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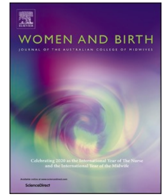

Exploring the impact of healthcare workers communication with women who have experienced stillbirth in Malawi, Tanzania and Zambia. A grounded theory study

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ABSTRACT

Background: Communication and interaction with healthcare workers at the time of stillbirth remain in parents' long-term memories and impact on emotional and psychological well-being. Cultural attitudes and norms influence how stillbirth is acknowledged and discussed in society. There is limited evidence on how women from sub-Saharan Africa became aware of the death of their babies. This research explored how women perceived the approach adopted by healthcare workers when the news of their stillbirth was disclosed to them.
Methods: Grounded theory study. Women (n = 33) who had birthed a stillborn baby in the preceding 12 months were purposively sampled and participated in in-depth interviews (9 in Zambia, 16 in Tanzania and 8 in Malawi). Informed consent was gained from all participants. Data were analysed via a coding process using constant comparative analysis.
Findings: Women sacrificed individualized and personal grieving strategies to conform and behave according to what was expected within their community. An overarching theme of *cultural conformity overrides personal grief* incorporated four sub-themes: *perceiving something was wrong, the unexpected outcome*, *experience contrasting emotions*, *bonding with the baby.*
Discussion and conclusions: Most participants embarked on a negative 'emotion work' to adapt and suppress emotions and grief due to cultural expectations. Inability to voice the trauma of losing a baby may lead to perinatal mental health issues and needs addressing. Maternity healthcare workers should encourage women to express their feelings and grief. Appropriate training in perinatal bereavement care including good communication, appropriate attitudes and provision of meaningful information to grieving women is recommended.

Statement of significance

Problem or Issue

Limited evidence exists about how women in sub-Saharan Africa become aware of the death of their stillborn baby.

What is already known?

Poor communication from healthcare workers exacerbates a woman's grief when having experienced a stillbirth and potentially results in long-term emotional and psychological ill-health.

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What this paper adds?

Women endured the loss of their babies through secrecy and suppression of emotions. Adherence to cultural norms in Malawi, Tanzania and Zambia hindered their grieving process. A new approach to grieving, which permits individualised and personal expression, my promote psychological wellbeing of these women.

Introduction

Experiencing the death of a baby before, during or immediately after birth, constitutes a traumatic and painful event for parents [1] with poor mental and physical health which can impact on family dynamics including attitudes towards existing children, tension between partners, and a potential for marriage breakdown [2,3].

In 2019, there were 2 million stillbirths worldwide, the vast majority occurring in Sub-Saharan Africa and South Asia [4]. Stillbirth has been defined as a baby born with no sign of life at or after 28 weeks gestation [5]. In the last decade, there has been substantial progresses in the reduction of stillbirth worldwide, with a decline in stillbirth rates from 21.4 stillbirth per 1,000 total birth in 2000 to 13.9 in 2019 [4]. Notwithstanding, this conceals huge inequalities between countries, with Sub-Saharan Africa bearing the highest burden [4]. As many parents are still confronted by this tragedy, to minimise the sequalae of poor mental health of affected families, health systems and communities need to offer adequate support.

The behaviours, attitudes and practice of healthcare workers impact on women experiencing stillbirth. Positive communication and interaction helps mitigate the trauma of the woman and her partner, while negative episodes increase parents' distress and are likely to be remembered by the woman and her partner for a long period [6]. Perinatal bereavement care includes sensitive communication, psychological support and counselling, and support in decision-making before, during and after birth [7]. Every person grieves differently [8] thus this care needs to be tailored to the specific needs of each family and be respectful and compassionate, to ensure a positive recovery process [9].

The way in which healthcare workers communicate and convey information to the woman and her family, at the time of stillbirth, shapes the overall experience of care. When a diagnosis of a stillbirth is made, either antenatally or in labour, parents appreciate being notified jointly of the death without delay and in a clear and honest way [10]. They also appreciate it when healthcare workers use compassionate language, express sympathy and provide the woman and her partner with an opportunity for some private time to share emotions [10]. Research has shown that families appreciate being offered the choice to spend time with the baby after birth, to have evidence of his/her existence [10]. Moreover, supporting parents in creating memorabilia of their child, including taking photographs, hand/footprints and keep the baby's clothing or blanket, validates emotions and their role as parents [11].

Conversely, delays in the verbal communication of death, poor and inconsistent messages and the use of medical terminology cause frustration for the woman and her partner and can result in them blaming healthcare workers for the poor outcome [6] and doubting their explanation of the cause of death [12]. Parents who perceived abrupt or intermittent communication and felt the healthcare worker did not give reassurance or showed empathy, experienced a sense of abandonment and a perception of carelessness from the health system [10].

Grief constitutes a normal response to the death of a loved one [13]. Complicated grief is when grief is prolonged and intense [14], preventing the bereaved to resume his/her normal life. Different studies have explored parents' emotions and grief following stillbirth [15], but there is limited evidence about how verbal and non-verbal communication around the time the woman becomes aware of the possibility of birthing a stillborn baby influences feelings and experiences of grief in Low and Middle-Income Countries (LMIC).

Communication around stillbirth is influenced by cultural attitudes and norms, which determines how stillbirth is accepted and discussed in society [16]. In many countries, the death of a child before birth is associated with curses and spirits, thus its disclosure its kept in the private sphere to avoid further harm and embarrassment for the woman [17]. Lack of public acknowledgment of these stillborn babies means parenthood is often not recognised, and grief is likely to be disenfranchised, resulting in stigma, isolation, and more suffering for the couple [15]. In some African settings, the absence, or limited explanation of the cause of death, and the associated traditional beliefs erroneously connect stillbirth with witchcraft or a woman's perceived promiscuity [18]. Women then may fell that they are to blame for the death [19]. In sub-Saharan Africa, the widespread perception that stillborn babies are "not human" [19], can mean that women are denied the possibility of morning openly [18]. The woman is discouraged to share her experience by her community due to the societal fear of "bad luck" associated with stillbirth [20]. As health facilities are situated within the community, healthcare workers may also share these erroneous views of perinatal death [21]. This inability to mourn openly reduces the capacity to seek and access support, and increases the potential for psychological harm and intense grief [22]. Importantly, growing evidence is reporting that women in LMICs want to acknowledge their baby's death and grieve openly for their infant [23]. Further exploration of women's experiences before, during and after birth is needed to learn how best to support them during bereavement. The purpose of this study was to understand how and when women who attended public health facilities in Malawi, Tanzania and Zambia became aware of the death of their babies and how the interaction with healthcare workers shaped their feelings and experiences of grief.

