Parents’ experiences of care and support after stillbirth in rural and urban maternity facilities: a qualitative study in Kenya and Uganda

TA Mills, E Ayebare, R Mukhwana, J Mweteise, A Nabisere, A Nendela, P Ndungu, M Okello, G Omoni, S Wakasiaka, R Wood, T Lavender

Objective To explore parents’ lived experiences of care and support following stillbirth in urban and rural health facilities.

Design Qualitative, interpretative, guided by Heideggerian phenomenology.

Setting Nairobi and Western Kenya, Kampala and Central Uganda.

Sample A purposive sample of 75 women and 59 men who had experienced the stillbirth of their baby (≤1 year previously) and received care in the included facilities.

Methods In-depth interviews, analysed using Van Manen’s reflexive approach.

Results Three main themes were identified; parents described devastating impacts and profound responses to their baby’s death. Interactions with health workers were a key influence, but poor communication, environmental barriers and unsupportive facility policies/practices meant that needs were often unmet. After discharge, women and partners sought support in communities to help them cope with the death of their baby but frequently encountered stigma engendering feelings of blame and increasing isolation.

Conclusions Parents in Kenya and Uganda were not always treated with compassion and lacked the care or support they needed after the death of their baby. Health workers in Kenya and Uganda, in common with other settings, have a key role in supporting bereaved parents. There is an urgent need for context and culturally appropriate interventions to improve communication, health system and community support for African parents.

Keywords Bereavement, parents, qualitative, stillbirth, sub-Saharan Africa.

Introduction Globally, 2.6 million babies die shortly before or during birth annually. Over half of these deaths occur in sub-Saharan Africa, where the average rates are eight times greater than in high-income countries (HIC). Across all settings, stillbirth disproportionately affects marginalised populations, those living in poverty and conflict zones. Stillbirth is acknowledged as being one of the most distressing and traumatic life experiences and is associated with long-lasting negative health and social impacts for parents and families, including serious mental health issues, associated physical health problems, relationship and family breakdown. Reducing the impact of stillbirth has been identified as an international health priority for sustainable development.
improvements in public health, access and uptake of high-quality maternity care is vital to achieving this aim; but it is also imperative that adequate support is provided for women and families when a baby dies.

Empathic and compassionate care from health workers in the days and weeks after the death of a baby positively influences the parents’ adjustment and recovery, including the ability to care for other children, and encourages future health services uptake. Evidence, derived mainly from HICs, demonstrates considerable variation in care provision, where parents are not always treated with respect and compassion or offered the support needed after stillbirth. Very few studies have addressed the experiences of parents after stillbirth in sub-Saharan Africa; however, women have reported stigma and ostracism. Common cultural practices in African communities such as rapid burial and restrictions on public mourning may also increase isolation. The aim of this study was to explore the lived experiences of parents in the period immediately following the death of their baby in health facilities in Kenya and Uganda, to gain an understanding of the response of health systems and barriers and facilitators to effective support.

Methods

This interpretative study, guided by hermeneutic phenomenology, aimed to capture the essence of parents’ lived experiences of care and support after stillbirth in facilities in urban, peri-urban and semi-rural areas of Kenya and Uganda. Heidegger recognised the difficulty in suspending preconceptions; therefore, the research team, which included midwives and nurses, did not attempt to suspend prior knowledge and experiences, although multiple analysts enhanced credibility. Core outcome sets were not relevant to this approach. In both countries, study conduct and interpretation of the findings were supported by community engagement and involvement (CEI) and stakeholder groups. Stakeholders were local academics, clinicians, managers and ministry of health representatives, recruited via established networks and CEIs compromised bereaved parents, at least 1 year following their baby’s death, who provided training and support through the NIHR Global Health Group Kenya and Uganda partners, as described previously by Bedwell and Lavender.

The study was funded by the NIHR Global Health Group on Stillbirth at The University of Manchester 16/137/53, Wellbeing of Women/RCM/Burdett Trust International Fellowship IFA 200.

