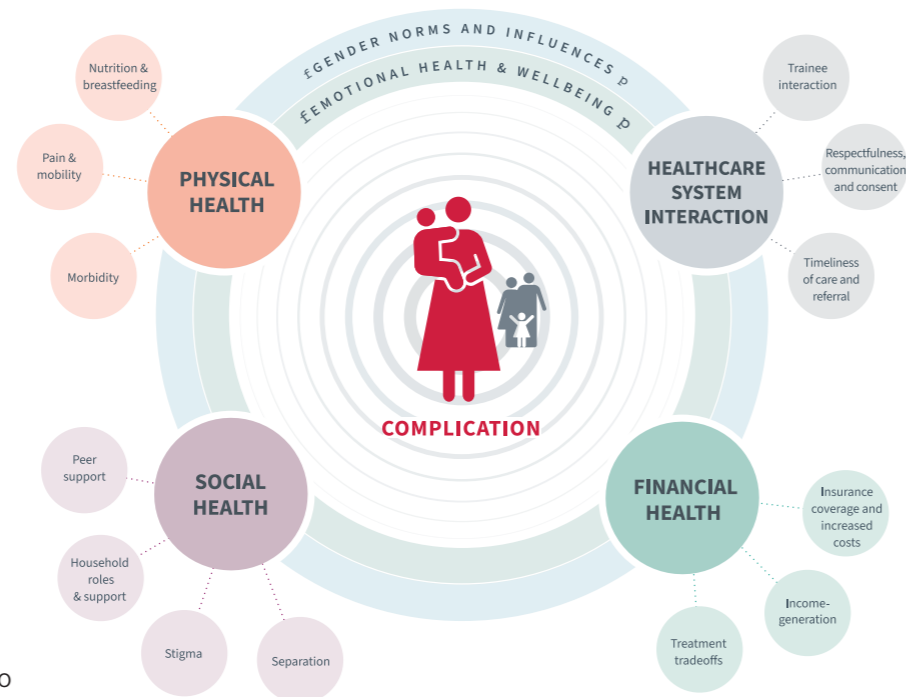


# The Beyond Survival Study

The Beyond Survival study followed women in low-resource settings in Kenya from delivery into the postpartum period to understand how complications during childbirth affect health trajectories for mothers, newborns, and households.

Our data gives an in-depth picture of the physical, emotional, financial, and social effects of a complication at the time of birth and beyond. It highlights the multiplier effect of birth complications — how they intensify the challenges of a vulnerable period and contribute to extended recovery times, lost wages, social isolation, and ongoing physical and emotional health challenges and decision-making.

In documenting women’s experiences, our findings bring attention to key opportunities to improve support and optimize health following a complication, giving every family the chance to thrive.



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# BEYOND SURVIVAL

## THE CHALLENGE

More than one-third of births around the world are affected by a complication. For mothers, this can look like an unplanned cesarean birth, eclampsia/pre-eclampsia, or postpartum hemorrhage. Newborns may be born too early, have trouble breathing at birth, or face serious infections and many require intensive care.

Great progress has been made globally to help women and babies survive these complications. **But surviving is just the start.** *The ripple effects of a complication can extend well beyond the birth event for mothers, newborns and their families, though these effects are often not recognized or well-understood.*



Join the conversation on strategies to improve wellbeing after birth:



KEMRI | Wellcome



# Key Actions for Clinicians, Nurses, and Birth Facilities

Creating change takes a team. Our full findings outline key steps all stakeholders can take to improve mothers', babies' and families' wellbeing after a birth complication. Here, we highlight key steps that clinicians and birth facilities can take around the time of birth to offset the long-term impacts of complications.

## Action 1:

Reduce mother-newborn separation during in-facility stays.

### WHAT WE FOUND:

For uncomplicated births, 93% of mothers remained with their baby throughout their stay in the health facility. However, after a complication, mothers and babies were often separated, especially when the baby required specialized care. In cases where both the mother and baby had a complication, just 27% stayed together.

### RIPPLE EFFECTS:

For mothers, separation can cause intense anxiety about the baby's survival and wellbeing, difficulty initiating breastfeeding, ongoing problems with milk production, and an overall feeling of helplessness. Longer term effects include poor infant growth and increased risk for infections.