Methods

Methodology

Grounded Theory (GT) methodology, underpinned by Symbolic Interactionism was adopted in this study. Symbolic interactionism enables exploration of the meanings that individuals place on events and social interactions, based on their beliefs, and how these meanings inform behaviours [24]. Using qualitative methods of data collection, GT allows one to uncover similarities and variations in people's subjective interpretations of the same phenomenon [25]. Through constant comparative analysis, participants' views are turned into concepts which are then integrated into a theory which is grounded in the data [26]. Commonly used in midwifery research studies, GT is appropriate when little is known of a certain area and to explore human interactions within a social context [27]. For instance, Barry et al., [28] used GT to explore midwives' work from the perspectives of other health workers to highlight social processes between professions. Whereas in Hall et al., [27] GT was applied to investigate midwives' behaviours and interaction with women regarding the use of complementary alternative medicine in hospitals. Akin to research taken in these contexts, our study uses qualitative narratives of women's experiences of stillbirth to analyse social interactions and communication with nurse-midwives and doctors and understand how these influenced women's feelings and experiences of grief. Strauss and Corbin approach [29] was pragmatically chosen for the interactive and iterative nature of the research process. Through this approach we could also accounts for the inevitable influence of interviewers' subjectivity in the research and the potential impact of this emotive area of investigation on them [26]. This study was part of a multi-country programme funded by the National Institute for Health Research (NIHR), focusing on prevention and management of stillbirth in Sub-Saharan Africa (16/137/53). The Standard for Reporting Qualitative Research checklist [30] was followed to report this study (Supplementary file 1).

Participants, recruitment and consent

Purposively recruited postnatal women of at least 18 years of age who held the capacity to consent, were included. The women had experienced a stillbirth in the preceding 12 months and had received care at one of the tertiary referral hospitals involved in this study. The WHO definition of stillbirth was adopted [4]. Informed by Grounded Theory, an initial purposive sample of three women per country was selected. After the analysis of the first 9 interviews, theoretical sampling of additional participants was used to enhance the depth of the theory being developed (for instance exploring women's grief journey for constant comparison with existing models of grief) until no new evidence was emerging [31].

Recruitment was carried out by locally trained research midwives (three in Tanzania, two in Malawi and two in Zambia) with input and support from the Community Engagement and Involvement groups (i.e., women who themselves gave birth to a stillborn baby) setup in each country at the outset of the NIHR programme. Women were recruited from regional referral hospitals (one per country) located in Mwanza (Tanzania), Mansa (Zambia), and Southern region (Malawi). These countries were chosen for their high national stillbirth rates (18.8, 14.8, and 16.3 per 1,000 total birth, respectively) [4] and for their involvement in the multi-country NIHR research programme.

Women were approached in the postnatal ward by midwives and doctors, then their details were supplied to the study's research midwives who then followed up and provided them with information about the study. Verbal and written information, in English or the local language (Kiswahili, Chichewa or Bemba), was provided to all participants, who were given four weeks to decide whether to join the study. A consent-to-contact form was completed for those women who agreed to be contacted by the research midwife.

Ethical considerations

Written informed consent was obtained from all women before the start of each interview and for audio recording, to which all participants agreed. Participation was voluntary, and the researchers reassured the women about the confidentiality of the interviews and reiterated that at any point women could withdraw from the research, without negative consequences or impact on care access and provision. Research midwives ensured that women could take breaks or opt-out from the interview. In addition, a distress policy provided referral pathways in case participants needed professional counselling. Ethical approval was awarded by University of Manchester Ethics Committee in the United Kingdom, College of Medicine Research and Ethics Committee in Malawi, the Joint Catholic University of Health and Allied Sciences/ Bugando Medical College (CUHAS/BMC) Ethical and Review Committee in Mwanza, Tanzania and Ethics and Science Converge Institutional Review Board (ERES Converge IRB Zambia in Zambia. Permission to conduct the study was also obtained from the district / provincial health authorities and each hospital involved.

Data collection

One-off, semi-structured interviews were conducted between October 2019 and March 2020, at participants' preferred location either at the woman's home, or at the clinic, or hospital. In-depth interviews were chosen to encourage participants to provide their own stories and meanings without the influence of others [32,33]. The geographical vastness of the research site required multiple researchers to be involved in data collection. These individuals were nurse-midwives with clinical experience and had previously cared for women who had birthed a stillborn baby. They were also familiar with conducting qualitative interviews and received protocol training for this study. A structured questionnaire, developed by our team (TL, CB, RL) was used to collect participants' demographic and obstetric details including age, civil status, education, religion, occupation, mode of birth, if the baby died before or during birth and whether the healthcare worker informed the woman about the cause of death. These details were used to contextualise findings.

A topic guide, specifically designed for this study, ensured consistency between interviewers. In line with Strauss and Corbin [29] approach, few questions were included to facilitate a respondent-led discussion, with the order of topics depending on the flow of participants' narratives. Community Engagement and Involvement (CEI) groups piloted the topic guide in each country and ensured questions were culturally appropriate, understandable by the participant. They also introduced the research team to the participants and suggested the appropriate language to use when asking about emotions and the baby. The interviews started with a general question such as *"Can you tell me about your last birth experience*?", allowing the women to talk freely, while rapport with the research midwife was established. Due to simultaneous data collection and analysis, the topic guide was constantly adapted as new ideas emerged, enabling a deep exploration of each communication component (language, wording, body language) of women's reaction and emotions, including their feelings around setting and arrangements in which notification of death occurred, before, during and after birth. A summary of key points at the end of each interview, ensured correct interpretation of data [32]. Moreover, researchers added field notes to acknowledge emotional responses, pauses and body language. Regular de-briefing sessions were also offered to researchers to mitigate the impact of stressful interviews and to allow reflections on positionality [32]. Interviews were digitally recorded and lasted between 35 and 90 min.