Sample

A purposive sample of 75 women, and 59 male partners of women, over 18 years, who had experienced a stillbirth (baby born ≥28 weeks’ gestation with no signs of life) within the previous 12 months were recruited. The sample included participants in both urban and peri-urban or semi-rural settings in each country, with up to 20 women and male partners recruited per site, reflecting previous phenomenological studies. Health workers invited women and partners, meeting the above criteria, who received care at five facilities in Nairobi and Western Kenya, Kampala and Central Uganda to complete ‘consent to contact’ forms, before discharge after the birth of the baby or at postnatal community contacts, if they were interested in participating. They were contacted by the research assistant (agreed method, a phone call, for example), not sooner than 2 weeks later and provided with study information. If the participant was agreeable, an interview was scheduled, not sooner than 8 weeks after the birth and consent confirmed prior to any data collection. Although not required for phenomenology, we consider that data saturation was reached, as no new themes emerged.

Data collection

Experienced midwife research assistants conducted recruitment and data collection. Demographic and clinical data were collected via investigator-designed questionnaires immediately prior to the interview. An interview topic guide was developed based on literature, discussions with the CEI group and stakeholders, with broad opening questions focused on experiences, followed by flexible prompts. One-to-one interviews were conducted at a place of the participant’s choice, with due regard for researcher safety, in the local language or English according to the participant’s preference. When couples both agreed to an interview, these were conducted separately, digitally audio-recorded and transcribed verbatim; pseudonyms protected anonymity. After each interview, researchers completed field notes and a reflexive diary to capture nuances and record emerging themes.

Data analysis

Interviews were translated into English by the research assistant (native speaker), where required, and approximately a 10% sample independently back-translated to ensure accuracy. Any discrepancies in meaning were reviewed with the lead local researcher; the emphasis was on accuracy rather than direct translation. Analysis was guided by Van Manen’s three-stage approach; first, transcripts were read and re-read in their entirety. Second, significant statements were highlighted throughout. In the third stage, every sentence and paragraph was considered in detail. Sentences were placed into clusters according to commonalities; sub-themes and main themes were identified through amalgamation of the clusters, returning to the original transcript for confirmation. This cyclical process reflected the hermeneutic circle, a key component of
Heidegger’s approach. This process was conducted by three researchers; local teams further shared summaries and emerging concepts with the relevant CEI and stakeholder groups and feedback was collated to provide new insight. The final interpretation of the data was confirmed with the wider research team.

Results

Interviews were conducted with 75 women and 59 men at 150 [47–340; median and range] days following their baby’s death (July 2017 to May 2019). Table 1 summarises the demographic and birth outcome characteristics for the participants. Three overarching themes were uncovered during analysis, informed by a number of sub-themes, common across all settings and included parents’ accounts of the ‘impacts and responses’ to the death of their baby, perceptions surrounding ‘care and interactions with health staff’ and ‘community support and coping’ (Table 2).

Theme 1: Impacts and responses

Despite perceptions that frequent exposure to stillbirth in low- and middle-income settings might somehow prepare parents for a poor outcome, women in this study recounted profound shock, bewilderment, lasting distress and despair when they discovered their baby had died:

‘It is something that I least expected and bearing in mind that all through I was okay with the pregnancy I never thought this would have happened... it left me in pieces.’

[Joy, mother, Peri-urban Kenya]

Suffering in vain

Emotional distress was often exacerbated by physical morbidity stemming from traumatic labour and birth, caesarean section scars and perineal wounds providing lasting reminders of futility of the pain and suffering women had endured:

‘I wanted her. Getting pregnant, carrying the pregnancy all those months and going through the caesarean pain and the baby dies, have I not suffered in vain?’

