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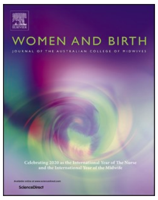

“I have to be strong”: A qualitative study of parental bereavement experiences in Uganda following the death of their baby

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ABSTRACT

Background: The death of a child is profoundly distressing for parents, often leading to acute grief and psychological complications. Most bereavement research is from high-income countries, with limited generalisability to low- and middle-income contexts where 98 % of newborn deaths occur. We explore the experiences of parents in Uganda following the death of their baby.

Methods: Qualitative interviews were conducted with 11 bereaved parents whose newborn participated in the OMWaNA trial and died while enrolled or shortly thereafter. In-depth interviews explored the experience of bereavement, the psychosocial impact, and economic consequences. Data were analysed using a deductive thematic approach.

Results: The death of a baby was consistently associated with parental stress, information delays, and uncertainty regarding the cause of death. While respondents reported a period of acute grief, many relied on their faith and social support to cope. Expectations for bereavement care from health professionals were low and instead parents focused on health professionals’ efforts to keep their baby alive and advice regarding future pregnancies. Despite financial precarity, costs and loss of income, many parents appeared comforted that they had done all they could to ensure the baby’s survival.

Conclusion: These findings illustrate the importance of understanding parental bereavement in different settings and circumstances. Rather than health worker-led models of active bereavement care, respondents relied on social support, their faith, and a focus on future pregnancies to ‘become strong.’ Further research to understand the longer-term impact of bereavement, men’s experiences and coping strategies could inform more contextually appropriate bereavement care.

Statement of significance

Problem

There is limited evidence on parental bereavement following newborn death in low- and middle- income countries (LMIC).

What is already known

Most studies are from high-income countries, with culturally specific understanding of bereavement and more resources to deliver care. Studies from LMICs offer conflicting accounts of societal perceptions of death and parental behaviour.

What this paper adds

This paper provides in-depth insights regarding bereavement experiences of parents in Uganda, including psychosocial and economic effects. Respondents did not experience any overt social stigma. Our findings emphasise that social networks are the main source of support

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and reiterate the importance of understanding parental bereavement and delivering contextually appropriate bereavement care.

Introduction

The death of a child is a profoundly difficult experience, affecting the families of 4.9 million children under 5 years of age [1] and 1.9 million late trimester stillbirths [2] worldwide each year. In 2022, there were an estimated 2.3 million deaths in the neonatal period (first 28 days of life), comprising nearly half of under-5 deaths [1]. The burden is highest in sub-Saharan Africa, which accounted for 57 % of under-5 deaths and 46 % of neonatal deaths [1]. In addition to increasing efforts to reduce newborn deaths, there is a critical need to understand the experience of bereavement to design and deliver contextually appropriate bereavement care.

The Kubler-Ross model outlines five stages of grief as individuals progress towards acceptance [3]. Bereavement care supports parents and family members to move through the stages of grief and reduce psychosocial stress and social isolation [4]. While traditional bereavement care models supported parents to ‘let go’ of their loss, newer models help parents to ‘hold on’ by touching the baby and creating memories [5]. Active ‘grief work’ models encourage the bereaved to revisit these memories to gradually accept their loss, with friends or through formal counselling [6,7]. However, bereavement care and grief studies are predominantly from high-income countries (HIC), with culturally and temporally specific understanding of grief and bereavement, including assumptions when a baby becomes a person [8,9] and about the resources available to deliver care.

Although 98 % of newborn deaths and stillbirths are in low- and middle-income countries (LMIC) [10], most evidence on parental bereavement experiences following the death of a child is from high-income settings. Whilst there are some published studies relating to care following a stillbirth from LMICs [11], including psychosocial and economic impacts [12], few consider deaths in the neonatal period. Where available, studies often offer conflicting accounts of societal perceptions of death and parents’ behaviour [13]. In addition to the psychosocial impacts of bereavement, the potential economic impacts are substantial and frequently overlooked. One UK study found stillbirth to be associated with 10–70 % higher costs when compared to a liveborn child [14], however there is little evidence from LMIC settings on the economic impact of death of a newborn. Within Uganda, cultural and personal beliefs regarding causes of stillbirths and neonatal deaths have been found to vary between settings [8,15–18], with implications for the provision of health and bereavement care.

The OMWaNA trial aimed to examine the impact of kangaroo mother care (KMC) initiated before clinical stabilisation on neonatal mortality and other important outcomes in Uganda [19,20]. KMC is an evidence-based practice consisting of early, continuous, and prolonged skin-to-skin contact, usually with the mother; promotion of exclusive breastmilk feeding; early hospital discharge; and supportive follow-up at home [21]. The OMWaNA trial recruited 2221 newborns weighing 700–2000 g across five Ugandan government hospitals between October 2019 and July 2022 [19].

Much of the evidence on bereavement is limited to deaths in health facilities and excludes the experience of parents who spent time at home with their infant prior to the death. While drawing on the perinatal bereavement literature, which includes deaths in the first week of life and stillbirths, we aimed to expand the evidence on bereavement related to early infant death. Further, relatively little is known about parental bereavement experiences in situations where the child was enrolled in a clinical trial [14]. The aim of this paper is to explore the experience of bereavement following early infant death among parents whose baby participated in the OMWaNA trial. Specific objectives were to examine a) the initial experience of bereavement; b) the psychosocial impact; and c) the economic consequences.

Methods

Study setting

This study was conducted at one of the five hospital sites that participated in the OMWaNA trial - a national referral hospital located in Kampala, the largest city and political capital of Uganda. The hospital has a 106-bed newborn special care unit (WHO level-2) [22], which admits approximately 6800 neonates each year [23]. Mothers of neonates receiving standard care stay in the postnatal ward and come to the newborn unit every 2–3 h to feed their baby.