Data analysis

Interviews were translated and transcribed verbatim from local language to English by research midwives and field notes added. Accuracy was ensured through translation and back-translation of a sample of transcripts. Transcripts were anonymised using unique study numbers. Strauss and Corbin [29] three-stage approach was followed and was coordinated by VAD, CB and SW who involved each country team in the analysis of their own data. The analysis began with 'open coping' of the first round of 9 interviews. Transcripts were read thoroughly to enable familiarisation with women's experiences and a manual line-by-line coding was performed, consisting in applying labels to portion of text, using participants words and researchers' understanding. Transcripts were compared among each other's and across countries to highlight similarities and differences among codes, and cultural practices and traditions. In the second stage 'axial coding' identified codes, fracturing initial data, were listed and reassembled to create more abstract concepts (sub-categories) [34]. In this process, we noticed that some sub- categories presented similarities to existing models of grief [35,36]. This encouraged a revision of these sub-categories and a re-interrogation of initial transcripts to consider women's experiences against grief cycles. Theoretical sampling of additional women in each country [31], was undertaken to gain further insights into feelings and emotions and how culture and norms influence the grieving process. Constant comparative analysis of existing and new transcripts enabled emerging of additional concepts and refining of existing ones, through a mix of inductive and deductive reasoning [29]. Theoretical sensitivity was applied throughout by keeping an open mind and the ability to identify data segments relevant to the theory [26]. Use of diagrams, in this phase, helped to refine sub-categories and frame them as emotions connected to a core category. In the last stage the analysis moved to 'selective coding' which involved coding the remaining transcripts to develop a storyline conceptualising the core category [29]. Senior (TL, CB) and early career researchers (VAD, FK, KL, TK), and a member of the CEI group (MM) confirmed that data saturation was achieved after the analysis of 28 interviews, as no new aspects were appearing [32]. The last five transcripts were used to

strengthen existing sub-categories and the theoretical model. Memoing was used along each state of theory generation to notes researchers' points of view around codes, category making, feelings and intuitions of emerging concepts and of the core category [34,37].

Findings

Thirty-three interviews were undertaken. Demographic information is provided in Table 1.

Regardless of the country of residency, participants felt that their experience of stillbirth was a forbidden topic of conversation within their community. For most participants it was their first opportunity to share their experience and they were grateful for the opportunity to reflect on the events and share their feelings for their baby.

A core category '*Cultural conformity overrides personal grief*' and four sub-categories *perceiving something was wrong*, *the unexpected outcome*, *experience contrasting emotions*, *bonding with the baby* were generated from the data (see Fig. 1). The core category highlights the subconscious process experienced by women after becoming aware of the death of their baby. The stigma attached to stillbirth results in women behaving according to what it is expected from them, rather than expressing their needs and inner feelings. Their emotional journey can be represented as a non-linear process: from an initial uncertainty and '*perceiving something was wrong*', women progress to a certainty – the death of the baby – which is also seen as '*the unexpected outcome*'. Culture and lack of explanation about the cause of death create new uncertainties, which are not always voiced. Interaction with healthcare workers and family members can trigger fluctuating '*contrasting emotions*' (double-sided arrows). By bearing and giving birth to a stillborn baby, women are well aware of entering a sphere of secrecy in which emotions, grief and actions, including '*bonding with the baby*' need to be concealed from the public domain (red triangle). The shape of the triangle (starting small and becoming bigger) indicates how concealment increases from suppressing emotions to hiding grief and actions.

Identified sub-categories and the core category were consistent across the three countries; where differences were noticed these are indicated.

Table 1
– Demographics of participants interviewed in each country.

Indicator	Zambia	Tanzania	Malawi
Age (median) – range	33 (27–44)	35.5 (21–40)	23 (18–25)
Civil status			
Married / Living with partner	9	14	6
Not married	–	2	2
Education			
No schooling / Primary	5	8	3
Secondary	3	6	5
College / Diploma / Degree	1	2	–
Religion			
Christian	9	15	7
Muslim	–	1	1
Occupation			
Formal employment	2	4	–
Informal work	2	10	6
Housewife	5	2	2
Mode of birth			
Spontaneous Vaginal birth	6	15	3
Cesarean Section	3	1	4
Unknown	–	–	1
Type of diagnosis / death			
Antepartum	4	9	2
Intrapartum	4	5	6
Unclear	1	2	–
Cause of death			
Communicated	1	10	3
Not communicated	8	6	5

Perceiving something was wrong

Preparing for the worst

The first sub-category 'perceiving something was wrong' captured the initial doubts and uncertainty that some women felt but did not always express. Perceptions were a result of changes in fetal activity either before birth or during labour. This uncertainty was triggered or strengthened by healthcare workers' implicit messages and poor communication of the status of the fetus during the screening process. Woman #8, whose baby died antepartum (Tanzania) recalled the following:

> *I had that strange feeling. Sometimes I could feel that he wasn't playing, and then he resumes his kicks. […] However, I realised that things may not be normal when I felt the heaviness at the base of my belly. That's when I went to hospital and got admitted.*

The same feeling was expressed by Woman #1, whose baby died intrapartum (Zambia):

> '*Even when you are in labour, you are able to experience fetal movements. I could not feel the way I usually felt and I knew that with my baby there was something wrong. The contractions were also slowing down. This was also an indication that the baby was not ok.*

Common to some women was the scenario in which the nurse-midwife explained her/his inability to 'pick the fetal heart' or that 'the fetal heart was faint' in the initial examination. These words were not an explicit declaration of death, but women matched them with their perception of reduced fetal movement (RFM). Through these words they became aware of the potential death of their babies; although without an explicit verbalisation about death, a level of uncertainty remained.

> *When the second nurse gave me the same report, I married the feedbacks to the absence of fetal movements that I experienced and concluded that my baby had died. To me, if the baby is not moving and nurses cannot hear the heartbeat, then the baby is dead. That was the first thing that come to my mind. (#8, Woman whose baby died antepartum, Zambia)*

For other women, who did not experience RFM, doubts were triggered by health workers' attitudes. For instance, when nurse-midwives requested more than one colleague to identify the fetal heartbeat, and/ or avoided explaining the ultrasound findings, women became suspicious that something was wrong but were unsure about the outcome, given their perception that the baby was still moving.