*“Without seeing the child, I didn't know where the child was. I thought they were lying to me; maybe he got there and died.” [Note: the baby survived] (Mother C3\_14, maternal complication)*

*“He was taken to the nursery.... I was told, ‘Once you have strength, you can walk, you will have a chance to....see your child’... It was just stressful because your head is full, you can't walk there, and you're thinking about your child.” (Mother C3\_01, maternal and newborn complication)*

### OPPORTUNITY FOR CHANGE:

Reducing mother-newborn separation and standardizing communication with the mother and family if separation is necessary can help alleviate mothers's anxiety and support better long-term wellbeing.

## Action 2:

Improve continuity from birth to postnatal care. Align routine health checks for newborn and mom.

### WHAT WE FOUND:

While 77% of women attended a postnatal care appointment, the care focused on newborn weight checks and vaccines, with minimal maternal care or specialty care for the baby. Mothers most often receive postnatal care close to home due to financial, transportation, and physical health constraints, but clinicians at local facilities may not know the mother or baby had a complication or consider the need for specialized care. This creates gaps in care for high-risk women and babies.

### RIPPLE EFFECTS:

When women and babies don't receive the postnatal care that they need, health problems may be overlooked, leading to worsened outcomes. Women are also less likely to adhere to medical guidance, advice, and referrals without adequate care.

*“They asked me if I have ever taken the child for check-up, I told them that was difficult....spending five hundred shillings to go back and forth is a lot.” (Mother C2\_007, delivered a baby with asphyxia)*

*“They just give the child an injection, tell you, ‘Hold your baby, go home...’. They don't even notice, maybe you're not okay mentally...your mind is elsewhere.” (Mother C2\_016, delivered via cesarean section)*

### OPPORTUNITY FOR CHANGE:

Information-sharing across facilities and standardization of care for complications can make care easier to navigate. Reducing financial barriers to care and aligning appointments for mothers and newborns can lead to earlier management of health concerns and fewer long-term health and financial impacts.

## Action 3:

Strengthen education around complications, and ensure consent for surgical procedures.

### WHAT WE FOUND:

Mothers and families often had a limited understanding of why a complication occurred, and mothers who underwent cesarean births often felt that they were not given the opportunity to consent. Around 25% of women in the study rated their care as low in autonomy and supportive care, particularly among those whose newborn had a complication.

### RIPPLE EFFECTS:

Mothers felt increased emotional stress and a loss of autonomy over decisions about their own health. Without additional information from providers about why a complication occurred, the mother was often blamed.

*“There is no decision-making [for the mother]... You're just told, just sign. You don't even know what you're signing up for.” (Mother C1\_14, on her experience of consenting to a cesarean delivery)*

*“It's something I'm also trying to understand. People wonder why someone would conceive and then fail to give birth naturally. They see it as abnormal and attribute it to witchcraft.” (Family member of Mother C1\_002\_R3 who gave birth via cesarean section)*

### OPPORTUNITY FOR CHANGE:

Ensuring full informed consent for treatment and providing women and families with prenatal education about complications can reduce stigma, leading to improved emotional wellbeing.



Citations

## Innovations to Build On

### REDUCING SEPARATION

Programs across Kenya and globally are innovating ways to enable skin-to-skin care in the midst of birth complications. Point of care quality improvement strategies, such as those tried in India (1) and Uganda (2), provide training and develop locally-relevant strategies with frontline clinicians to improve skin-to-skin care and reduce maternal newborn separation. Examples of strategies include adapting operating theatre protocols, reorganizing operating theaters, ensuring maternal support during recovery to reduce separation, and empowering the father or other caregivers to provide skin-to-skin care while supporting the mother.

### CONTINUITY OF CARE

Standardizing follow-up pathways for mothers and newborns following common birth complications is a key step to improving health trajectories. Innovative programming is underway globally to balance specialty care standardization with postpartum mothers' financial, transportation, and physical limitations. These programs include community health worker home visits, peer mentoring to improve care navigation, and digital tracking and reminder systems. One example of digital postpartum support in Kenya is the PROMPTS digital platform that can provide critical information and support care navigation for parents after discharge from the hospital.

### RESPECTFUL CARE

A family-oriented prenatal education program in Malawi used picture-based dramas to engage ANC groups and their family members in discussions about what a complication and its treatment may look like. This intervention improved families' identification of a health facility for emergencies, accompaniment to facility birth, attendance at antenatal visits, and involvement of women in decision-making, leading to less bleeding and seizures at birth, fewer neonatal complications, and fewer cesarean deliveries. Education during the ANC visits, rather than during the in-patient admission for birth, provided a less hurried environment to share education and answer questions.