Study design and participants

This qualitative study recruited 11 parents whose newborn participated in the OMWaNA trial and who died while enrolled or shortly thereafter [20]. Ethical approval to interview parents whose babies had died was obtained as an amendment to the original study. During the trial, KMC was initiated as soon as possible after randomisation among newborns assigned to the intervention arm. To facilitate prolonged skin-to-skin contact, mothers/caregivers of neonates in the intervention arm stayed in the newborn unit with their baby. For newborns assigned to the control arm (standard care), routine (intermittent) KMC was initiated only after pre-defined clinical stability criteria were met. Therefore, whilst some babies in the control arm received KMC, others died before KMC was initiated.

Sampling and recruitment

A purposive sampling approach was used to recruit study participants. Parents were invited if at least one month had passed between the death of their baby and the interview request. Both parents were invited to join, although by the time the target sample size of 10 participants (5 from each trial arm) was reached, only mothers had attended interviews. Following additional outreach, two fathers were invited to interview; however, only one attended.

Data collection

In-depth interviews were conducted at the study hospital in April and May 2022. Interviews took place within a year of the death. The interview guide explored study objectives and sub-themes across parents’ experience of bereavement, the psychosocial impact, and the economic consequences, which were identified a priori through a literature review (Table 1). A Ugandan social science researcher, who had experience leading in-depth interviews and focus group discussions, conducted the interviews in Luganda or English, depending on participant preference. Interview duration ranged from 30 to 60 min. Interviews were audio-recorded. The audio-recordings were transcribed verbatim in the original language by a Ugandan social science research assistant in coordination with the interviewer, and translated to English where necessary.

Table 1
Thematic analysis.

Theme	Sub-theme
1. Experience of bereavement	- Hope for survival - Discovery of death - Cause of death - Memory making - Care after the death
2. Psychosocial impact	- Impact on self - Relationship with partner and other children - Interactions with family and community
3. Economic consequences	- Increased expenditure - Reduced income - Financial assistance

Participants were given monetary reimbursement [20,000 Ugandan Shillings (~$5 USD)] for their time and travel costs. The study nurse counsellor was available in the hospital, where the interviews took place, to provide necessary psychosocial support whenever there was a need. However, none of the participants in the study required referral to the nurse counsellor.

Data analysis

This analysis primarily took a deductive thematic approach; three themes of (a) experience of bereavement, (b) psychological impact, and (c) economic consequences were identified based on existing studies of perinatal bereavement from high-, middle-, and low-income countries. Transcripts were anonymised to maintain confidentiality. Three interview transcripts which had particularly rich descriptions were uploaded to NVivo 12 to review the framework and add third level codes. The framework was then applied to the remaining eight transcripts, using this process for further refinement. The data were charted in a framework matrix to organise data excerpts in a systematic way [24,25].

Role of the funding organisation

The funders had no role in study design; collection, analysis, or interpretation of data; manuscript writing; or in the decision to submit for publication.

Results

Participant characteristics

In total, 10 mothers, along with 1 father from the same couple, of 10 babies who died before 2 months of age were interviewed. Participant age ranged from 20 to 34 years, with a mean age of 26 years (standard deviation 4.7 years). Most respondents (8/11, 72 %) were married, and the remaining three had a partner. Two respondents (male and female) were married to each other but interviewed separately. Educational level was mixed: eight had not completed secondary school, one completed secondary school, and two graduated from university. Most participants (6/11, 54 %) were employed and a further two were self-employed. Three did not work and were reliant on their partner's income. For most participants, this baby was their first-born (7/11, 63 %). One mother had five older children, and one mother had one older child. For one mother and one couple, the baby who died was a twin, but the other twin survived. Most babies died within the neonatal period, and all died within the first two months of life. The characteristics of the babies are provided in Table 2.

Themes

Three thematic areas were identified through a review of existing studies of perinatal bereavement from high-, middle-, and low-income countries to give insights on the experience of bereavement and its impact. We started chronologically with the initial experience of bereavement, with parents recounting what happened in the immediate aftermath of their babies' death: how they discovered the death and the care that was provided at the health centre. Secondly, the interviews explored the subsequent impact of the death, on their emotional state and their relationship with their partner, children, family, and communities. Finally, the interviews explored the economic consequences of the death, including the cost of treatment prior to the death and burial. Sub-themes for each theme are shown in Table 1.

Theme 1: Experience of bereavement

Hope for survival. All babies with information on gestational age available (9/10, 90 %) were born preterm. Many respondents initially had "*no hope that [s]he would survive*" (R1, Mother, age 20). However, many of the babies lived for several weeks which led to growing optimism for survival. All parents, except two, named their baby despite concerns about prematurity. In Uganda, naming is usually done after birth, either immediately or after a few days.

Discovery of death. Three babies had been discharged from the health facility and their deaths appeared sudden, in contrast to respondents' growing optimism for their survival.

> "All that had stopped when we were at home. Our hope was restored; the father and I were very happy and knew that our baby was going to grow… On removing the child from the chest and breastfeed, I realised the baby was no longer breathing. I did not believe it… I shook and changed the child in different positions to confirm" (R1, Mother, 20)

Eight babies were hospitalised at the time of death. Some respondents found their baby dead or were present at their time of death, but for some others, health workers delayed informing them of the death.

> "I reached and asked a nurse that I wasn't seeing my baby and she told me that she didn't know and told me to ask the others, and I asked another nurse who also told me that they didn't know and told me to check another ward. I looked for the baby in another ward and the baby wasn't there; that is when I thought about it that the baby was dead." (R11, Mother, 24)

The respondent knew her baby had died because health care workers "*hid it from me*" and she knew that "*whenever a baby had died, they would take that baby away*" (R11, Mother, 24).

