with various participants, including imams, priests, pastors, traditional birth attendants, buriers, community leaders, health practitioners, and body preparers. Semi-structured interviews ($n=6$) were conducted with health officials, political officials, and health center heads. Six focus group discussions (FGDs) were held with 8–10 participants, including parents of children under five, fathers who lost a child, and religious leaders. The interviews lasted 45–60 min, while the FGDs lasted 60–90 min.

Over the course of a year, we conducted participant observation to gain insight into local perceptions towards

child death and to assess the possibility of implementing mortality surveillance. This involved attending burial ceremonies, interacting with grieving families, and visiting morgue facilities in health institutions. The data we collected helped us to identify the obstacles and opportunities for implementing mortality surveillance among the participants, as well as the societal power dynamics at play. The study also aimed to explore the influence of religion, values, traditions, and practices around child death.

During the data collection process, the researchers used the local languages of Amharic and Afan Oromo. This helped us to clearly understand the conversation with participants and probe for further questions. In addition, it supported the data analysis process.

The study explored perceptions of child death, the body, religious beliefs about child death, and ritual practices during the funeral ceremonies. In addition, barriers and facilitators of the MITS procedure were identified. Data from focus group discussions showed us the processes of body preparation and leaving the dead for the burial ceremony. Also, the role and responsibility of religious leaders during the burial ceremonies were identified, and appropriate ways of approaching a family who lost children for post-mortem were explored. During observations, the authors explored burial ceremonies and grief rituals to understand how people express grief after a child's death and how burial attendants offer condolences.

Data analysis and interpretation

Researchers analyzed and interpreted the study's findings using an iterative approach to data collection and ongoing analysis. The authors stored audio recorders in locked cabinets, and databases and computers were password protected. The research team, which had received training in data management, security, collection, standard coding, and data analysis, followed data quality protocols for consistency. After data collection, the research team developed weekly data summary sheets to document the main themes derived from interviews, focus group discussions and observations. We summarized the socio-demographic characteristics of participants involved in the research and the main themes emerging. All data collected through key informant and in-depth interviews, semi-structured interviews, and focus group discussions were digitally recorded, transcribed, and translated. We transcribed the audio file verbatim into local languages and then translated it to English. To protect the participants' privacy, we assigned them four-digit numbers and labelled the data types (audio, transcripts, translated data) using their initials instead of their names.

After the authors conducted quality checks, we imported PDF documents into NVivo, version 11, a

software used to manage and code large qualitative data sets. The research team then coded transcripts, observation reports, and field notes. We created a general outline of nodes and codes, known as a coding tree, to allow flexibility in including emerging themes during data collection from different sources. We used an inductive approach to code the data from the transcripts. We regularly discussed the coding tree and emerging themes for analysis. Once we reached a consensus on the emerging themes, we conducted the analysis, which included the field reports and non-verbal communication observed during data collection. All the themes included in this paper emerged from the collected data. Grounded theory was used as a framework for data analysis, which allowed us to code the data and let new themes emerge in the process.

In this article, grounded theory is used to understand the acceptability of postmortem minimally invasive tissue sampling in a predominantly Muslim community. The study includes constructivist grounded theory strategies. It allows us to explore perceptions about child death, delay of burial time, and doubt about the procedure that may influence the acceptability of MITS. The study uses several strategies as part of grounded theory: collecting data in iterative stages, using theoretical sampling, coding the data, interpreting data to link with the theoretical foundation of the study, and constructivist grounded theory.

After conducting open coding, new themes emerged, including the parent node or code and child node or code.

Parent node/code: Beliefs about child death, religious acceptance of MITS, and doubt about the MITS procedure.

Child node/code: Children are born sinless, belief in life after death, stigma of stillbirth, MITS procedure mutilates the body, MITS requires Fatwa approval, MITS procedure delays the burial ritual, MITS disfigures the body, suspicion regarding hospital mortuaries, and why the study focused on dead children Table 1.