[Jennifer, mother, Urban Uganda]

Male partners were also deeply affected, describing feelings of anger, sadness, upset and powerlessness. The baby’s unexpected death disrupted much-anticipated life-transitions to

Table 1. Characteristics of parent participants

| Characteristic/Country | Kenya n = 85 | Uganda n = 49 |
|------------------------|-------------|--------------|
| Gender                 | Women n = 44 | Men n = 41 | Women n = 31 | Men n = 18 |
| Age, median [range]    | 28.5 [19–43] | 31 [20–51] | 25 [19–40] | 34 [23–63] |
| Urban dwelling         | 19 (43%)    | 22 (54%) | 18 (49%) | 8 (44%) |
| Married or cohabiting, n (%) | 39 (89%) | 40 (98%) | 22 (72%) | 16 (89%) |
| Years of education, median [range] | 12 [4–17] | 15 [6–20] | 10 [3–16] | 11 [3–17] |
| Employed [full or part time], n (%) | 23 (52%) | 38 (96%) | 15 (48%) | 15 (83%) |
| Religion               | Christian 44 (100%) | Christian 38 (93%) | Muslim 3 (7%) | Christian 23 (74%) | Muslim 8 (26%) | Christian 7 (39%) | Muslim 9 (50%) | Other/None 2 (11%) |
| No living children     | 15 (34%)    | 15 (37%) | 9 (29%) | 0 (0%) |
| Experience previous stillbirth or neonatal death of baby | 9 (20%) | 5 (12%) | 1 (3%) | 2 (4%) |
| Gestation, median [range] | 36 [28–42] | 36 [28–42] | 40 [28–42] | 40 [29–44] |
| Type of stillbirth [partner for men] | Antepartum: 17 (39%) | Antepartum: 15 (37%) | Antepartum: 9 (29%) | Antepartum: 9 (50%) |
| Mode of birth [partner for men] | Intrapartum: 27 (61%) | Intrapartum: 23 (61%) | Intrapartum: 22 (71%) | Intrapartum: 9 (50%) |
| Spontaneous            | Caesarean: 38 (86%) | Spontaneous: 33 (80%) | Spontaneous: 11 (36%) | Spontaneous: 7 (39%) |
| Caesarean: 6 (14%)     | Caesarean: 8 (20%) | Caesarean: 20 (64%) | Caesarean: 11 (61%) | Caesarean: 7 (39%) |
| Knew of cause of stillbirth | 24 (54%) | 25 (61%) | 11 (35%) | 7 (39%) |
| Maternal postnatal health complications* [affecting partner, for men] | 8 (18%) | 7 (17%) | 9 (29%) | 2 (11%) |

*Any maternal postnatal health complication including infections (urinary tract, wound, breast), haemorrhage or anaemia, obstetric fistula, mental health.
fatherhood or expansion of the family. Men’s accounts illustrated that they often felt it necessary to suppress their own emotions and be ‘strong’, as their role was to support their partner, and to deal with practicalities around death such as arranging burials or paying hospital bills:

'I was traumatised by the sight of her condition, but I had to pull myself together as a man, and confront the situation.'

[Erick, father, Urban Kenya]

Several women experienced serious and sometimes life-threatening complications associated with the birth including severe pre-eclampsia, eclampsia and post-partum haemorrhage. In these circumstances, distress at the baby’s death was often tempered by relief that his partner had survived:

'I didn’t feel good about the news, because I lost the baby but what consoled me was that the mother had survived.’

[Ali, father, Semi-rural Uganda]