Despite frequent communication delays, most parents had a positive view of staff behaviour whose main role, parents believed, is to save lives. Some parents reported empathetic treatment from staff, as "*you could really see that they put themselves in my shoes,*" despite "*beating around the bush*" (R5, Mother, 28) and avoiding informing them of the death.

However, not all respondents felt they were treated with empathy. One respondent wanted health workers "*to know how you are doing when you go back home but they don't care about that, it ends when they tell you the baby died*" (R9, Mother, 21).

Cause of death. No respondents received a full explanation about the cause of death. Some were unable to speak to health workers because of their grief, while for others, it was discussed but they received only a partial explanation from health workers.

> "All I can say is that they told me it was an infection… they couldn't explain what sort of infection." (R5, Mother, 28)

Without a full explanation, speculation about care was common. Some parents had concerns about the level of care that their baby

Table 2
Characteristics of babies whose parent(s) participated in the study.

	Baby 1	Baby 2	Baby 3	Baby 4	Baby 5	Baby 6	Baby 7	Baby 8	Baby 9	Baby 10
Gestational age at birth, weeks	26	30	26	Not known	34	36	30	34	35	32
Single or twin birth	Single	Single	Single	Single	Single	Single	Single	Single	Twin	Twin
Age at death, days	51	17	20	29	14	14	4	10	14	1
Location of death	Home	Home of relative	Home	Facility	Facility	Facility	Facility	Facility	Facility	Facility
Months between death and interview	3	Not known	4	9	Not known	5	Not known	7	Not known	4

received and suggested that delays to care or equipment issues had led to the deterioration of their baby's condition:

> "One time the power went off when we were here in the hospital and the electricity shocked many of them especially those who were on oxygen and that is when my baby changed and became weak." (R7, Mother, 20)

Some parents were taught how to provide care, such as feeding through tubes, and often focused on the failure of these methods when discussing the death. Several speculated that the baby had been released from hospital too soon, although they tended to blame the lack of support from health workers rather than themselves:

> "If only they had been calling us on the phone every four days; it would have helped, and our child would still be alive." (R4, Mother, 32)

Although some respondents mentioned thoughts of self-blame, most blamed the care that had been provided by the health centre.

> "Sometimes I ask myself, was I careless, was I lazy; did I contribute to his death because they said the infection was caused maybe by hygiene, but I tried to be so clean. So, I keep thinking about that but then I say, that probably it is God's plan." (R5, Mother, 28)

Religion was an important part of rationalisation, with many respondents (7/11, 64 %) talking of "*God's plan*".

> "I didn't come with any child to this earth. If the One who gave has taken, then I have no loss." (R2, Father, 34)

While faith was typically a source of strength, one respondent described her anger with God for "*giving me a boy child and then God taking him away*" (R4, Mother, 32).

Parents did not focus on the cause of death "*because it is now something of the past*" (R3, Mother, 30), instead focusing on having healthy pregnancies and healthy babies in the future.

Memory making. Most only held or touched the body after death for practical reasons, such as verifying the identity or preparing the body for burial. Some parents took photos or kept clothing, but felt the reminders were distressing, at least in this acute phase:

> "I took some photos on my phone but every time I look at them, I become sad and cry." (R6, Mother, 22)

Other respondents avoided reminders, although for different reasons. Several wanted to avoid their emotions, while others didn't see the value of thinking about the dead:

> "Because of the many thoughts I had, I deleted all the photos of the child." (R1, Mother, 20)
>
> "I don't think it is important… I can't keep anything related to the dead." (R2, Father, 34)

Care after death. Respondents spoke of limited follow-up care after the death of their baby, except for parents with a surviving twin. Although respondents were interested in counselling from healthcare professionals, their interpretation was ambiguous as many spoke of medical information rather than bereavement support.

> "The first support I needed was counselling, even to explain to the parents the dos and don'ts for preterm babies." (R6, Mother, 22)

The focus on medical information may have been influenced by the interviews taking place at the hospital and a perception that the interviewer was a healthcare professional, to which some respondents alluded.

> "If I got pregnant again, can you people be there for me and support me?… Things like following up on me and calling up to check on my progress and health." (R3, Mother, 30)

Theme 2: Psychosocial impact

Impact on self. Most respondents (9/11, 82 %) experienced the death of their first-born and described the importance of the transition to parenthood.

> "They see it as a good thing because it makes one get respect." (R11, Mother, 24)

Conceiving and bearing a child offered purpose and social fulfilment.

> "On the day I left hospital carrying a baby, I felt very alive, and I was happy to be a mother." (R3, Mother, 30)

Bereavement is a painful contrast to the initial fulfilment of parenthood. Respondents described their sadness, loss of appetite and physical pain after the death.

> "In that first month, February, I did not eat. Even when they told me to eat, I failed. I always thought about my late child." (R1, Mother, 20)

Becoming strong was an important narrative across all accounts, using rationalisation and focusing on the future. Religion was an important part of rationalisation, with many saying, "*probably it is God's plan.*" *(*R5, Mother, 28). Hope for future pregnancies was another coping mechanism:

> "I will no longer think about the past since I will be having another baby." (R1, Mother, 20)

Relationship with partner and other children. Most respondents reported no change in their relationship with their partner: "w*e have always been close*" *(*R6, Mother, 20); although one respondent felt "*the bond became stronger*" *(*R5, Mother, 28) through supporting and confiding in each other. However, children and fertility were an important theme in several interviews, particularly in relation to previous losses or relationship breakdowns. One respondent had experienced nine neonatal deaths during a previous relationship(s) but said, "*my husband doesn't know anything about it; he asked if I have children and I said no and that I had never given birth*" (R8, Mother, 25). Another participant and her partner separated "*when we spent five years without a child"* (R3, Mother, 30).