Results

Beliefs about child death

Children are born sinless

Understanding specific cultural, religious, and socio-behavioural factors that may influence the acceptability of MITS for children under five is essential to conducting mortality surveillance. Beliefs about child death, corpses, religion, tradition, and confidentiality impact the feasibility (acceptability, practicality, and implementation) of sample taking, and the deceased family is not sure of the approval of examining a dead body. In addition, in

Table 1 Socio-demographic characteristics of study participants from September 15, 2017 and February 4, 2019, Harar and Kersa District, Eastern Ethiopia. A total of 76 participants took part in the study and a majority of the participants were muslim (81.5%)

Participants	Harar n(%)	Kersa n(%)	Total n(%)	Number of children in the household
Gender	18 (23.6)	26 (34.2)	44 (57.8)	1–3 children are among the 44 households
Male				
Female	12 (15.7)	20 (26.3)	32 (42.1)	
Age group, years				
18–30	7 (9.2)	9 (11.8)	15 (19.7)	
31–49	18 (23.6)	22 (28.9)	40 (52.6)	
> 50	10 (13.1)	11 (14.4)	21 (27.6)	4–6 children are among the 19 households
Education				
No schooling	1 (1.3)	17 (22.3)	18 (23.6)	
Primary	5 (6.5)	24 (31.5)	29 (38.1)	
Secondary	8 (10.5)	3 (3.9)	11 (14.4)	
Professionals	10 (13.1)	8 (10.5)	18 (23.6)	7–8 children among 4 households
Occupation				
Gov't Employee	5 (6.5)	4 (5.2)	9 (11.8)	
Farming	1 (1.3)	29 (38.1)	30 (39.4)	
Church service	12 (15.7)	26 (34.2)	37 (48.6)	
Religion				
Muslim	27(35.5)	35 (46)	62 (81.5)	No children among 9 households
Orthodox Christian	6 (7.8)	3 (3.9)	9 (11.8)	
Protestant Christian	3 (3.9)	2 (2.6)	5 (6.5)	
Catholic	1 (1.3)	-	1 (1.3)	
Ground total			76	

Ethiopia, it is not common to examine early pregnancy loss, stillbirth, and neonatal death. An interview conducted with a father who had lost a child due to a hospital based stillbirth said: 'People say that the soul of the child goes to paradise; that means the child did not commit any sin when alive, and there is a belief that the soul will go to paradise.' Many people at the research sites believed that children would automatically enter paradise because they did not sin. God will not question children under 15 because they are innocent. Children under 15 will not be questioned by God because they are innocent. Religious 'guarantees' ensure that children enter paradise; hence, they do not commit sins Table 2.

A belief in life after death

Another belief that impacts the acceptability of knowing the causes of child death is that of life after death. This ensured the family of the deceased child to have hope for the future after death. During a discussion with a religious leader in Harar, Abdela described: 'There is life after death, and the child's soul will have a function to wait and welcome their parents at the gate of paradise.' The participants in the FGD in Harar and interviews in Kersa shared a similar understanding in life after the child's death. Community members explained that when a child dies,

their soul separates from the body and advocates for their parents to enter paradise. 'As I have heard from elders, child's soul goes to heaven to host and protects their parents,' Fatuma explained. In addition, Kemiya stated: 'As I heard from my grandparents, even though God takes it away, the soul also waits for parents after that death.' Participants said that God trusts the child for the advocator role since children are considered clean from sin. Chaltu, 32 years old, said: 'We usually tell mothers not to cry much; do not cry for what you lost because tomorrow is yours.' Chaltu added if the mother cries about the death, relatives or neighbours tell her not to do so because the child's soul hosts her in paradise. According to our findings, grief for many days is unacceptable for children under five, and it should instead be accepted as the will of God.

Stigma of stillbirth

There is also stigma associated with stillbirths and neonatal deaths for the mother. A mother who has lost multiple children is usually perceived as having a personal health problem. Data collected during participant observation shows that community members stigmatise mothers who lose children continuously and perceive that she has sinned or has bad fortune from God. Usually, a mother

Table 2 Data collection approach and type of study participants from September 15, 2017 and February 4, 2019, Harar and Kersa District, Eastern Ethiopia

