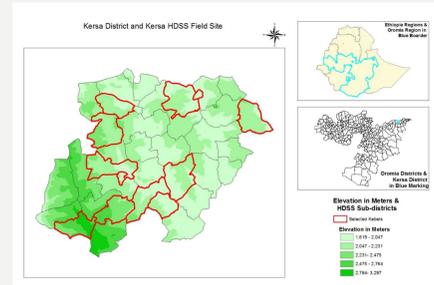


Formative research to understand culturally appropriate ways to collect post-mortem tissue samples using Minimally Invasive Tissue Sampling (MITS) for children under five: an overview from Ethiopia

Ketema Degefa¹, Berhanu Damise¹, Caroline Ackley³, Getahun Wakwaya¹, Adugna Tadesse¹, Lola Madrid^{1,2}, Nega Assefa^{1,4}, Ahoua Kone⁵, Maria Maixenchs⁶, John Blevins⁵

1.Hararge Health Research Partnerships College of Health and Medical Sciences Haramaya University, Ethiopia , 2.London School of Hygiene & Tropical Medicine London , 3. Brighton and Sussex Medical School United Kingdom 4.College of Health and Medical Sciences Haramaya University, Ethiopia , 5. Emory Global Health Institute, Emory University, Atlanta, Georgia, USA, 6. IS Global, Hospital Clinic-Universitat de Barcelona, Barcelona, Spain

Background



"Showing sympathy and comforting grieving family before approaching for consent, will increase acceptance"
(Interview with religious leader)



- Although progress has been made to reduce childhood mortality in Ethiopia, the under-five mortality rates are 55 deaths per 1,000 live births and, in Kersa, 72.8 per 1,000 live births (KHDS,2017).
- In Kersa and Harar health and demographic surveillance sites, children often die without having been seen by medical personal and are buried before an evaluation of the causes of death can be conducted.
- The CHAMPS Program uses **minimally invasive tissue sampling (MITS)** procedure to collect post-mortem tissue samples from vital organs and is accompanied by blood and urine samples, cerebral spinal fluid, and pictures of the deceased child to determine the cause of death.
- Tracking under five mortalities and determining cause of death is central to public health and to reduce child mortality in countries across Africa and south Asia.

Methods

- The study was conducted from **September 2017 to August 2019**.
- A total of **106 participants** took part of the study. Participants were recruited through purposeful sampling from Kersa District and Harar City.

Data collected :

- The study used qualitative data collection tools.
 - Focus group discussions (N=6): Pregnant women, Parents who had lost children under five years old, Religious leaders and Midwives. ~~The discussions aimed to learn about child death and handling of corpses, religions and traditions, confidentiality, family issues, and appropriateness of MITS.~~
 - Key informant interviews (N=12): Imams, priest, pastors, traditional birth attendants, community-based organizations, health practitioners and body preparers and nurses.
 - Semi-structured interviews (N=6): Health officials, political officials, head of health center and nurses.
 - Participant observation: (N=19): Burial ceremony and site, grieving family home, hospital, health center and health post.
- Data was managed and coded in Nvivo 12, and **thematically analyzed** to identify patterns related to **the acceptability, practicality and implementation** of mortality surveillance, commonalities, and differences among the emerging themes.

Conclusion

- CHAMPS formative research was significant to understand the specific cultural, religious, and socio-behavioral factors that should be considered to investigate child deaths (<5 years) by using MITS, but also to suggest recommendations to improve the feasibility and sustainability of surveillance system procedures and community engagement approaches.
- **Regular education on CHAMPS activities and MITS procedure is essential to reduce community suspicion about MITS procedure.**
- To increase the acceptability of MITS while the family is grieving and mourning it is necessary to: (1) **comfort the family before approaching for MITS consent;** (2) **share emotions and grief while asking for consent as this is valued in the community;** (3) **work in line with religious and socio-cultural practices** in this context of eastern Ethiopia;(4) and **communicate with the grieving family using the local language.**

Results

- Most study participants said that **MITS is hypothetically acceptable**, but that it depends on long term community engagement activities.
- Findings showed that the approach to MITS consent should pay close attention to **specific religious and cultural factors** associated with the timing of death to burial and the type of burial is associated with differences in age at death (i.e., stillbirth, neonate, or child). These include comforting the family before approaching for MITS consent, sharing emotions and grief, and follow-up and reciprocal feedback with community and local leaders.
- The study identified **study participant's fears, suspicions, and rumors**, including concerns about organ theft and blood looting during the MITS procedure.
- **Beliefs related to child death and corpse:** *If the bone of the dead body is broken it is the same as the killing of a living person.* Touching the corpse is allowed only if the relatives (Aali/fira) of the dead child give consent.
- The study also identified the importance of **radio program** outreach to have **two-way communications** with the study community and share research findings for people to learn how to avoid child death in the future.
- **Involving religious leaders in the family decision-making process** was seen as important to provide the family with the opportunity to address any questions related to religious rules and ensure that participating in MITS is not contrary to religious rules. Findings also showed receiving a fatwa reference from the Muslim legal committee helped improve MITS acceptability.

See more data at
champshealth.org



Contact Information

Ketema Degafa
Social and Behavioral Scientist
CHAMPS-Ethiopia / Haramaya
University
T: +251 963 345 206
degefaketema30@gmail.com

Berhanu Damise
Social and Behavioral Scientist
CHAMPS-Ethiopia / Haramaya
University
T: +251 910 436 315
damiseberhanu@gmail.com