> *Because she (the nurse-midwife) was the one who picked me up and wrote everything for me, yes, so after writing she said that let me scan you and after scanning me, she did not tell me anything but she told me that 'just wait, let me find a colleague so that she should also scan you in order to see'. I had doubts. (#03, Woman whose baby died antepartum, Malawi)*

For other women who had intrapartum stillbirth, the first indication of a problem came when they did not hear the baby cry. However, it was only when healthcare workers confirmed the death by showing the baby, that women believed that their baby had died.

> *While still lying on that labour bed, the nurse showed me the baby and told me to witness that my baby didn't cry at birth. She said that they would try resuscitating him and save his life, but it was too late. I had already lost hope. (#8, Woman whose baby died intrapartum, Tanzania)*

An unexpected outcome

Emotional and silent pain and regret

The sub-category 'an unexpected outcome' reflects the devastation and pain that women felt when the definitive news of the death of their baby was explicitly communicated. Unexpectedness was common across all women, irrespective of whether they were notified about the death antenatally, during labour or after birth. This is clearly explained by

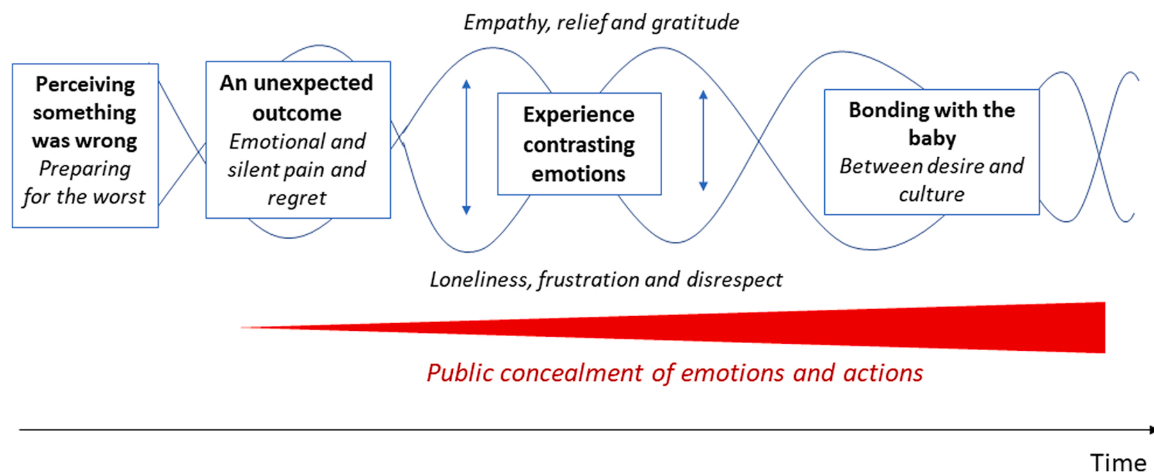

Fig. 1. – Theoretical model of women's emotions and grief after becoming aware of the death of their baby.

woman #3 from Malawi:

> *It pained me quite a lot when they told me the news because it was not something that I was expecting (#3, Woman whose baby died antepartum).*

Some women described feeling sad, emotional and overwhelmed by the death. Their reactions included "having no words", remaining silent and stating that they were experiencing emotional and physical pain. This woman's narration convey these emotions:

> *After about five minutes, the nurse came to my bed from the machine holding the baby in her hands. She said, "I am sorry to tell you that the baby is not breathing. As you saw we tried to help but the baby cannot still breathe". Then she showed me the baby. I could not believe that my baby had died. I was so devastated (#1, Woman whose baby died intrapartum, Zambia).*

Crying for the death of the baby was a common response in Tanzania and Malawi, as expressed by this woman:

> *[…] There was nothing I could do besides crying (#1, Woman whose baby died intrapartum, Tanzania).*

In Zambia women tended to mourn in silence, to comply with the belief that if the woman cries for her stillborn baby, the spirit of the deceased can prevent her from conceiving again.

> *She was a beautiful baby. I felt bad. I felt like crying but I remembered what my mother told me about our tradition. I could not cry because I wanted another baby (#8, Woman whose baby died antepartum, Zambia)*

Women's sadness and devastation was compounded by a sense of disappointment for "going home empty handed". Women felt their efforts of being pregnant for a 9-month period, including spending energy and money to access facilities and prepare for the newborn's arrival, was not rewarded. This feeling was evident in woman #4's narrative:

> *I was sad because I did struggle with the pregnancy for 9 months (Woman whose baby died intrapartum, Tanzania).*

The same sensation was explained by woman #7 from Malawi:

> *'I felt like I have just done some work (being pregnant) without any payment (live baby) (Woman whose baby died intrapartum, Malawi).*

Experience contrasting emotions

The third sub-category *'experience contrasting emotions'* captured the shift between positive and negative emotions, as a consequence of women's interaction with nurse-midwives and doctors. Despite the trauma of losing a child, healthcare workers' empathy, the use of sensitive language and compassionate care comforted the woman in this difficult time. In contrast, inadequate and casual communication of death and the non-conducive hospital environment in which death was confirmed, enhanced loneliness and distress.

Empathy, relief and gratitude

Devastation and regret were mitigated by healthcare workers' manner and attitudes in delivering the news. In many accounts, women acknowledged providers' compassionate attitudes and the use of sensitive respectful language. Simple wording, a low tone of voice and being called by name transmitted a sense of closeness and concern. For instance, sentences like "*sorry for your baby" or "sorry for your loss"* made women feel that the healthcare worker was sharing their grief. Women also noticed when healthcare workers adopted a polite and non-discriminatory language in such a circumstance.

> *He (the doctor) used a polite language like he told "sorry God will bring to you another gift like this, since he took from you now". This made me feel comfortable (#05, Woman whose baby died antepartum, Tanzania)*

For some participants it was a surprise to discover that a stranger, such as a nurse-midwife or a doctor, could speak in a sensitive way and take care of them like a family member.