Data collection approach	Types of participants	Acceptability of knowing the causes of child death	Objections to MITS
FGDs (n = 6)	Parent of under five children, Fathers who lost child, Religious leaders (Imams, Sheiks, Pastors and Priests)	<ul style="list-style-type: none"> -MITS can help improve children's future health and save lives -MITS results might help protect women in subsequent pregnancies or their newborn babies 	<ul style="list-style-type: none"> -MITS procedure mutilate of the dead body -MITS delay the burial procedure
KI (n = 12)	Imams, Priest, Pastor, Traditional birth attendants, Burier, Community based organizations leader, Health practitioners and Body preparer	<ul style="list-style-type: none"> -Identifying the causes of children's deaths would support health policy formulation and intervention actions 	<ul style="list-style-type: none"> -Fatwas (decisions made by Islamic scholars) are needed before the mortality surveillance -Why the study focused on child deaths rather than sick children
SSI (n = 6)	Health officials, Political officials, Head of health center and Nurses	<ul style="list-style-type: none"> -MITS findings would suggest a new vaccine or medicine for infectious disease 	<ul style="list-style-type: none"> -Only MITS and the health centre should receive medical supplies and medications to reduce infant mortality in the study sites
PO (n = 5)	Burial ceremony and site, Grieving family home, Hospital, Health center and Health post	<ul style="list-style-type: none"> -MITS can save lives and help children's health in the future. 	<ul style="list-style-type: none"> MITS delay the burial procedure and prayer time
Community Advisory board meeting minutes (n = 10)	Religious leaders, Community based organizations, Women representatives, Health bureau representatives, and DSS officer	<ul style="list-style-type: none"> -MITS was deemed a valuable innovation in identifying the causes of deaths 	<ul style="list-style-type: none"> -Hospital mortuaries would not release bodies for burial soon -It's better to build a new room to perform MITS procedures

who faces multiple stillbirths is stigmatised more than in cases where a neonate dies. The loss of a child may also contribute to divorce, which was observed during the surveillance activities where some families divorced after multiple stillbirths or neonatal deaths. As a result, some families are eager to participate in MITS to know the cause of death, and not be blamed for their child's death. Knowing the cause of death gives some families hope for the future as they felt that the knowledge gained from MITS might protect them in subsequent pregnancies or their newborn babies.

Religious acceptance of MITS

MITS procedure mutilates the body

There were various points of view on the acceptability of MITS when it is perceived that the procedure can help save children's lives and avoid burial delays. One concern is that the Quran never mentions the issue of MITS. For instance, a community leader, Hussain, said that studying dead children cannot reduce what God has already decided, and death is decided only by God. During an FGD, Usman, a religious leader, stated that conducting MITS helps prevent children from dying from similar causes in the future by identifying cause of death. However, Usman stated that while no religious teaching allows MITS, it can be done for the benefit of future children to be healthier. On the contrary, Ahmad, another religious leader, stated that while he agreed with the importance of the knowledge gained from MITS in saving children's lives, the procedure should not mutilate the body, and the body should not 'feel' pain during the procedure because religion does not allow the dead body to feel pain. This concept addresses physical pain and indicates the body's transition to the next journey without disturbing or mutilating the body.

MITS requires Fatwa approval

Key community figures, such as village leaders, religious leaders, and leaders of community-based organizations, asked the research team for formal religious documentation to clarify MITS acceptance. Kamal, a religious leader, said 'We need to be presented documented and official Fatwas [decisions made by Islamic scholars] about MITS from the National Islamic affairs council.' In response, the research team obtained a Fatwa from the Ethiopian Islamic Council which helped facilitate the MITS procedure by sharing this formal approval at community awareness sessions. We clarified that the National Fatwa Committee approved MITS to be conducted in as part of the study and, upon request, provided the letter to religious leaders and the family of the deceased child before

consenting to MITS. Some families requested the letter and consented to participate in MITS. However, one year after MITS introduced religious leaders in Harar and Kersa did not fully agree with the national letter and suggested an additional letter of confirmation from regional and district-level approval. They clarified that the regional letter is as significant as the national one due to widespread concerns that MITS may harm the body and not be accepted in Islam. In response, the Regional Islamic Affairs Office confirmed the acceptability of MITS use in the study through an additional approval letter. Religious leaders did not express any concern about this after being provided with the regional letter. The acceptance of MITS was not, however, completely resolved by the letter. The desire to understand the causes of child death is common among religious leaders, including those from Orthodox Christianity, Protestantism, Catholicism, and Islam. However, there are differences in the burial process and timing.