Many of the respondents had gendered expectations that "*men act strong*" (R11, Mother, 24). Most women described how their male partners were "*the one functioning at the time*" (R5, Mother, 28); leading interactions with health workers, paying for medical treatment, and arranging the burial. However, some men did express their emotions freely:

> "It was too much for him, he was crying." (R6, Mother, 22)

Two respondents had older children and three respondents (one couple and another mother) had a surviving twin. Most described focusing their energy on caring for "*the one that is still alive*" (R2, Father, 34) and the fear that their other child might "*also die at any time*" (R10, Mother, 27). However, for one mother, bereavement was initially a barrier to caring for her surviving child:

> "She didn't want to enter the special unit the days that followed. Even when the baby girl was still in the special unit, she feared to go there." (R2, Father, 34)
>
> "I had no energy to take care of Babi… I was also worried about Babi but she gave me some hope. I spent two days without going to the nursery to check on the baby because I was grieving." (R11, Mother, 24)

Interactions with family and community. Grief was strongly influenced by social norms whereby parents grieved openly during their initial period of mourning, "*because here we cry when we lose someone*" *(*R6, Mother, 22), before suppressing emotions publicly: "*after some time had passed, I would cry from the house*" (R6, Mother, 22).

However, some respondents who moved regularly for work or lived away from their family grieved privately as, "*in our community everyone is on their own*" (R8, Mother, 25). Another respondent avoided more distant social contacts, such as people in the village, but valued her close friends "*with whom I shared my experience; my experience in the hospital and the way the child died*" *(*R1, Mother, 20).

Many spoke of the practical and emotional support offered by family, friends and community members, including church groups. Some spoke of the shared sadness that (particularly female) family members felt.

> "They had prepared and bought so many things for the baby. But when they heard about the child's death everyone got depressed… I noticed that it was my mother and sisters that were mostly hurt." (R3, Mother, 30)

Only one of the respondents reported experiencing any stigma directly, although another said, "*there will always be those that have ill feelings against others; overall, most of the people care*" (R1, Mother, 20). Instead, the respondents spoke of the consolation they received from others.

> "According to my experience, I don't think [stigma] is there because people were there to comfort me." (R5, Mother, 30)

> "They used to encourage me while telling me that such things happen and that I have to be strong. They told me it was the will of God and that I will make other babies." (R5, Mother, 28)

> "It was very comforting. When people are there for you, it eases the pain." (R7, Mother, 25)

Deaths were not associated with a sense of self-blame as many respondents instead spoke of issues with the care provided by the health centre. This may also reduce stigma experienced by parents.

> Interviewer: "Do you think that it is shaming, or just like some diseases, for example HIV, where people face stigma when one loses a baby in our communities?"

> Respondent: "I think that we grieve but others don't feel pity for you because you got it out of carelessness in the case of HIV."

> Interviewer: "What about when your newborn baby has died?"

> Respondent: "They don't stigmatise you because it's normal people die." (R9, Mother, 21)

Not all respondents experienced positive support from family and the community. Some responses were more forceful and repressive which may be due to their own experience of bereavement of social expectations regarding grief:

> "They told me that if I wanted to stay alive, then I shouldn't cry… When I failed to control the tears, the people at home started barking at me… Then someone comes and mocks you that you think you are the first to lose a child! Such a statement takes away all your strength." (R3, Mother, 30).

Theme 3: Economic consequences

Increased expenditure. To pay for medical treatment while their baby was alive, many respondents and their partners needed to withdraw savings or borrow money:

> "He borrowed the money and sent it to me, 30,000 Shillings. I withdrew the money and paid the nurse to give the baby treatment to help in breathing… whenever we needed anything, he used to withdraw the money and, at the end of it all, he ended up using 1500,000 Shillings of the savings." (R8, Mother, 25)

Most participants reported that treatment was dependent on (often recurring) payments, creating a double burden of uncertainty and financial hardship. Some reported having to pay to buy drugs from private pharmacies outside the hospital, which is common practice in Uganda due to frequent stock-outs within government health facilities.

> "I had to buy the drugs continuously." (R2, Father, 34)

Other respondents spoke of paying health care professionals themselves for the drugs, suggesting that staff may have been soliciting bribes for treatment, which is a separate issue to medical stock-outs.

> "The nurse got the medicine from where the baby was, she did not get out of the hospital she got it from within. The nurse told me to pay her/him 35,000 Shillings in order to treat the baby and that, without the money, she was not going to work on the baby." (R8, Mother, 25)

Participants also had to pay to retrieve the body, transport the body, and organise the funeral. While the proportion of the income or savings that these expenditures represented could not be clearly established, one respondent said that her partner spent 1.5 million Ugandan Shillings (approximately USD 400), which is 100 times higher than the median household out-of-pocket monthly expenditure on health [26].

Despite the financial hardship, respondents appeared satisfied that they had done all that they could to save their baby's life, often going beyond their own means to do so.

> "I wanted my baby to survive, even if a lot of money was to be used as long as my baby survived. But unfortunately, the baby died after spending money." (R9, Mother, 21)

One respondent regretted that she hadn't been asked to buy additional medicine as, "*maybe the baby wouldn't have died*" (R10, Mother, 27).