**Table 2. Sub-themes and main themes**

| Sub-themes | Example quotes | Main theme |
|------------|----------------|------------|
| **Theme 1** | 'I was so down, I was so disappointed, I was so devastated. I don’t know how to describe it.’ | Emotional impacts: The death of the baby triggered profound emotional distress for parents |
| Suffering in vain | ‘Like do you know when they told me the baby is dead, I was like ehh... so God you mean I have suffered for nothing I have not seen my baby?’ | Shafiq, Father, Urban Uganda |
| Jackie, Mother, Semi-Rural Uganda | | |
| **Theme 2** | ‘... being unable to understand what caused the death of my baby until today. I know that God decides anyway but I remained with many questions asking myself what could have resulted into the death of my baby. Unfortunately, I didn’t get a chance to know and that too disturbs my head...’ | Left in the dark: Health workers and facility environments were pivotal, but not always positive, influences on parents experiences |
| Kasim, Father, Semi-rural Uganda | | |
| **Theme 2** | ‘Everyone who you would see would tell you that they are busy and I should wait and then they leave until when we were told that the health workers need a bribe.’ | Not a priority: Health workers and facility environments were pivotal, but not always positive, influences on parents experiences |
| Linnet, Mother, Urban Uganda | | |
| **Theme 2** | ‘He travelled from [name of town] and by the time he got here it was raining and he was late and he was told to leave the ward and he left because it was past visiting hours.’ | Unsupportive rules and practices: Health workers and facility environments were pivotal, but not always positive, influences on parents experiences |
| Lynn, Mother Peri-Urban Kenya | | |
| **Theme 3** | ‘You know people talk a lot and now they will talk and talk... Neighbours, the community where you come from. They can see you like a bad omen.’ | Community support and coping: After discharge, social support for parents was inhibited by separation from family and stigma surrounding stillbirth in communities. |
| Besh, Mother, Peri-urban Kenya | | |
| **Theme 3** | ‘What gave me the strength was the support from my mother and the fact that my wife was alive, at least I didn’t lose both of them and I know that given that my wife is still around we still have a chance to get another child.’ | Hope for the future: After discharge, social support for parents was inhibited by separation from family and stigma surrounding stillbirth in communities. |
| Willy, Father, Peri-urban Kenya | | |

© 2020 The Authors. *BJOG: An International Journal of Obstetrics and Gynaecology* published by John Wiley & Sons Ltd on behalf of Royal College of Obstetricians and Gynaecologists
Parents were often dissatisfied with how they were informed of the baby’s death, recounting delays and misinformation. Intrauterine death was often confirmed by ultrasound, but women were not always told the findings at the time of the scan. Some women only guessed that something was wrong because of staff demeanour or overheard conversations. For example, Bukirwa learned her baby had died only when the scan results were explained to medical students:

‘She told them, “when this happens, I hear when the placenta detaches from the baby!!!” Something like that “the baby suffocates, if the baby is not getting oxygen, so this has led to death, so the baby has died”. She did not tell me direct, but she told them, and I was listening, yes. So, I realised that my baby was no more.’

[Bukirwa, mother, Semi-rural Uganda]

Most women who experienced intrapartum stillbirth appeared to be unaware of any problems until after the birth. Several described being left alone, worried and confused, as the baby was immediately removed from the delivery room, not having cried. In these circumstances, women often waited for long periods, sometimes several hours, before being told the baby had died. Women who required caesarean section under general anaesthetic for severe complications, also recounted not learning that the baby had died for some hours or days after regaining consciousness. Withholding bad news was justified by concerns around exacerbating medical complications, and partners and relatives were sometimes complicit in this behaviour.

‘We don’t usually want to show them the babies because; since she has had a caesarean section, she might get high blood pressure and the condition worsens when she sees the baby. So for most of them, we can even tell them about it like after 1 day. If she keeps asking where the baby is; you can lie to her that “the baby is still in theatre, the doctors are bringing him” so you keep her in that state.’

[Obei, father, Semi-rural Uganda]

Women were extremely upset at being deceived; this behaviour intensified rather than reduced distress:

‘I really felt very bad. Because even when I gained consciousness, I asked for my baby but they confused me around, they didn’t want to tell me the truth.’

[Mariam, Mother, Semi-rural Uganda]

Many women, and some partners, saw their baby as a valid part of their parenting role and in creating memories. Some to hold, their stillborn baby after birth as helpful in validation their parenting role and in creating memories. Beyond receiving brief condolences, very few parents had any opportunity to discuss the baby’s death in depth. None of the parents recalled being offered any formal investigations into the cause of their baby’s death, such as a post-mortem examination. The limited information they received appeared to derive from health workers’ interpretation or opinion based on clinical history and, occasionally, external examination of the baby at the time of birth. Poor communication increased feelings of isolation and perceptions among women and partners that they were less of a priority to staff than those with live babies.