MITS procedure delayed the burial ritual

Another concern regarding the acceptance of MITS is timing issues during the procedure. Religious leaders found that the MITS procedure delayed the burial ceremony. Timing of the MITS procedure (starting from death to releasing the body to the family) impacts acceptance of the MITS procedure for the deceased child's family since the Qur'an has suggested that the burial be done quickly or before sunset. Yusuf, a community member, explained that preparing the body for the next steps must be done carefully and takes time; it includes washing the body, wrapping it with cloth, preparing the burial place, and performing the prayer ceremony; therefore, MITS should align with these steps and timeline. Observation data during the MITS procedure and burial ceremonies showed that the MITS practitioners washed and wrapped the body after the procedure to give the body back to the family for quicker burial. Initially, the MITS procedure took two hours or more to complete. However, as MITS practitioners gained skill, the duration was lowered to an average of one hour. Health workers with more MITS experience can release the deceased for burial in less time. In addition to time issues, religious practice mandates proper bodily cleanliness. Participants also emphasised that the body should be clean because of religious funeral rituals, and even a tiny amount of blood is unacceptable. During burial ceremonies, religious leaders state that body purity is essential and that the body should be thoroughly cleaned before burial. Following the MITS procedure, the religious leader would check the body and clean it again if there is any blood or fluid on it.

Doubt about the MITS procedure

MITS disfigures the body

In addition to concerns about MITS delaying burial, there were concerns that MITS would disfigure the body. Community leaders and families of children under five were concerned that the MITS procedure opened and mutilated the body and took vital organs, like kidneys. Yasin, a religious leader who observed the dead body following the MITS procedure, had concerns about the punctures he saw. He mentioned that the sample is taken from different parts of the body, and the body parts samples are taken from is visible and sometimes has a small amount of blood. Furthermore, worries about MITS disfiguring the body were heightened by the sound of the needle during sample collection. The participants who observed the procedure were worried about the sound that occurs when a small piece of tissue is taken from the body. The needle used to take the sample was one of the MITS procedure's concerns. Ahmed, a community health worker who notified the research team about a child's death and observed MITS, noted that the loud noise of the needle during sample was frightening to hear.

Suspicion regarding hospital mortuaries

Another issue that community leaders were worried about was the location of the MITS procedure. There was widespread worry that hospital mortuaries would not release bodies for burial. In Ethiopia, the MITS procedure was initially proposed to be performed at the hospital mortuary, and the protocol was designed accordingly. The study team needed confirmation regarding conducting MITS in the mortuary as they conveyed the idea to religious leaders and community members. According to community leaders, doing MITS at the hospital mortuary would raise suspicions of organ theft. The procedure for doing MITS in the mortuary was changed after consultations with community leaders, and a separate MITS room was constructed on at the hospital and at community health posts. As a result, doing MITS somewhere other than the mortuary lessened the concerns about organ theft. In addition, a room was built where the family or guardian could wait while the procedure was underway.

Why the study focused on deceased children

Additional questions religious and community leaders raised include why the study focused on death rather than sick children. One religious leader called Mohamad advised, 'It is better if your study focuses on alive children than dead bodies.' He said: 'I believe working with living children reduces child mortality more.' Healthcare workers and religious and community leaders expressed worries about the MITS method. Usam said, 'Why only MITS and the health centre should be given medical

supplies and medications to lower infant mortality in the study sites?' He added, 'We know the most common causes of child death among children who died at the health centre; what value does the MITS technique add to reducing child death? However, most health centre workers acknowledged that knowing the causes of children's deaths would support health policy formulation and interventions.'

Discussion

This study highlights that a desire to know the causes of child death is the primary facilitator of MITS acceptability in Ethiopia. MITS was seen as a valuable innovation for figuring out the causes of deaths. This knowledge can support future pregnancies, freeing mothers from the stigma associated with stillbirth and neonatal death, as well as preventing future child deaths. Similar findings have been reported from India and central Mozambique; the primary drivers of MITS participation are the desire for a subsequent healthy pregnancy, prior pregnancy loss, and neonatal loss [8]. Health workers also highlight that knowing the causes of children's deaths supports health policy formulation and intervention actions. Local health workers feel that the findings might support a vaccination intervention or additional medicines for infectious diseases, which is a common cause of child deaths [12]. MITS requires a thorough understanding of the various cultural, religious, and socio-behavioural beliefs that may affect how community members and leaders accept MITS.