> *It was all encouraging to me. I did not know that healthcare providers can feel bad when someone who is not even their relative loses a baby. To be honest I was really encouraged. (#08, Woman whose baby died antepartum, Zambia)*

Women also acknowledged the stress experienced by the healthcare workers:

> *I think they (health staff) did not want me to feel bad. It was as if my relatives were talking to me. Maybe they liked me? Maybe it was a case after a long time. I think they were also stressed about what happened. (#14, Woman whose baby died intrapartum, Tanzania)*

Women were receptive to health workers' body language and gestures. They felt the pain was shared when they had a sad facial

expression, or their eyes filled with tears. Empathy was also perceived from gestures such as holding hands, patting the woman's back, wiping tears and sitting nearby.

They (health workers) were calm […]. She (the nurse) was talking like she was concerned and was really calm when they were talking to us. (#8, Woman whose baby died antepartum, Malawi)

Across the countries, women valued being given the full attention (for instance, maintaining eye contact, sitting down) of the attending healthcare worker when informed about the death. They also highlighted the need to be told the truth, to avoid suspicions.

I was satisfied, but the fact that she [the nurse] did her things in a rush and was not fully concentrating to talk to me about the cause of death, made me suspicious of her. I wondered why she was in such a hurry. (#8, Woman whose baby died antepartum, Tanzania)

For one woman having to *"labour for nothing"* after being informed that her baby had died was extremely demoralizing; she felt it would have been preferable to be told after the baby was born. Timing of sharing the news was also an issue for a woman who had hypertension and was distressed by labor pain but was not offered pain relief.

I feel offended because they told me that my baby was dead before I gave birth, while I was in pain; because if you have high blood pressure you can also die. I was in pain, there was no pain relief… (#02, Woman whose baby died antepartum, Malawi)

Other women accepted the notification of death after giving birth as a normal practice. Some participants emphasized the need for a proper assessment of each woman before disclosure to avoid emotional breakdown, accusations, and psychological consequences. This was eloquent in this narrative:

'*She [the nurse] also did not prepare me psychologically for the news. I thought that there was something she was hiding, but I let it lie. (#8, Woman whose baby died antepartum, Tanzania)'.*

Some expressed their relief when healthcare workers offered to disclose the news to their relatives, as they were not present when the news was broken. This shift of responsibility also helped women to ease potential blame from family members.

'*She told me [about the death of the baby] and because I did not have the courage to tell my husband, she told him. […] There was no way I could break this news to my husband (#15, Woman whose baby died before birth - unclear time of death, Tanzania)*

Loneliness, frustration and disrespect

In all narratives, except four, the news of stillbirth was broken by a healthcare worker (nurse-midwives, doctors). Many women took for granted it was health workers' duty to break the news to them. Women who received confirmation of the stillborn baby by a family member (mother, mother-in-law, husband) considered it inappropriate. Despite sharing their hidden pain with this person, they lacked the opportunity to interact with a professional and to inquire about the cause of death.

When I asked my mother-in-law that is the baby fine? I just saw her with sweat and tears. I knew that that's it [sobbing]… they (doctors) did not tell me anything. The health care workers, during the time they were cleaning and suturing me, they would have told me that time that I lost the child and the causes [sobbing]. I would have been strong. (#5, Woman whose baby died intrapartum, Malawi)

In contrast, a woman who experienced severe complications and expected that these would have caused the death of the baby found relief when her husband confirmed the news after she had recovered.

For sure, I started gaining consciousness after two weeks from the day the operation was done. I understood and assured my husband not to worry about me because I already anticipated to hear that news. […]. I felt very encouraged by what he told me, I was low and feeling bad about the death of my baby. When I spoke to my husband that day, it was like I was getting the confirmation and imagine the relief I felt. [takes a deep breath]. (#7, Woman whose baby died antepartum, Zambia)

Healthcare workers' language and behaviour, and the setting in which women became aware of the death influenced their experience. Learning about the death accidentally, in a place with limited privacy and being alone during notification increased women's sense of vulnerability. Some of the women noticed healthcare workers were uneasy in disclosing the news. Although their apprehensiveness may have intended to be supportive, it caused frustration, as narrated by woman #6:

(Clearing her throat) When we were in the room, the midwife got up and closed the two windows and came back to sit. Just a few seconds of sitting she went back again to check on the same windows she closed. […] I felt nervous. I began suspecting the midwife had bad news for me but maybe did not know how to start with breaking the news (Woman whose baby died antepartum, Zambia).

The experience was worsened when the news was withheld. For instance, three women learnt about their baby who was stillborn from overhearing health workers whispering among themselves, with the assumption that the woman was not listening. This made them feel neglected and afraid of the birthing process, as explained in this narrative:

No, no one came to tell me. I just heard the nurses say "how did it happen because the baby was fine. They must be something (witchcraft)". (#1, Woman whose baby died antepartum, Tanzania).

In this population, only a few women were offered the opportunity of a companion when informed that their baby had died, and this helped them to share the burden and be consoled. For the majority of women, who were notified alone, feelings of abandonment and loneliness were common.

[…] It would have been good if someone else was around when the nurse was telling me. I was just alone. This made me feel worse. She also just told me in short, 'your baby born death". (#7, Woman whose baby died antepartum, Tanzania)

The place of disclosure also had an influence on women's emotions. Participants who received the news in a conducive environment (for instance: a separate room, scanning room, doctor's office) were grateful for having some time to absorb the information and mourn privately. However, for most of the women, disclosure of the death occurred in open spaces such as labour ward, obstetric theater, and the post-natal ward, where privacy could not always be guaranteed. Knowing that other women and health workers could see them and hear about their baby's death, provoked frustration and shame. These feelings were exacerbated in the postnatal ward when women were placed next to mothers of living babies. Woman #3 in Zambia, recalled the following:

It made me feel neglected and not cared for. I felt like that midwife did not mind my feelings by putting me next to a woman who had a baby. That was so devastating, I covered my face all the time. It was hard to be with someone who was smiling and playing with a baby when I did not have mine (Woman whose baby died intrapartum, Zambia)

Women complained about the minimal amount of time that healthcare workers spent with them after confirming the death of their baby, as this shortened their opportunity to be consoled. It also prevented them from inquiring about the cause of death and receiving counselling for subsequent pregnancies. In a few narratives, disrespectful care was also noticed. Use of harsh language, an inadequate tone of voice, and lack of empathy made women feel disrespected.