Reduced income. Most participants reported a reduction in their income due to time spent at the hospital, recovery from caesarean section, or grief:

> "I spent two months without working because I did not have the energy to work." (R8, Mother, 25)

> "My husband was not working; he was home with me because he couldn't leave me by myself." (R7, Mother, 20)

The reduction in income was temporary as many spoke of the financial need to return to work:

> "I was able to go back… I have to work because we need the money." (R1, Mother, 20)

However, decreased productivity or reduced income due to bereavement once they returned to work was not mentioned by any respondents, despite some being self-employed which means that reduced productivity would impact their income directly.

Financial assistance. A recurring theme was financial support from family and community members, which was absent from the existing literature. Some financial assistance was targeted for specific costs, such as medication or burial.

> "They helped my husband with burial arrangements by giving him money." (R7, Mother, 20)

Some received general condolence money, which was an important source of comfort.

> Respondent: "Whenever people came and consoled me with money, I became strong."

> Interviewer: "So, money somehow healed your wounds."

> Respondent: "Yes, it healed my wounds. I had consumed all the business capital, but the condolence money assisted me with getting back on my feet and I pushed on with life." (R3, Mother, 30)

The financial support that friends and family provided, alongside emotional support, appeared to play an important role in helping respondents to cope and 'grow strong' following their bereavement.

Discussion

This in-depth, qualitative study of parents' experience of bereavement following the death of their baby in Uganda and its psychosocial and economic effects, adds to the limited evidence on bereavement care in LMIC settings. Despite the stress and uncertainty at the time of their baby's death and acute grief, respondents spoke of the support offered by family and community members and the strength they found in their religious faith. In contexts with high rates of neonatal mortality, often due to preterm birth complications [27], studies have found a sense of fatalism among some parents of preterm babies. This fatalism can affect uptake of healthcare, including the provision of KMC [28,29]. These findings were not supported by this study, as parents spoke of their growing optimism about their baby's survival and hope for future pregnancies.

Many of the respondents discussed stress and uncertainty at the time of their baby's death, which may reflect health workers' lack of time or skills to provide compassionate bereavement care. Providing parents with clear and accurate information, including on the cause of death, is central to the principles of family-centred and high-quality care [30]. Health workers in Uganda receive minimal formal training on bereavement care, particularly regarding communication with parents [18]. This leads to some staff avoiding parents in the hope that someone else will inform them about the death, as reflected in some participants' accounts. A study in Nigeria found similar avoidance or even deception among health workers and family members, which several attributed to the need for the mother to recover physically from labour [31]. Studies in Malawi and Zambia also found that some women felt they had been "deprioritised" as health workers focused care on women with live babies [32]. Distancing from bereaved parents may also be a strategy for self-protection for staff to manage their own feelings [33].

A meta-summary of women's experience of stillbirth in LMICs found that poor communication, neglect, and insensitivity on the part of health workers led to women feeling dissatisfied with their care [11]. Poor communication can also exacerbate grief and may lead to long-term emotional and psychological ill health [32]. Although some respondents spoke of concerns about the care their baby received while alive, others spoke of the compassion with which they were treated after the death. While other studies have considered health workers' perspectives [18], infrastructure requirements, and training methods [34], further research with parents and health workers could identify approaches to bereavement care that recognise the needs and constraints of both groups.

Although no respondents received a full explanation of the cause of their baby's death, many received partial explanations and speculated as to other reasons. In contrast to previous studies which found that stillbirths or early deaths at home were believed to stem from witchcraft or bad omens [13,15,16], most participants' reports focused on medical or clinical factors associated with the care their baby received. This could be due to several reasons. Being interviewed at the hospital where their baby died may lead them to focus on the health care that was provided rather than other factors. It could also reflect respondents' engagement with medical facilities through the birth and subsequent care or social norms among relatively educated and urban populations compared to some previous studies. A recent study from northern Uganda also found perinatal deaths are commonly associated with biomedical explanation, in contrast to the past when they were attributed to superstitious beliefs and witchcraft, or as a consequence of unacceptable social behaviours [35]. Despite an apparent lack of self-blame, participants may prefer to focus on health care providers' actions rather than their own out of fear of being blamed for the death themselves. Being back in the hospital may also trigger intense feelings and memories, some of which they may not want to share with the interviewer. Despite the discussion of medical causes of death, many participants spoke of the death being 'God's plan' which was used to rationalise deaths and as a source of strength [8].

In contrast to much of the bereavement literature, often from high-income countries [6,7], memory-making practices did not resonate with participants. Many preferred not to have reminders of their baby and instead focused on the future. A study in Malawi, Tanzania, and Zambia found that some women defied cultural norms to hold their stillborn babies and discreetly keep some mementoes (such as medical records) [32]. This study noted that these processes of memory-making are less frequent in African settings, where rates of infant mortality are high, and where focusing on "letting go" can be a coping strategy for the bereaved [32,36]. However, the interviews took place during the first year of bereavement and parents' attitudes towards memory-making or active grief work may change. For example, reminders may be painful during acute phases of grief but may be valued more highly after some time has passed. After a period of acute grief, respondents focused on 'becoming strong,' echoing the stages model of grief which describes progression of emotions from denial and isolation towards acceptance [3]. Other studies have observed the life-long impact of bereavement, particularly amongst parents who have experienced the death of a child [37]. A study with a longer time horizon that enables follow-up of participants at multiple points throughout their grief journey could build a more complete picture of the bereavement experience and what a high-quality bereavement care package would comprise in a low-resource setting.

In contrast to the existing literature, which describes parents avoiding public memorials after a perinatal death due to fear of social stigmatisation [13,38], respondents did not report keeping their baby's death a secret or experiencing any overt stigma from family or community members. This may be due to varying social norms regarding deaths at different points in the perinatal period (e.g., stillbirths versus neonatal deaths), or differences in perceptions of perinatal deaths across different contexts. Another study from northern Uganda found that public mourning was encouraged at babies' funerals to show sympathy for the parents and create a sense of solidarity [17]. This was echoed in our findings, with some respondents speaking of shared sadness, particularly with female relatives. Between respondents, the extent to which they shared their grief tended to reflect their social ties, and they often preferred to confide in close family and friends rather than more distant social contacts.