A Fatwa letter from Islamic scholars served as a facilitator for MITS acceptance. MITS involves extracting tissue specimens (and body fluids sampling) from a predefined set of organs without opening the body and undertaking histopathologic, microbiologic, and molecular investigations. Considering all this, Fatwa scholars found the advantage of MITS greater than the disadvantages if it serves to save lives, and the committee provided a letter of legal acceptance. Islam now accepts autopsies when beneficial and is not against the actual procedure of autopsy [4]. Similar findings came from CHAMPS Bangladesh, which also obtained a Fatwa from the Islamic Foundation of Bangladesh, which they shared with families at their request during the informed consent process [13]. The acceptance of MITS can be increased by openly discussing the procedure, building trust, and practicing respectful body management with parents and community leaders. In Ethiopia, Fatwa letters from different levels of religious authority also contribute to the acceptance of MITS. However, some barriers that limit MITS acceptance remain.

MITS delaying burials is a significant concern. The acceptance of MITS is impacted by a failure to adhere

to religious ritual requirements. The funeral ceremony before sunset is a religious requirement, and parents must follow it. Parents of the deceased child feel that after the procedure, the body should be released as soon as possible. In Malawi, interruptions in funeral and transportation arrangements have been identified as the main concerns for accepting MITS [14]. Findings from Mozambique further emphasise the threat of delaying the child's burial, the financial cost of delays, the difficulty of making decisions, and how MITS objectives conflict with family values [15]. Results from a study in western Kenya have also shown that there are specific times prescribed for burial, and it was emphasized that leaders in the community would need to approve the procedure [16]. Also, in Pakistan, the most common concern related to MITS was a potential delay to the funeral [17].

MITS disfiguring bodies is another issue related to MITS acceptance. People are worried that the MITS procedure will mutilate the body. In addition, performing MITS at the hospital mortuary raises suspicions of organ theft. The procedure for doing MITS in the mortuary was changed after consultations with community leaders, and a separate MITS room was constructed in the hospital and rural health center. Doing MITS in a room other than the mortuary lessens concerns about organ theft [18]. In addition, a room was built where the family or guardian can wait during the procedure.

Proper body handling is a religious requirement, and similar studies in Africa and Southeast Asia also confirm the findings. Mishandling the body during MITS, including not suturing sufficiently, calls into doubt the holiness of the body. Medical practices contrary to Islamic religious practices have been noted as a potential hurdle in Mozambique [5]. Similar cultural obstacles exist in India regarding MITS acceptance [8]. The findings of a similar study also showed that an autopsy is considered a "disfigurement" of a person [19]. In Malawi, fears of organ and blood harvesting, disfigurement to the body, and interference with transportation and burial were some potential obstacles to acceptability [14]. In Ethiopia, the plan to conduct MITS in the hospital mortuaries was also a source of concern and many feared that the body might be disfigured. Findings from Malawi showed that parents and religious leaders emphasised fears about common hospital post-mortem procedures, like carrying the body in the mortuary, washing the body by mortuary workers, and harvesting organs to produce medicines [14]. To reduce this concern, the Ethiopian site built a separate MITS room and waiting room for the family or guardian to wait and to ask for further clarifications.

Finally, the concept that children do not commit sin and automatically enter paradise may influence the acceptance of MITS. This belief follows that the child's

soul has a function to wait and welcome their parents at the gate of paradise. Study that aimed to understand the willingness to know the cause of death in different countries (Gabon, Kenya, Mali, Mozambique and Pakistan) found that religious leaders and relatives of deceased individuals considered death was beyond their control and was reflected in expressions associating death with "God's will", "destiny", or "human nature [11]. To understand views around child death and life after death, working with religious leaders is significant to comprehend the potential advantages of MITS. Religious leaders are often comfortable with accepting MITS, however, an explanation regarding MITS is required [8]. At the same time, religious leaders and immediate relatives need detailed information about the advantages of identifying cause of death and the benefits it will have for future generations.

The desire among people in eastern Ethiopia to know the cause of child death are consistent with earlier studies, and it has also been concluded that MITS has potential to provide a learning opportunity for enhanced clinical care practice among healthcare workers [20] and that MITS has the potential to be part of hospital services [21]. In Malawi, given the sensitivity of death and autopsies, social interactions and power dynamics within healthcare institutions and households were a crucial part of MITS acceptability [14]. Health-seeking behaviours are not only determined by the parents, including participation in MITS, but the extended family plays a crucial role. Grandparents can consent to participate in the MITS procedure in Ethiopia, and the extended family is often involved in the decision. In Ethiopia, the study identified preventable causes of death across all age groups, including neural tube defects, hypoxia, neonatal sepsis, vaccine-preventable diseases, and malnutrition [12], which was only possible through extensive socio-behavioural research and long-standing engagement with local communities.