They (nurses) didn't listen to me when I wanted then to give me a bed sheet. I felt so sad. There is also a time when I called a nurse to come and help me, she said 'just push if you want and stop making noise' I was in pain. So, I didn't like such services. Though few nurses were nice. (#1, Woman whose baby died intrapartum, Tanzania)

This was reinforced by a woman from Malawi:

An example is in my case; I was going to them (health workers) to tell them how I was feeling. If it was others, they could have encouraged me and give me hope that they would have attended me; but these ones were chasing me with bitter words; how could somebody feel in that way? It is painful. (#6, Woman whose baby died intrapartum, Malawi)

In two experiences (Malawi and Zambia), women also felt discriminated against because their baby had been stillborn. Although the baby's death was clear before birth, women were not notified immediately. They recalled being "de-prioritizsed" as nurse-midwives in charge of them were moved to care for women who had a live baby.

Definitely what caused all that was the stillbirth. Those nurses felt I didn't need the care that women with live babies did, yet I needed more care because I was psychologically traumatised. I was so depressed giving birth to a dead child. (#5, Woman whose baby died antepartum, Zambia)

Bonding with the baby

The fourth sub-category 'bonding with the baby' reflects women's desire to connect and meet with their dead baby, despite being self-conscious of the cultural bans against viewing and mourning stillborn babies.

Between desire and culture

After birth, a potentially important moment of communication between women and healthcare workers involves the encounter with the stillborn baby. In high-income countries, couples are given the opportunity to meet and parent the baby before burial is arranged. This contrasts with the practice in Malawi, Tanzania and Zambia where showing the baby constitutes a visible demonstration of the baby's death. In the three countries, hospital protocols required that after giving birth, the woman is shown the baby, alive or dead, to confirm the sex. Immediately after birth the baby's body and genitalia are shown to the woman without prior preparation or explanation.

No, it was not my wish, the nurse just told me that 'can you raise up your head so that you can see your baby?'. (#3, Woman whose baby died antepartum, Malawi)

This is also done to relieve health workers from potential accusations of having swapped the baby, as explained in this quote:

I was in the theater. It was the same time the baby came out. They showed me the baby and asked for forgiveness. They did not want me to demand for the baby later on. I saw her lifeless body. The doctor also said that I have to see it there and then because he feared that I may accuse them. They were very sorry and sad. (#14, Woman whose baby died intrapartum, Tanzania).

In Zambia, four women who were shown their baby's face and sex felt viewing was against their wishes; whereas two were grateful for having seen their infant, even though this contravened their traditional norms. In Malawi women did not express fear of seeing their babies.

Although our culture does not allow us to see a stillborn baby, I preferred to see. This is my baby whom I was expecting at the end of 9 months. The fact that it is born dead does not disqualify it to be mine. I deserve the right to see how my baby looked like and identify the sex. […] But then some of us have seen our stillborn baby. I am yet to see what will happen to me. (#1, Woman whose baby died intrapartum, Zambia)

In Tanzania most women were offered to see the baby more than once, in addition to be shown their sex immediately after birth. They did so without reluctance, as narrated by this woman:

She (the nurse-midwife) asked if I was willing to see her. I said yes and they brought her. Later on I asked again to go and see her and they allowed me. (#12, Woman whose baby died antepartum, Tanzania).

Offering to hold the baby and creating memories, mainly photographs, baby layettes and the baby's card, were different across the three countries. Traditional beliefs played an important role in Zambia. All women were either instructed by relatives or had a self-awareness of the cultural ban of touching and keeping anything related to the stillborn baby (for instance: baby layettes), due to the belief that his/her spirit could affect the woman's future pregnancies.

My grandmother told me that we should not have memories because the stillbirth's spirit will be following us, so I had to follow what my tradition says (#4, Woman whose baby died antepartum, Zambia)

Although some women desired to connect with their baby, none of them held him/her or took photographs. If given a choice, four women expressed a genuine wish for not taking pictures to avoid having bad memories. In Malawi, some women would have appreciated to spend some time and hold their babies but were not offered this. None of them took pictures.

Yes, I saw him [the stillborn baby], the nurse-midwife placed it on my tummy and they said that the stillbirth happened not long time ago because the child looked normal. I wished I could carry him but I didn't ask. […] Since it was the first time that this thing happened, I thought that's how the hospital does it. (#8, Woman whose baby died antepartum, Malawi

In Tanzania, most women were offered to touch and hold their babies, as explained in this quote:

Yes. After showing me the baby, she [the nurse] placed him in my arms. [.] The nurse gave him to me to hold him. (#8, Woman whose baby died antepartum, Tanzania)

Half of the women explained that "it did not cross their mind" to take photographs of their infant and they did not have a phone (not allowed in labour ward) or felt it was not necessary. A few women had pictures taken by the husband or other relatives (sister, brother, sister-in-law) but kept it secret to avoid their elders blaming them for having kept a memory of a stillborn baby. Five women kept the clinical card or the new clothes as memory of their infant but concealed it from their families.

Discussion

This ground theory study explored women's emotions and experiences of grief around the time of becoming aware of the death of the baby. These experiences have been previously explored [18,38]; uniquely in this study we have focused on communication and issues around the time of learning about the death of the baby in three LMICs. The core category and sub-categories which emerged from the data are now discussed in relation to perinatal bereavement theories and other literature.

The theoretical model (Fig. 1) indicates that women began to have doubts about their fetus when they noticed a change in fetal activity. Healthcare workers' attitudes and blunt communication about the status of the baby, enhanced their uncertainty, prompting a fear for the worst. Conversely, when the truth is told in a simple way, it is preferred and considered as a sign of professionalism [6]. Several studies have reported accounts of parents who were given incomplete and/or unclear explanations of the death of their baby [12], with medical jargon, causing them anger and long-term bad memories [39]. In a sensitive moment such as the death of a baby, honest communication and use of simple terminology to avoid misunderstanding and frustration is critical

[11]. Overwhelmed by the trauma, parents are often unable to process the information that is shared with them, especially during notification of death [12]. Guidelines on perinatal bereavement care suggest using a sensitive language, select appropriate and simple messages, and ensure enough time is given for their absorption [11].