UNSUPPORTIVE PRACTICES, POLICIES AND RULES

Many women and partners expressed a desire to see, and some to hold, their stillborn baby after birth as helpful in validating their parenting role and in creating memories. Although many women, and some partners, saw their baby after birth, fewer reported holding. Contact was not offered to all parents and this was often a source of regret:

‘You know a mother is a mother even to a dead body. I would have wished to hold the baby but I think the nurses saw my grieving and they thought that would have aggravated my pain more so they immediately took the baby away.’

[Cece, mother, Peri- Urban Kenya]

Where parents did see or hold their stillborn baby, interactions were not always supported appropriately. Few women recalled any discussion of the possibility of seeing and or holding or how the baby might appear, prior to birth. Although cultural constraints were occasionally raised, fear was the most commonly cited factor for parents opting not to see their baby. Some facilities actually enforced contact to confirm the death and identity of the baby, one woman was
told this was to ensure you... ‘don’t say your baby was stolen, your baby passed on’. Partners or family members were required to confirm death in writing before the body was transferred to the mortuary. One woman was prevented from visiting her surviving twin in the neonatal unit until her partner arrived to complete the paperwork. Several women felt traumatised after being left with the baby for long periods waiting for family members to attend:

‘From 5 pm that evening, through the night I slept with the baby box...the hospital required next of kin consent to the hospital burying the body. The stillbirth really traumatised me especially having to lie down besides [a] dead baby.’

[Beryl, mother, Urban Kenya]

Inflexible institutional policies were also a barrier to companion support after stillbirth; partners who were not permitted to be present during birth, were also excluded from the hospital outside visiting hours:

“When I came to the hospital the watchman told me that visiting hours were over, I almost cried, I was confused. I went home with a bad headache, tears on my face. Also, we did not have a phone because I had lost my phone – the whole experience was a nightmare.’

[James, father, Urban Kenya]

Following birth, women were normally accommodated in open postnatal wards. The lack of private space inhibited expression of emotions and the close proximity of other mothers and healthy newborns was often distressing:

‘... then after that delivery and the incident of losing my child I was being put in the same room with other women holding their baby. I felt very bad because I too wanted to hold mine and feel like them.’

[Lilly, mother, Peri-urban Kenya]

Theme 3: Community support and coping

Women were often discharged from facilities very rapidly, within hours or a day of the birth, unless they were unwell, and had little or no contact with health services in the postnatal period. Although some couples reported increased closeness, others experienced major relationship difficulties and some male partners abandoned women in the wake of stillbirth:

‘These days he has few words...when he speaks to me he always finds a way to say something like ‘you are not like other women. I feed you, you keep well yet there is no baby in this house [silence]...it hurts so much.’

[Ruth, mother, Urban Kenya]

Family and friends were the principle source of ongoing support, but the wider community was also important for parents, particularly those living at a distance from families. Many drew and support comfort from religious beliefs and faith communities; most participants identified themselves as Christian and several women were visited by ministers and other church members soon after leaving hospital. Opportunities to talk through experiences, as well as keeping busy and distractions were reported to be helpful:

‘People really came to my rescue; they helped me because I didn’t have any sister or relative in that place, it was just the hearts of people in the village.’

[Nahweyiso, mother, Semi-rural Uganda]

Many parents did not feel they received enough support in the early days and weeks after their baby’s death. Several described a sense of isolation, even though they were surrounded by other people, reflecting a lack of understanding of their labile emotional state. A few women were aware of unpleasant gossip, among neighbours, surrounding their stillbirth:

‘Some of them are very understanding, others were suspecting that I was bewitched and others started saying I was HIV positive. All in all, I have kept my faith in the Lord.’