Our findings support existing evidence that social networks, including faith communities, are the main source of follow-up support, offering help with domestic work, childcare, and financial support [11,12,39]. After sharing their grief, respondents valued distraction and support to become strong. This may echo other studies which found that grief is believed to cause infertility [40]. Focusing on future pregnancies and rationalising through their faith were important coping mechanisms [8,35]. Although no respondents received follow-up care from health care professionals, they wanted advice for future pregnancies rather than bereavement support. This may also have been influenced by the interview setting, as many respondents closed the interview with medical questions for the interviewer. Further research with family and health workers could identify additional coping mechanisms that could support bereaved parents – including during subsequent pregnancies.

Although most of our respondents did not have other living children, those with children spoke about the impact on their relationship. Caring for a surviving twin while grieving can result in complex and divergent emotions [41]. One respondent spoke of her temporary inability to care for her surviving twin due to her grief, while others appeared to put their grief on hold while focusing on their surviving baby.

Little is published about the financial consequences of infant loss, particularly in low-income settings. The evidence on the financial impact in this study was limited to interview responses, which focused on the cost of treatment while the baby was still alive and payments to health care professionals. This may not present a full picture of all financial expenses and opportunity costs to households. Although routine maternity services are provided free of charge in government health facilities in Uganda [42], stocks-outs of medical supplies and drugs mean that out-of-pocket payments for childbirth are the norm

[17]. The higher costs for treatment and burial were further exacerbated by a reduction in income during the period of mourning, although respondents did not report any longer-term effects on income due to lower productivity after returning to work [43].

A recurring theme in this study regarding financial support from family and community members was absent from the existing literature. Participants spoke of relatives 'filling the gap' in their finances by helping pay for medication and funeral costs. Some financial assistance was targeted to specific expenses where the parents' finances fell short; however, some individuals also provided more general condolence money when they came to comfort the bereaved. Parents appeared to have more discretion to spend condolence money and spoke of it helping to 'heal my wounds' and get back on their feet.

Despite a context of financial precarity, most respondents took comfort from the fact they had done all they could financially to ensure survival of their baby. Despite the suggestion that infant bereavement led to higher costs for both treatment and burial, as well as reduced income during the period of mourning, this cannot be concluded definitively without further research. We found that male partners typically took on traditionally gendered roles, including making payments for care. Further research with male partners could provide more insights on the financial impact of losing an infant as well as men's experience of bereavement.

This study had several limitations. Grief is not linear, which creates methodological challenges in deciding the right time to collect data as well as a lack of consensus on appropriate measures [5]. The amount of time which had elapsed between the death and the interview varied, and the interviews reflect self-reported feelings at one point in time. There may be some decisions they accepted at that time but later regret, such as deleting photographs because the memories were too painful. Respondents were recruited from the OMWaNA trial which may have affected their experience of bereavement and their interview responses. Respondents were recruited from one of the five trial hospitals. Participants at other sites may have had different bereavement experiences. The interview location may have also influenced responses, which were more medicalised than much of the existing literature. Respondents appeared to perceive the interviewer as a member of the clinical team, which may have limited any critical responses regarding the care provided. Except for one father who participated in this study, male partners, family and community members, and health workers were not included; thus, our findings are limited to external perspectives of these stakeholders' experiences of death. Other studies have suggested that fathers lack adequate support and attention following bereavement [44]. Finally, this study intended to explore differences between participants whose baby had been assigned to the intervention arm (KMC initiated prior to stabilisation) and those whose infant had been assigned to the control arm; however, it was not possible to ascertain any differences between the two trial arms. Strengths of this study included a local Ugandan social scientist conducting the interviews, a standardised interview format, and a systematic approach to thematic analyses.

Conclusion

Parents in Uganda who experience the death of their baby described stress and uncertainty at the time of the death followed by a period of acute grief. Rather than health worker-led models of active bereavement care, respondents relied on support offered by family and community members, using their faith and a focus on future pregnancies to 'become strong.' These findings reiterate the importance of understanding the experience of infant death in different settings and circumstances. Further research is needed to understand the longer-term impact of bereavement including on future pregnancies, experiences of male partners and other family members, the effects of practicing KMC and participating in clinical trials, and how coping mechanisms could inform more contextually appropriate bereavement care.

List of abbreviations

KMC Kangaroo mother care
LMIC Low- and middle-income country
OMWaNA Operationalising kangaroo Mother care before stabilisation amongst low birth Weight Neonates in Africa

Authors contribution

This study was conceived by MMM, DE, and JEL as a component of the process evaluation linked to the OMWaNA trial. GS conducted a literature review to inform the development of the interview guide, which was reviewed by MMM, HB, DE, JS, SN, and VT. SN conducted the interviews, with support from VT. JK transcribed and translated (as necessary) the interview data, in coordination with SN. GS analysed and coded the interview data, with support from HB and MMM, and drafted the manuscript. MMM, DE, HB, CJT and JS supported interpretation of the study data. All authors provided feedback on the manuscript, alongside final approval.

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Ethical statement

This study was approved by the Research Ethics Committees of the London School of Hygiene and Tropical Medicine (reference: 27546), the Uganda Virus Research Institute (reference: GC/127/717), and the Uganda National Council of Science and Technology (reference: HS 2645). Written informed consent was obtained from all participants. All study procedures were carried out in accordance with applicable ethical and regulatory requirements.