In this study, most women received the news of the death of the baby through healthcare workers. Their behaviour and language impacted on their experience. Women appreciated when staff approached them in a sensitive way and adopted a compassionate attitude. Similar to Downe et al., [12], women were pleased with the manner in which nurses-midwives empathised with their loss, demonstrated by their body language (displaying a sad face, giving a hug) and verbal messages of sadness and disappointment, which validated their emotions. Further, Ellis et al., [21] has also reported the sense of protection felt by parents, from health workers' caring touch and their visible sorrow for the unexpectedness of the loss [21]. In contrast, a few women in this study learnt about their baby's death by overhearing healthcare workers' conversations or from their apprehensive behaviour in breaking the news. Research with healthcare workers has shown how an apparent lack of empathy and being distant to the couple may not be necessarily intentional [40]. This behaviour is likely to reflect healthcare workers' attempts to deal with the impact of stillbirth at a personal level, and a genuine lack of competency and training in perinatal bereavement care [41].

Confirmation of death produced a range of emotional responses including devastation, physical and emotional pain, remaining silent and crying, which are similar to previous research [2]. These feelings were exacerbated when women received the news of their infant's death alone and in a non-private room. In many facilities in LMICs, being unattended during birth is common [42]. Having a labour companion, although highly encouraged and beneficial to the woman [43], is not implemented in every setting. Notification of death often prompts an immediate emotional response, and as see in this study, initiates grief. Thus, it should not occur unless the woman is offered support. The presence of a companion can help mitigate the trauma and be a source of strength in the grieving process [39]. Not having that support when learning about the death is likely to worsen the woman's grief and recovery process.

Where the woman was when she was told about the death and the environment she was cared for in after the birth impacted her experience. Women found it distressing that news of the baby's death could be heard by other clients and health workers, and that they often shared the same ward with women who had live babies. Having individual consultation rooms to notify a woman of a stillbirth represents a challenge for many hospitals, including in HICs [9] and it is not uncommon that parents who had perinatal losses are placed in proximity to families with living babies [44]. Choosing an appropriate place to confirm death, which ensures silence, privacy and time for questions can help parents to better cope with the loss and to be involved in the decisions concerning birth, the burial of the baby and support in the postnatal period. In addition, where hospital space is unavailable, simple interventions as installing curtains could be an important step towards meeting the need of privacy of these families [45].

Participants in this study had different emotional responses after becoming aware of the death of their babies. The trauma of death was compounded by contrasting feelings resulting from the interaction with healthcare workers and the influence of culture. As women were unable to express their emotions and grieve in the public domain, the Kubler-Ross Model of Grief [35], which is often drawn upon to explain the grieving process, was not an ideal fit to explain their journey. Women's emotions and experiences of grief seemed to resonate better with Hochschild's concepts of "feeling rules" and "emotion work"[46]. *Feeling rules* refer to existing norms which establish the correct feeling in a certain situation and for how long the feeling can last. *Emotion work* applies when an individual manages and adapts his/her emotions to make them appropriate to a situation [46]. The latter has been used to explain how people adjust their emotions within organizational and work environments (i.e. flight attendants), including in healthcare settings [47]. *Feeling rules* and traditions influence people's emotional responses to events and what they portray to others. In face of the death of an individual, crying, showing sadness and mourning for some time, are common responses. Keeping memories of the deceased may also occur to facilitate the healing process [48].

In many societies, including the countries in which this study took place, these conventions are overturned when the deceased is a stillborn baby. In this case, women are expected to suppress their emotions [17,19], to not mourn [19] and to not talk about the death of the baby with their family members and with other childbearing women [18]. Birthing a stillborn baby means also being denied the possibility to attend the baby's burial in these settings [17,19]. Seeing, touching and holding the infant is discouraged, as is the creation and preserving of memories [18]. Motherhood of a stillborn baby is often not recognised, with women being encouraged to forget their pregnancy and its outcome [18,49]. These rules may find validation among healthcare workers when the death of the baby is given little attention and treated as a casual event [21,50,51]. In this study, these rules seemed to be reinforced by family members when provision of support was aimed to conform with culture and to move on, rather than reassuring the woman of the normality of her trauma and the importance to express her feelings as they emerge.

In addition to the effort of sustaining the physical labour of birthing a dead baby, which can also explain women's feeling of "struggling without a reward" [52], the participants in this study also embarked on emotion work. They 'put on a brave face' to show that they were in control of the situation enabling them to meet cultural expectations, but potentially preventing them from going through the stages of grief [35]. Women's emotional efforts reflected the contrast between their desired feeling (desperation) and the expectations of others about what they were supposed to feel (forgetting) [53]. Examples of this negative emotional control, include hiding grief, non-verbalising doubts, not asking questions about the absence of fetal activity, not questioning healthcare workers, not asking to see and hold the baby. Moreover, as showing true feelings and needs would challenge existing stillbirth norms [54], and increase chances of being held accountable for the stillbirth [18], women had to accelerate their return to previous daily living activities. This element contrasts with the Dual Process Model of Grief [36] in which the desire to progress with life (restoration phase) occurs at a slower pace to enable the bereaved to adapt to their new reality. In the original model [36], restoration often alternates with a phase of pain and grief (loss-oriented phase) aimed to process the loss of the person who died, through reminiscing of him/her actions and life. Women involved in this study experienced this phase but barely expressed it. Interestingly, some of the participants tried to connect with the stillborn baby by seeing his/her face, holding him/her (when it was offered), keeping clothes and the hospital card. This desire to connect with the deceased baby and to keep memorabilia has also parallels with Attachment Theory [55] and Continuing Bonds Theory [56]. The first theory supports the idea that the mother-infant attachment initiates before birth through important events such as confirmation of pregnancy, feeling fetal movements and giving birth [51]. This attachment is strengthened after birth by seeing, touching and holding the baby. Despite cultural bans, participants in this study saw their stillborn babies and some were offered to touch and hold them, a practice which is frequently offered in many high income countries [12] to validate parenthood and alleviate grief. In the second theory the relationship with the person who died is adjusted and turned into a life-lasting bond, which is recognised as a natural and human responses to the death [56]. Some participants in this study kept simple memorabilia of their infant (hospital card, baby layettes), although this process of memory-making was not facilitated by healthcare workers and was kept hidden. Moreover, having a long-lasting relationship with the stillborn baby, is unlikely to apply in these African settings given social prescriptions of forgetting and "letting go" of the overall experience. Furthermore,

