NIHR Global Health Research Group
on Stillbirth Prevention and Management in Sub-Saharan Africa

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Uganda Report 2021

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Globally, around 2 million stillbirths occur every year – one baby dies every 16 seconds leaving behind a grieving mother and family.

Sub-Saharan Africa accounts for 64% of all stillbirths, with women in these settings being around eight times more likely to experience stillbirth than those living in high-income countries.

In Uganda, the stillbirth rate is reported at 17.8 per 1,000 births. Responding to international targets, Uganda aims to reduce this rate to less than 12 per 1,000 women by 2030.

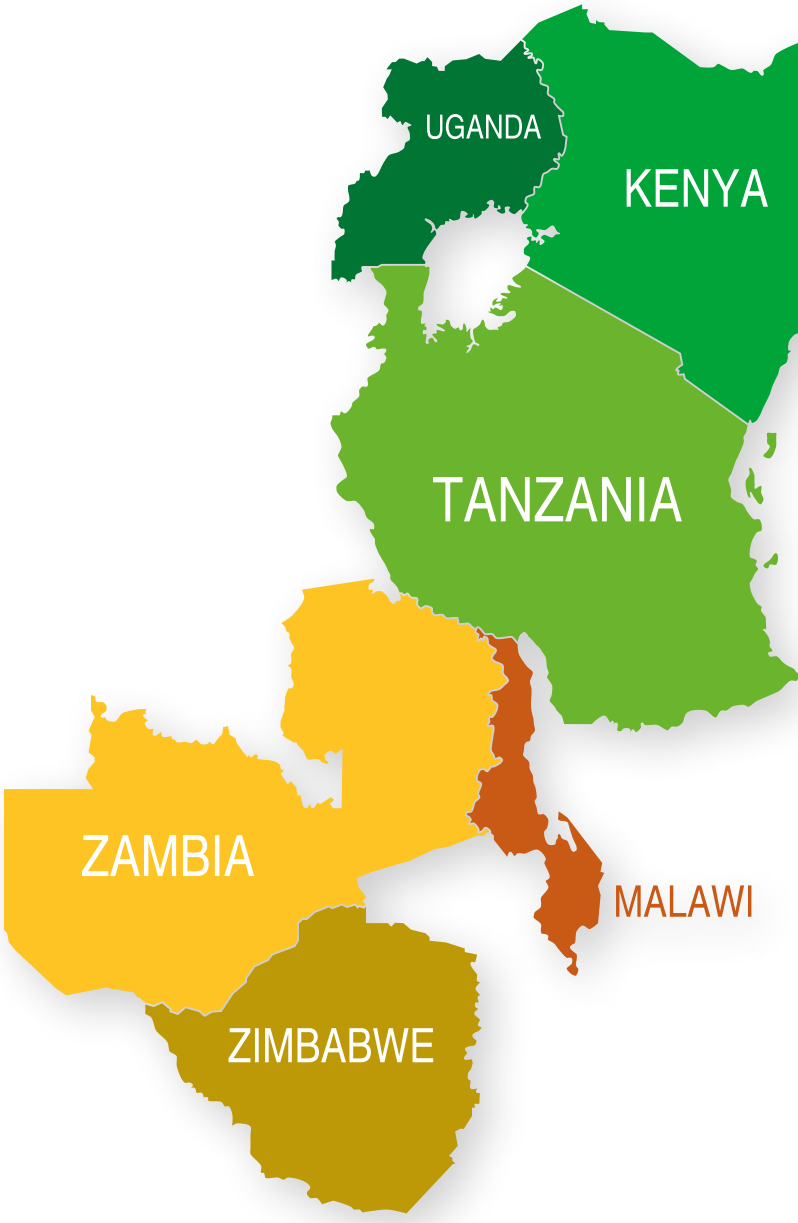
The NIHR Global Health Group on Prevention and Management of Stillbirth, established in 2017 and led by Professor Dame Tina Lavender, is a unique midwife-led research partnership between Liverpool School of Tropical Medicine/ University of Manchester (until 2020), and the Lugina Africa Midwives Research Network (LAMRN). In Uganda, the programme is led by Elizabeth Ayebare, LAMRN focal lead at Makerere University, Kampala.

Our research has focused on addressing the critical lack of research surrounding ending preventable stillbirths and providing appropriate support to bereaved parents in sub-Saharan Africa.

Dr Rose Laisser (Lead Tanzania) and Elizabeth Ayebare (Lead Uganda) sharing experiences and learning.

This project has provided a first ever opportunity for practitioners to reflect on their role when it comes to caring for bereaved parents. I feel humbled to see how it has motivated both them and peer supporters to take on the role of supporting bereaved parents, and their enthusiasm to see the networks growing so that we can reach every parent in Uganda.

Elizabeth Ayebare, LAMRN Uganda Stillbirth Project Lead



The research programme addressed two main themes:

1 - Stillbirth prevention

2 - Developing bereavement care and support for parents

Our Work in Uganda:

Theme 2 Developing bereavement care and support for parents

The death of a baby before or during birth is recognised as among the most traumatic life events for parents. Partners are also impacted, with increased risk of relationship and family breakdown. In LMICs culture and traditions may increase stigma and isolation. There is very little understanding of parents' experiences and care and support offered in sub–Saharan Africa.