Declaration of Competing Interest

The authors declare that they have no competing interests.

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References

[1] United Nations Inter-agency Group for Child Mortality Estimation. Levels and trends in Child Mortality: Report 2023. New York; 2024 [cited 2024 Mar 19].

Available from: ⟨https://data.unicef.org/wpcontent/uploads/2024/03/UNICEF-2023-Child-Mortality-Report-1.pdf⟩.

[2] UN Inter-agency Group for Child Mortality Estimation, Never Forgotten The situation of stillbirth around the globe: Report of the United Nations Inter-agency Group for Child Mortality Estimation, 2022, UNICEF, New York, 2023. ⟨https://data.unicef.org/resources/never-forgotten-stillbirth-estimates-report⟩. cited 2023 Nov 20]. Available from.

[3] E. Kubler-Ross, D. Kessler, On grief and grieving: finding the meaning of grief through the five stages of loss, Scribner, New York, 2005.

[4] A.L. Forte, M. Hill, R. Pazder, C. Feudtner, Bereavement care interventions: a systematic review, BMC Palliat. Care 3 (2004) 3.

[5] S. Harvey, C. Snowdon, D. Elbourne, Effectiveness of bereavement interventions in neonatal intensive care: a review of the evidence, Semin Fetal Neonatal Med 13 (2008) 341–356.

[6] R. Beverley, K. Nunn, Counselling the bereaved, J. Soc. Issues 44 (1988) 191–206.

[7] W. Stroebe, H. Schut, M.S. Stroebe, Grief work, disclosure and counseling: do they help the bereaved? Clin. Psychol. Rev. 25 (2005) 395–414.

[8] J. Kiguli, S. Namusoko, K. Kerber, S. Peterson, P. Waiswa, Weeping in silence: community experiences of stillbirths in rural eastern Uganda, Glob. Health Action 8 (2015) 24011.

[9] C.K. Nalwadda, P. Waiswa, D. Guwatudde, K. Kerber, S. Peterson, J. Kiguli, As soon as the umbilical cord gets off, the child ceases to be called a newborn": sociocultural beliefs and newborn referral in rural Uganda, Glob. Health Action 8 (2015) 24386.

[10] P. Agravat, E.M. Loucaides, M. Bruce Kumar, A. Howells, A. Molina Garcia, I. Sebina, et al., Research funding for newborn health and stillbirths, 2011-20: a systematic analysis of levels and trends, Lancet Glob. Health 11 (2023) e1794–e1804.

[11] C. Shakespeare, A. Merriel, D. Bakhbakhi, R. Baneszova, K. Barnard, M. Lynch, et al., Parents' and healthcare professionals' experiences of care after stillbirth in low- and middle-income countries: a systematic review and meta-summary, BJOG 126 (2019) 12–21.

[12] A.E.P. Heazell, D. Siassakos, H. Blencowe, C. Burden, Z.A. Bhutta, J. Cacciatore, et al., Stillbirths: economic and psychosocial consequences, Lancet 387 (2016) 604–616.

[13] E. Ayebare, T. Lavender, J. Mweteise, A. Nabisere, A. Nendela, R. Mukhwana, et al., The impact of cultural beliefs and practices on parents' experiences of bereavement following stillbirth: a qualitative study in Uganda and Kenya, BMC Pregnancy Childbirth 21 (2021) 443.

[14] H. Mistry, A.E.P. Heazell, O. Vincent, T. Roberts, A structured review and exploration of the healthcare costs associated with stillbirth and a subsequent pregnancy in England and Wales, BMC Pregnancy Childbirth 13 (2013) 236.

[15] P. Waiswa, S. Nyanzi, S. Namusoko-Kalungi, S. Peterson, G. Tomson, G.W. Pariyo, I never thought that this baby would survive; I thought that it would die any time": perceptions and care for preterm babies in eastern Uganda, Trop. Med. Int. Health 15 (2010) 1140–1147.

[16] E.L. Nabiwemba, L. Atuyambe, B. Criel, P. Kolsteren, C.G. Orach, Recognition and home care of low birth weight neonates: a qualitative study of knowledge, beliefs and practices of mothers in Iganga-Mayuge Health and Demographic Surveillance Site, Uganda, BMC Public Health 14 (2014) 546.

[17] A.A.O. Arach, J. Kiguli, V. Nankabirwa, N. Nakasujja, D. Mukunya, et al., Your heart keeps bleeding": lived experiences of parents with a perinatal death in Northern Uganda, BMC Pregnancy Childbirth 22 (2021) 491.

[18] T.A. Mills, E. Ayebare, J. Mweteise, A. Nabisere, R. Mukhwana, A. Nendela, et al., There is trauma all round': a qualitative study of health workers' experiences of caring for parents after stillbirth in Kenya and Uganda, Women Birth 36 (2023) 56–62.

[19] V. Tumukunde, M.M. Medvedev, C.J. Tann, I. Mambule, C. Pitt, C. Opondo, et al., Effectiveness of kangaroo mother care before clinical stabilisation versus standard care among neonates at five hospitals in Uganda (OMWaNA): a parallel-group, individually randomised controlled trial and economic evaluation, Lancet 403 (2024) 2520–2532.

[20] M.M. Medvedev, V. Tumukunde, I. Mambule, C.J. Tann, P. Waiswa, R.R. Canter, et al., Operationalising kangaroo mother care before stabilisation amongst low birth Weight Neonates in Africa (OMWaNA): protocol for a randomised controlled trial to examine mortality impact in Uganda, Trials 21 (2020) 126.

[21] A. Conde-Agudelo, J.L. Díaz-Rossello, Kangaroo mother care to reduce morbidity and mortality in low birthweight infants, Cochrane Database Syst. Rev. 8 (2016) CD002771.