[Kate, mother, Peri-urban Kenya]

Hope for the future

Realisation that stillbirth was more common than thought, and a shared experience with others was a source of comfort for some women. Several described chance conversations with women in hospital or their community with a personal experience of baby loss and relief in feeling they were ‘not the only ones’. Also, for many women and partners, maintaining a sense of hope that there would be another chance and they would have a live baby in the future was important:

‘I cope by reminding myself that I already lost another baby and even if I lost this one again, I should not worry, I will still be able to deliver another baby, and God will give me more children if I want.’

[Molly, mother, Peri-urban Kenya]

Discussion

Main findings

This qualitative study explored the lived experiences of parents in the days and weeks following the death of their baby in urban, peri-urban and semi-rural facilities in Kenya
and Uganda; settings facing a high burden of stillbirth. Our findings confirm the devastating impact on parents, and that care and support provided in facilities had a pivotal influence on experiences and adjustment. Although some parents were complimentary about their care, many had negative experiences. Health workers lacked sensitivity and empathy and often failed to provide clear information. The baby’s existence was not validated, and opportunities for parenting were not adequately supported. Limited separation from other women compounded distress, and rigid adherence to policies inhibited companion support in facilities. Social support was important once women were discharged, but was impeded by geographical separation from family and persistent stigma in communities surrounding baby death.

**Strengths and limitations**

Despite the disproportionate burden of stillbirths in sub-Saharan Africa, very few studies have explored bereavement support in this context. This study provides the widest-ranging in-depth exploration of experiences of bereaved parents in health facilities in Kenya and Uganda to date. Experienced local researchers conducted the interviews and parents were overwhelmingly positive about having, for most, their first opportunity to discuss experiences surrounding their baby’s death. Involvement of local service users and clinicians in the design, conduct and interpretation added trustworthiness to our findings.

The study was conducted in Kenya and Uganda; although experiences resonated strongly with other East African partners in our Global Health Group, the findings might not extend to other African settings. Only a small number of women who gave birth outside health facilities or accessed traditional birth attendants (TBAs) in one site in Uganda were included. Despite initiatives to discourage (or prohibit) involvement in childbirth care, TBAs have an important influence and status, particularly in rural areas. It would also be helpful to understand the experiences of other family and community members who supported women and partners. Since health worker’s behaviour was a key determinant of the quality of support received, their views and experiences would also contribute to the design of context-appropriate and sensitive interventions.

**Interpretation**

The profound and lasting trauma experienced by parents after the death of a baby before or during birth is increasingly being acknowledged. Our study confirms comparable emotional responses among parents in Kenya and Uganda. In common with other settings, fathers were observed to internalise grief, reflecting socio-cultural role expectations of ‘manliness’. Outward detachment did not reflect men’s inner feelings but likely contributed to relationship difficulties encountered by some couples. Women perceived stigmatisation and a lack of understanding among peers. Motherhood confers particular esteem in African society, and scorn and isolation by communities and abandonment by partners are not uncommon after stillbirth.

Health workers had a critical role in influencing parent’s adjustment and recovery after the death of their baby. However, our findings suggest opportunities to prevent further trauma were often missed. Poor communication after stillbirth has often been linked to limited societal awareness of the impacts, lack of pre- and in-service preparation of health workers and, here, paucity of context-specific educational materials and resource pressures could also contribute. The lack of routine investigations into causes of death might have acted as a barrier to effective communication, and it is possible that health workers felt unable to answer parents’ questions and therefore avoided discussions. Opportunities to validate the baby’s existence, including seeing and holding the baby, were important to many parents. Although widely practised in HIC, the benefits of encouraging contact are debated and cultural appropriateness might be a concern in some LMIC settings. However, our findings support a Nigerian study which found that many women wanted to see/hold their baby after stillbirth despite traditional prohibitions on mourning, suggesting changing attitudes.