PHASE 1 DEVELOPMENT WORK

Parents' and health workers' experiences of care and support after stillbirth (Qualitative study in Kenya and Uganda)

A study of the lived experiences of 195 mothers and fathers who had experienced the death of their baby and health workers who provided care in 5 facilities in urban and more rural areas in Kenya and Uganda. Despite some positive reports, women and families were not adequately supported by health workers after the baby's death. Health workers felt unprepared for this aspect of their work and did not receive adequate support from organisations. Some beliefs and cultural practices in communities compounded trauma increased isolation and stigma, particularly for women.

PHASE 2 INTERVENTION DEVELOPMENT AND TESTING

Improving bereavement care and support (Feasibility study in Kenya and Uganda)

With input from CEI and stakeholder groups in Kenya and Uganda, we identified improving care in facilities and postnatal community support as target areas for improvement. The intervention included training health worker volunteers from maternity and neonatal units as '**bereavement champions**' who would work to identify areas for development and promote good practice in facilities. Women with previous experience of stillbirth willing to provide support to others would be trained as **peer supporters**, enabling women to be offered access to telephone support in the first few weeks after the death of their baby.

The feasibility of research to evaluate the intervention was assessed with 44 women in Kenya and Uganda, recruited after the bereavement champion group had been introduced, who were offered peer support. Their experiences and outcomes were compared with 56 women cared for in the same hospitals, before the change was introduced. Despite COVID 19 interrupting the research, women were willing to take part and stay in the study until completion. Initial data suggests overall positive experiences of the intervention and a few improvements which could be made in a larger trial.

Bereavement champions and peer supporters

Advancing Bereavement Care in Africa (Feasibility study in Malawi, Uganda, Zambia and Zimbabwe)

Lack of preparation and education for health workers was a major theme arising from exploratory work across the 6 LAMRN countries. Therefore, we developed a one-day training workshop to improve health workers' understanding of the impact of baby death on parents. The workshop also introduced the evidence-based care covering good communication, supporting choices, making memories and information giving. The importance of self-care for staff was also covered.

We have also developed an educational film **the Heartbeat**, with Nabwiso Films in Kampala, to support the training. An accompanying preparatory workshop, prepared local midwife trainers to deliver the course in-person.

The feasibility of a large-scale evaluation of the training package is currently being assessed (May 2021) with midwives, nurses and students across 4 countries, including 30 midwives and nurses, and 32 students in Uganda. Initial feedback has been extremely favourable with more sites requesting to take part in the programme across the network.

Staff attitudes to communication are gradually changing and they are more sensitive and respectful in their speech. We have created a private room for counselling and further discussion away from the very loud wards with crying babies and continue to follow them up using the peer support staff to know how they are coping. Women now acknowledge and recommend others to come to Naguru hospital because of this approach – where women feel respected and handled with dignity.

Sarah Muwanguzi, Senior Nursing Officer and Midwife, Naguru China Friendship hospital

Our team agreed that the male partner's point of view and their experiences need to be accounted for in future research. We facilitated the creation of CEI group which has contributed to the intervention study. This experience has shown how difficult it is for men to express their emotions and devastation in these circumstances. They are in a vulnerable position and require an appropriate level of care.

Jonan Mweteise, Research Assistant in Uganda

Community Engagement and Involvement

This programme has been unique in including service users in stillbirth research across the LAMRN network.

CEI groups were set up in all countries to ensure that the views of those most affected by the death of a baby help to shape the direction of the programme. In addition to a CEI group of mothers who had experienced stillbirth, bereaved fathers in Uganda created a separate group for fathers to share their experiences and needs. Men often feel they should supress their feelings after stillbirth because of social and cultural expectations about their role to be strong and provide support to their partner.

Engagement with CEI groups has been a success from providing insight into optimal recruitment processes, reviewing participant facing information and supporting interpretation of research findings and dissemination at all levels.

Impact

The NIHR Global Health Research Group on Stillbirth Prevention and Management in sub-Saharan Africa has successfully delivered this programme of research and capacity development. This programme has catalysed acceleration of progress in preventing stillbirth and improving bereavement support, through building equitable sustainable partnerships with researchers in sub-Saharan Africa and generating high quality evidence.

Our research strengthening programme has enabled south-to-south collaboration to develop, with the Uganda team mentoring their colleagues from Tanzania on how to conduct audit and research-related activities in their facilities.

On a larger scale, working closely with the Ministries of Health and non-governmental organisations in each country we have already seen a raft of important changes take place, from informing national strategies and guidelines for stillbirth reduction in Uganda and Kenya, to triggering medical inquiries in hospitals with high numbers of stillbirths in Tanzania.

Dame Tina Lavender, Professor of Maternal and Newborn Health and Director of the Centre for Childbirth, Women's and Newborn Health at Liverpool School of Tropical Medicine in the UK, said:

This work has made important strides towards raising the profile of stillbirth in Uganda and across Africa, encouraging conversations and engagement with a topic that would often be viewed as taboo.

The changes that we have already started to see are paving the way for real improvements in care for all those affected by stillbirth, and on behalf of all those families, thank you. We really appreciate your input.

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