[22] WHO, UNICEF. Survive and Thrive: Transforming care for every small and sick newborn. Geneva; 2019 [cited 2023 Nov 04]. Available from: ⟨https://www.unicef.org/media/58076/file⟩.

[23] M.M. Medvedev, V. Tumukunde, C. Kirabo-Nagemi, G. Greco, I. Mambule, K. Katumba, et al., Process and costs for readiness to safely implement immediate kangaroo mother care: a mixed methods evaluation from the OMWaNA trial at five hospitals in Uganda, BMC Health Serv. Res. 23 (2023) 613.

[24] N.K. Gale, G. Heath, E. Cameron, S. Rashid, S. Redwood, Using the framework method for the analysis of qualitative data in multi-disciplinary health research, BMC Med. Res. Method. 13 (2013) 117.

[25] J. Green, N. Thorogood. Qualitative Methods for Health Research, Third ed., SAGE, London, 2014.

[26] Uganda Bureau of Statistics. The Uganda National Survey Report 2019/20. Kampala; 2021 [cited 2023 Aug 08]. Available from: ⟨https://www.ubos.org/wp-content/uploads/publications/09_2021Uganda-National-Survey-Report-2019-2020.pdf⟩.

[27] D. Chou, B. Daelmans, R. Jolivet, M. Kinney, L. Say, Ending preventable maternal and newborn mortality and stillbirths, BMJ 351 (2015) h4255.

[28] H. Brotherton, M. Daly, P. Johm, B. Jarju, J. Schellenberg, L. Penn-Kekana, et al., We all join hands": perceptions of the kangaroo method among female relatives of newborns in the Gambia, Qual. Health Res 31 (2021) 665.

[29] M. Lydon, M. Longwe, D. Likomwa, V. Lwesha, L. Chimtembo, P. Donohue, et al., Starting the conversation: community perspectives on preterm birth and kangaroo mother care in southern Malawi, J. Glob. Health 8 (2018) 010703.

[30] WHO. Standards for improving the quality of care for small and sick newborns in health facilities. Geneva; 2020 [cited 2022 Jun 29]. Available from: ⟨https://www.who.int/publications/i/item/9789240010765⟩.

[31] O. Kuforiji, TraceyA. Mills, K. Lovell, An exploration of women's lived experiences of care and support following perinatal death in South-Western Nigeria: a hermeneutic phenomenological study, Women Birth 37 (2024) 348–354.

[32] V.A. Danna, T. Lavender, R. Laisser, A. Chimwaza, I. Chisuse, C.T. Kasengele, et al., Exploring the impact of healthcare workers communication with women who have experienced stillbirth in Malawi, Tanzania and Zambia. A grounded theory study, Women Birth 36 (2023) e25–e35.

[33] A. Ellis, C. Chebsey, C. Storey, S. Bradley, S. Jackson, V. Flenady, et al., Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences, BMC Pregnancy Childbirth 16 (2016) 16.

[34] Family Centred Care Health System Building Block Team. Neonatal care: How to support families, and what happens after bereavement? Implementation realities from Kenya, Malawi and India. NEST360; 2022 [cited 2023 Nov 20]. Available from: ⟨https://nest360.org/implementation-toolkit-series-family-centred-care⟩.

[35] A.A.O. Arach, N. Nakasujja, J. Rujumba, D. Mukunya, B. Odongkara, M. W. Musaba, et al., Cultural beliefs and practices on perinatal death: a qualitative study among the Lango community in Northern Uganda, BMC Pregnancy Childbirth 23 (2023) 222.

[36] N. Scheper-Hughes, Death Without Weeping: The Violence of Everyday Life in Brazil. Berkeley and Los Angeles, University of California Press, California, 1992.

[37] N. Moor, P.M. de Graaf, Temporary and long-term consequences of bereavement on happiness, J. Happiness Stud. 17 (2016) 913–936.

[38] A.C. Meyer, C. Opoku, K.J. Gold, They say i should not think about it:" a qualitative study exploring the experience of infant loss for bereaved mothers in Kumasi, Ghana, Omega. J. Death Dying 77 (2018) 267–279.

[39] L.R. Roberts, S. Montgomery, J.W. Lee, B.A. Anderson, Social and cultural factors associated with perinatal grief in Chhattisgarh, India, J. Community Health 37 (2012) 572–582.

[40] R.A. Haws, I. Mashasi, M. Mrisho, J.A. Schellenberg, G.L. Darmstadt, P.J. Winch, These are not good things for other people to know": how rural Tanzanian women's experiences of pregnancy loss and early neonatal death may impact survey data quality, Soc. Sci. Med. 71 (2010) 1764–1772.

[41] J. Richards, R. Graham, N.D. Embleton, C. Campbell, J. Rankin, Mothers' perspectives on the perinatal loss of a co-twin: a qualitative study, BMC Pregnancy Childbirth 15 (2015) 143.

[42] C. Lindberg, T. Nareeba, D. Kajungu, A. Hirose, The extent of universal health coverage for maternal health services in Eastern Uganda: a cross sectional study, Matern Child Health J. 26 (2022) 632–641.

[43] S. Murphy, J. Cacciatore, The psychological, social, and economic impact of stillbirth on families, Semin. Fetal Neonatal. Med. 22 (2017) 129–134.

[44] J. Mirlashari, A. Nikbakht Nasrabadi, L. Holsti, F. Ghorbani, Bagher Hosseini, M. Fadaei, Z. Caring for the bereaved parents in the NICU: fathers-the missing piece of the puzzle, J. Perinat. Neonatal. Nurs. 36 (2022) E31–E39.