Our findings also highlight the importance of organisational factors and system support in facilitating adequate care provision. Some environmental changes, e.g. providing separate spaces for bereaved women and families, might be challenging where resources are already limited. However, simple low-cost measures, for example use of screens to provide some additional privacy in postnatal wards, could significantly improve experiences. Contact with faith leaders and religious communities was an important source of comfort. However, this was only available to parents after discharge from hospital. Increased availability of pastoral and spiritual care in facilities might also be beneficial in the immediate wake of the death of a baby, this could be supported through involvement of dedicated chaplains where engaged, or encouraging visits from the parents’ preferred religious leaders. Recognising additional needs of bereaved families in facility policies and guidelines is also important; for example, flexible visiting policies could help to facilitate improved companion support for women after stillbirth. Policies and guidance for bereavement care can also demonstrate organisational commitment to providing respectful and supportive care. Increased perinatal bereavement education in pre- and post-registration programmes would help staff understand parents’ needs and develop communication skills, but there should also be emphasis on staff support, such as developing skills in self-care and resilience.
Conclusion
This study has demonstrated that mothers and fathers were not always treated with compassion and were not, despite some good practice, offered the support they required after their baby’s death in Kenya and Uganda. This is important, as all individuals, wherever they live, should have a basic right to expect respectful care and support after the death of a baby. There were many commonalities with issues identified in HIC, suggesting some transferability in approaches, but there is a need for development and testing of specific interventions to improve immediate care in facilities and access to support in communities after stillbirth in the African context.

Disclosure of interests
None declared. Completed disclosure of interest forms are available to view online as supporting information.

Contribution to authorship
TM and TL conceived the study and wrote the study protocol with input from EA, SW and GO. EA, SW, GO, JM, RM, AN and ANe recruited participants and collected the study data. TM, RW, JM, RM, AN and ANe analysed the data with input from TL, EA, GO, PN and MO. All authors interpreted the data. TM drafted the manuscript with input from RW. All authors commented on manuscript drafts and approved the final version.

Details of ethics approvals
Ethical approvals were obtained from The University of Manchester (UREC 2017-0233-4462) 017 05/04/2017; University of Nairobi/Kenyatta National Hospital, Nairobi (P240/05/2017) 17/07/2017; Makerere University School of Health Sciences (SHS: 2017-097) 27/04/2018/Uganda National Council for Science and Technology (SS 4666), 12 July 2018.

Funding
This research was funded by a Wellbeing of Women/RCM/Burdett Trust International Fellowship (IFA 200) and by the National Institute for Health Research (NIHR; 16/137/53) using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK Department of Health and Social Care. The funders had no role in the design of the study, data collection and analysis, interpretation of the findings or writing of the manuscript.

Acknowledgements
We would like to thank Joyce Cheptum, Hannah Inyama, Irene Mageto, A. George Nyadimo and Mary Waichanguru for their assistance with initial participant recruitment and data collection. We would also like to thank our CEI groups, led by PN and MO, for their assistance in reviewing the protocol, participant-facing materials and interpretation of the data.