Limitations

The study was conducted in eastern Ethiopia, and while results show the acceptability of MITS, the findings are not necessarily applicable to other contexts or regions. The acceptance of mortality surveillance is not static, and it requires continuous community engagement activity. This paper's weakness is that it is challenging to generalise the acceptability of MITS for all community populations and the findings from this study might have limited relevance to other places inside Ethiopia.

Conclusion

Mortality surveillance requires specific, tailored strategies instead of a single approach that applies to all research sites that utilise MITS. There are various

cultural, religious, and socio-behavioural factors across sub-Saharan Africa where mortality surveillance is being conducted. Therefore, customizing approaches or being flexible with them will increase the acceptance. This may include thinking about the spaces where MITS is conducted and making sure that this is close to the communities to reduce delays to burials. The research team needs to be compassionate in caring for the body in culturally appropriate ways and involve family or neighbours in the sample-taking process. In many places, this will require incorporating religious perspectives into the research protocol by engaging in open dialogue between the researchers and key community leaders to address concerns and fears about biomedical research. In addition, community engagement on maternal and child health through health outreach campaigns, health education sessions, communicating procedure results, and community services activities, are just a few of the actions that can contribute to reducing the perception that the research is only about collecting samples. Instead, this can generate community buy-in of surveillance activities and increase acceptability of MITS. The strengths of this article include the exploration of socio-cultural views on child death from different community perspectives by collecting qualitative from parents who have lost children under the age of five. Additionally, the exploration of mortality surveillance using MITS is new for Ethiopia, and this paper can serve as a baseline for future MITS interventions.

Abbreviations

CHAMPS	Child Health and Mortality Prevention Surveillance
HDSS	Health Demographic Surveillance Site
FGDs	Focus group discussions
KII	Key informant interviews
MITS	Minimally invasive tissue sampling
PICK-CHAMPS	Participatory Inquiry into Community Knowledge of Child Health and Mortality Prevention Surveillance
SDG	Sustainable development goals
SSI	Semi-structured interview
TBAs	Traditional birth attendants
WHO	World Health Organization

Authors' contributions

K.D.M.A.C.A.B.D.G.W.A.T.B.S.Y.Z.Z.G.N.A. and A.S. designed the study. K.D.M.A.C.A.B.D.G.W.A.T.B.S.Y.Z.Z.G.L.M.Y.T.G.F.H.Y.E.T.K.A.S.T.A.A.N.S.A.K. performed data collection, data analysis, drafting, and editing. K.D. and M.A. data analysis and wrote the draft. A.S. and M.B. performed data Interpretation and substantial revision. C.A. L.M. N. J.B. M.M. supervised the data analysis and discussed and contributed to the manuscript. The author(s) read and approved the final manuscript.

Funding

This work was supported by the Bill & Melinda Gates Foundation through a grant EPDIJ66.

Data availability

Due to the sensitive nature of the data collected for this study, including in-depth information about families under study, it is not possible to deposit the entire data set in a publicly accessible repository. The data for this study will be stored under managed access by the Haramaya University Hararge Health

Research Partnership. However, data are available upon reasonable request from the corresponding author (degefaketema30@gmail.com).

Declarations

Ethics approval and consent to participate

This study was approved by the institutional ethics committee of the College of Health and Medical Sciences, Haramaya University and by the National Committee at the Ministry of Sciences and Higher Education (30.10/70/2018). In addition, it was approved by the London School of Hygiene and Tropical Medicine Ethics committee (LSHTM Ethics Ref:12104). Written informed consent was secured in the local language from the participants by signing (or thumb-printing where appropriate) on the consent form. Participation in this study was voluntary, and participants were informed that they could withdraw from the study at any time without any consequences. All people mentioned in this paper have been anonymized and given pseudonyms.

Consent for publication

Not applicable. All data used has been anonymized and de-identified.

Competing interests

The authors declare no competing interests.

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Received: 8 December 2023 Accepted: 20 December 2024

Published online: 26 December 2024

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