awareness of cultural expectations means keeping actions discreet and silent, as shown in the theoretical model (red triangle). The invisibility of grief and self-control, also noticed in other studies [19], gives the impression that the woman is coping with the situation, whereas the magnitude of her suffering might be deeper and unsettling. As a result of this, women may struggle to elaborate on the trauma and risk, which in turn may progress into a longer state of mourning (prolonged grief) preventing them from healing. Women may also feel that it is inappropriate to ask for help, for fear of being blamed for the death of the baby [49]. By feeling intimidated to access support, these women are likely to worsen their physical and perinatal mental health (including depression, post-traumatic stress, suicidal ideation etc.) [2] in the short and long term.

Implications for practice

The theoretical model (Fig. 1) disentangles women's emotional journey and grief after becoming aware of the death of their baby. The model should be used to better understand women's trauma and negative emotion work, and to enable identification of actions with the potential to assist women to acknowledge and disclose their hidden grief. Failure to do so may increase women's isolation, and physical and psychological ill-health, including depression, anxiety, post-traumatic stress disorders and suicidal tendencies [38]. Changes at different levels are needed: firstly, women who birth a stillborn baby should be recognised as in need of special attention and be made aware of the death through clear and explicit messages to avoid doubts and uncertainty. Women will be suffering emotional distress and a minority also develop prolonged grief with consequences to their mental health, such as depression [22]. Health workers' reassurance about the breadth of the normal process of grief following stillbirth as well as the critical role of externalising feelings should also be part of bereavement care [7], including signposting women to bereavement counselling and psychological services if needed. Educating families and communities about grief and potential consequences of silent grief (i.e., depression, complicated grief and emotion work) could mitigate the pressure of cultural expectations and help women to feel supported by their inner circle. Healthcare workers might also need to challenge unhelpful behaviours with families and communities to avoid potential harm to women, including blame, stigma and social isolation. In addition, further research should follow-up women in the postnatal period to explore the impact of emotion work on their healing process. Secondly: to accommodate parents' needs of being together and in a private space during notification of death, and have adequate time to process the news, hospital management should consider innovative ways of findings private space for these families, including upgrading existing protocols to enable parenting of the baby, if desired. Thirdly, formal education and in-service training for healthcare workers on perinatal bereavement care, which include good communication, appropriate behaviour and language, supporting parents' choices and information giving will equip midwives and doctors to offer appropriate care to bereaved women and their families.

Strengths and limitations

Our study had several strengths. Firstly, conducting the study across three countries enhanced understanding of women's emotions and grief in East African settings, allowing other to assess the transferability of the findings to similar settings. However, the qualitative nature of this study was not meant to be representative of all women who had stillbirth in sub-Saharan Africa. Secondly, women narrated their experiences from four weeks to 12 months from the occurrence of the perinatal loss. Their memories were vivid with details of wording, gestures, and interactions with health workers, thus sharing these experiences was particularly sensitive for some women. Research midwives adopted a culturally sensitive approach, informed by the Community Engagement and Involvement groups, and enabled women to take breaks, reschedule or cancel the interviews if too distressing. None of the women withdrew, one rescheduled the appointment a few weeks later to feel more emotionally prepared. The study also has some limitations: firstly, interviews were conducted by research midwives with their own experiences of providing care to mothers of stillborn babies. To minimise researcher's positionality, reflections on own assumptions were encouraged after each interview, through notetaking and considered during the analysis. Moreover, having different expertise within the team (midwifery, social science and public health) and contributions of the Community Engagement and Involvement groups helped to question each other's interpretation of the data, increasing trustworthiness of the study. Second, being interviewed by a health worker, could have introduced power imbalance and social desirability bias. Research midwives were introduced to each participants by the CEI group, which help them to build trust. The CEI group also contributed to wording of the interview guide to make it understandable to the participant. As women found it therapeutic being able to share their story in a context were talking about stillbirth is forbidden, we think their narratives, including clear examples of substandard care and cultural practices, are true account of their experiences.

Conclusion

The death of a stillborn baby constitutes a traumatic event for women, but in many settings grief remains disenfranchised. Uniquely, in this study we have identified that women who suppress emotions, after stillbirth, engage in a considerable amount of emotion work to conform with cultural and societal expectations. As a result of this, women's suffering becomes invisible and their ability to voice their needs and seek care might be hindered with potential negative consequences for their physical and mental health. Women's discreet attempt to bridge the culture, through seeing, holding and asking questions about their stillborn baby, should be seen as an opportunity for healthcare workers to create more parent-focussed services. Healthcare workers and community members have a key role in recognising grief and supporting women's individual unmet needs for bereavement and compassionate care. It is only then that stigma and secrecy will be reduced and women's healing after perinatal loss optimised.

Ethics approval and consent to participate

The authors declare that the study presented in the manuscript was approved by University of Manchester Ethics Committee in the United Kingdom (reference n. 2019–7451–11496; approval date: 24/07/2019), College of Medicine Research and Ethics Committee in Malawi (reference n. P.09/19/2793; approval date: 22/11/2019), Joint Catholic University of Health and Allied Sciences/Bugando Medical College (CUHAS/BMC) Ethical and Review Committee in Mwanza, Tanzania (reference number CREC/399/2019, approval date: 12/09/2019) and Ethics and Science Converge Institutional Review Board in Zambia (ERES Converge IRB Zambia; reference n. 2019-Aug-020, approval date 27/08/2019).

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CRediT authorship contribution statement

TL, CB, RL contributed to the design the study. DK, HS, FK, IC, KL, KT, conducted the interviews and participated in the analysis of transcripts. VAD, CB and SW coordinated data collection, and analysis across the three countries. All authors interpreted the data. VAD drafted the first version of the manuscript. All authors commented on drafts of the manuscripts and have read and approved the final version.

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Conflict of Interest

None declared.

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