References
1. Blencowe H, Cousens S, Jassir FB, Say L, Chou D, Mathers C, et al. National, regional, and worldwide estimates of stillbirth rates in 2015, with trends from 2000: a systematic analysis. Lancet Glob Health 2016;4:e98–e108.
2. Heazell AE, Siasakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, et al. Stillbirths: economic and psychosocial consequences. Lancet 2016;387:604–16.
3. Cacciatore J. Psychological effects of stillbirth. Sem Fetal Neonatal Med 2013;18:76–82.
4. de Bernis L, Kinney MV, Stones W, Ten Hoope-Bender P, Vivio D, Leisher SH, et al. Stillbirths: ending preventable deaths by 2030. Lancet 2016;387:703–16.
5. Flenady V, Boyle F, Koopmans L, Wilson T, Stones W, Cacciatore J. Meeting the needs of parents after a stillbirth or neonatal death. BJOG 2014;121(Suppl 4):137–40.
6. Watson J, Simmonds A, La Fontaine M, Fockler ME. Pregnancy and infant loss: a survey of families’ experiences in Ontario Canada. BMC Pregnancy Childbirth 2019;19:129.
7. Kiguli J, Munabi IG, Sseguija E, Nabulaisa J, Kabonesa C, Kiguli S, et al. Stillbirths in sub-Saharan Africa: unspoken grief. Lancet 2016;387:e16–e8.
8. Heidegger M. Being and Time. Oxford: Blackwell Publishing; 1962.
9. Bedwell C, Lavender T. Giving patients a voice: implementing patient and public involvement to strengthen research in sub-Saharan Africa. J Epidemiol Community Health 2020;74:307–10.
10. World Health Organization. Stillbirth 2015 [cited 26 September 2016]. Available from: http://www.who.int/maternal_child_adolescent/epidemiology/Stillbirth/en/.
11. O’Brien E, Rauf Z, Alfirevic Z, Lavender T. Women’s experiences of outpatient induction of labour with remote continuous monitoring. Midwifery 2013;29:325–31.
12. Van Manen M. Researching Lived Experience: Human science for an action sensitive pedagogy. Albany: State University of New York Press; 1990.
13. Shakespeare C, Merial A, Bakhakhti D, Baneszova R, Barnard K, Lynch M, et al. Parents’ and healthcare professionals’ experiences of care after stillbirth in low- and middle-income countries: a systematic review and meta-summary. BJOG. 2019;126:12–21.
14. Turinawe EB, Rwemisita JT, Musinguzi LK, de Groot M, Muhangi D, de Vries DH, et al. Traditional birth attendants (TBAs) as potential agents in promoting male involvement in maternity preparedness: insights from a rural community in Uganda. Reprod Health 2016;13:24.
15. Murphy S, Cacciatore J. The psychological, social, and economic impact of stillbirth on families. Semin Fetal Neonatal Med 2017;22:129–34.
16. Bonnette S, Broom A. On grief, fathering and the male role in men’s accounts of stillbirth. J Social 2012;48:248–65.
17. Jones K, Robb M, Murphy S, Davies A. New understandings of fathers’ experiences of grief and loss following stillbirth and neonatal death: A scoping review. Midwifery 2019;79:102531.
18. Kiguli J, Namusho S, Kerber K, Peterson S, Waiswa P. Weeping in silence: community experiences of stillbirths in rural eastern Uganda. Glob Health Action 2015;8:24011.
Experiences after stillbirth in Kenya and Uganda

19 Modiba L. Experiences and perceptions of midwives and doctors when caring for mothers with pregnancy loss in a Gauteng hospital. Health SA Gesondheid 2007;13:29–40.

20 Kingdon C, Givens JL, O'Donnell E, Turner M. Seeing and holding baby: systematic review of clinical management and parental outcomes after stillbirth. Birth 2015;42:206–18.

21 Redshaw M, Hennegan JM, Henderson J. Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey. BMJ Open 2016;6:e010996.

22 Kuti O, Ilesanmi CE. Experiences and needs of Nigerian women after stillbirth. Int J Gynaecol Obstet 2011;113:205–7.

23 Nuzum D, Meaney S, O’Donoghue K. The spiritual and theological challenges of stillbirth for bereaved parents. J Relig Health 2017;56:1081–95.

24 Siassakos D, Jackson S, Gleeson K, Chebsey C, Ellis A, Storey C, et al. All bereaved parents are entitled to good care after stillbirth: a mixed-methods multicentre study (INSIGHT). BJOG 2018;125:160–70.

25 Shorey S, Andre B, Lopez V. The experiences and needs of healthcare professionals facing perinatal death: A scoping review. Int J Nurs Stud 2017;68:25–39.

26 Ellis A, Chebsey C, Storey C, Bradley S, Jackson S, Flanady V, et al. Systematic review to understand and improve care after stillbirth: a review of parents’ and healthcare professionals’ experiences. BMC Pregnancy Childbirth 2016;16:16.

27 Shakespeare C, Merriel A, Bakhbakti D, Blencowe H, Boyle FM, Flanady V, et al. The RESPECT Study for consensus on global bereavement care after stillbirth. Int J Gynaecol Obstet 2020;149:137–47.