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Lived experiences and perspectives of women who had undergone perinatal loss in Nairobi county, Kenya: a qualitative study

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ABSTRACT

Background This study explored the lived experiences and perspectives of women who had suffered a perinatal loss in Nairobi county, Kenya. Existing research works have established that perinatal loss often comes with a significant psychosocial burden, which has been made worse by negative cultural beliefs and practices. Despite this, perinatal loss grieving is rarely recognised or socially legitimated in many countries. This study aimed to shed light on the experiences of bereaved women to come up with effective interventions and combat the stigma associated with perinatal loss.

Methods The study used a qualitative research design employing a descriptive phenomenological approach targeting women of reproductive age who had experienced perinatal loss within the previous 3 years. The study was conducted in three subcounties of Nairobi. Purposive sampling was used to identify and recruit 22 women to participate in focus group discussions. After the discussions, the audio recordings were transcribed, translated and analysed thematically. Triangulation was then done per thematic area to allow for a deeper understanding of the experiences and perceptions of the study participants.

Results The research identified 3 themes and 7 subthemes: (1) 'Psychosocial challenges of perinatal loss' with five subthemes;—'Emotional trauma and grief', 'Multiple losses and reproductive pressure', 'Broken relationships,' 'Violence and abuse' and 'Familial stigmatization'. (2) 'Healthcare experiences.' (3) 'Stigma and cultural influences' with 2 subthemes 'Societal stigmatisation', and 'Cultural perceptions and norms surrounding perinatal loss'.

Conclusion Women who have experienced perinatal loss often suffer psychological torture, discrimination, abuse, stigma and trauma. The findings from this study highlight the urgent need to set-up robust support systems to assist individuals coping with perinatal loss. This will require a range of interventions, including implementing trauma management programmes, training of healthcare workers, advocacy, sensitisation and establishing support networks to address discrimination and stigma faced by those affected.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Research shows that perinatal mortality is not only a major public health problem but that the loss also carries with it significant psychological, social and financial implications for the affected women and families. In Kenya, few studies have been conducted to assess the lived experiences and perspectives of mothers who have undergone perinatal loss. However, there are inadequate interventions to support bereaved women, especially in low and middle-income countries.

WHAT THIS STUDY ADDS

⇒ This study reveals that women in Nairobi county, Kenya experience severe emotional and social trauma following perinatal loss which is further exacerbated by cultural beliefs and inadequate healthcare support. The study also highlights the important role of the community health system, particularly Community Health Volunteers in providing essential emotional, educational and referral support to women experiencing perinatal loss.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This research aims to influence policy changes to integrate perinatal loss as part of the national health system. Also, the findings may assist policymakers and other stakeholders in coming up with maternal health interventions that target women who have experienced perinatal loss.

BACKGROUND

Perinatal loss is the loss of pregnancy at any time before or during birth or the death of a newborn within the first month of life.[1] However, there have been differing opinions as to whether to include or exclude early fetal and late neonatal fatalities within the definition. For instance, Shandeigh[2] and Donegan *et al*[3] define perinatal loss to include miscarriage, which is fetal death before 24 weeks of gestation,[4] stillbirths that occur after 24 weeks[5]

gestation or neonatal deaths if the death is between birth and 28 days after birth.[6]

According to the WHO, on the other hand, the perinatal period begins after 22 weeks (154 days) of gestation and extends until seven completed days after birth.[7] Based on this, WHO defines perinatal mortality as the number of stillbirths and deaths in the first week of life per 1000 total births.[7] WHO, however, recommends using 28 weeks after gestation for stillbirths, given that the legal requirement for registering deaths and live births varies both between and within countries.[7]

Perinatal mortality is a significant indicator of the accessibility and quality of healthcare services for both mothers and newborns. According to recent United Nations estimates, the global stillbirth rate stands at 13.9 stillbirths per 1000 total births, using the international comparison of gestational age after 28 weeks.[8] Additionally, the global neonatal death rate is reported to be 17 deaths per 1000 live births.[9] There are considerable variations in these figures globally, with a majority of stillbirths and neonatal deaths occurring in low- and middle-income countries (LMIC). Specifically, sub-Saharan Africa (SSA) and South Asia have the highest perinatal losses worldwide, contributing to 93% of total losses.[10 11] In Kenya, data from the last two demographic health surveys show that perinatal mortality has been on the increase from about 29 deaths per 1000 births in 2014[12] to 32 deaths per 1000 births.[13]

Despite the relatively high rate of perinatal mortality in LMIC countries, there are inadequate community-based or hospital-based interventions to assist women and families in coping with the loss.[14] Consequently, mothers are often left with various challenges ranging from psychosomatic illnesses to sadness, grief and pain. While most bereaved parents may not experience grief at the level of illness,[15] they are likely to experience physical, psychological and social effects.[16] On a psychological level, individuals who have experienced perinatal loss have a greater predisposition to suffer anxiety, depression and even increased risks of suicide.[16] The effects of perinatal loss on a woman's psychosocial health can be long-lasting and even affect subsequent pregnancy.[17]A case-cohort study carried out by Mainali *et al*[18] found that pregnant women with previous perinatal loss reported higher symptoms for both anxiety and depression during their subsequent pregnancy compared with mothers in the same cohort who had no previous perinatal loss. Furthermore, studies also show that stillbirths have significant financial expenses for parents as well as long-term economic effects on society, including massive psychological costs such as postpartum depression.[19]

These challenges are further compounded by cultural beliefs and practices surrounding perinatal loss which amplify risks for negative experiences and outcomes after the death.[20] Cases of neglect, abuse and rejection are common among women who have experienced perinatal loss, with the situation notably worse for women with multiple losses.[21] In many African cultures, there is the deep social significance attached to childbearing[20 22] and the number of children determines the worth of a woman she can carry to term. Thus, women who cannot give birth or those who lose their children are often perceived as inadequate, cursed bewitched, outcasts or even bad omens.[21 23] Similarly, in SSA, cultural beliefs often attribute stillbirths to supernatural forces,[20 24] a situation which often led to rejection by both close family members and the communities at large.[25] Moreover, the rapid burial and restriction on public mourning further rob many of the bereaved women of the space to appropriately mourn their loss.[20 21] For instance, in the Lango community in Uganda, stillbirths are often mockingly buried, denying proper respect.[23]

Supporting bereaved women in healthcare settings, particularly in LMICs like SSA, poses a significant challenge. While compassionate care and support in hours and days after stillbirth is recognised as critical[20] many of the bereaved parents often do not receive adequate and appropriate care in health facilities after suffering loss. Studies indicate that insensitive communication, deficiencies in information and lack of emotional support contribute to negative experiences for parents mourning their loss.[26]

Currently, perinatal mortality is under-reported. Moreover, Sustainable Development Goals (3.1 and 3.2) do not have specific targets for perinatal mortality. This has led to perinatal mortality not being considered among national or global public health priorities despite a large number of known solutions. As a result, policies are also so silent about stillbirths; thus, there are limited interventions, a lack of investment, a lack of recognition of the social burden of stillbirth on the affected families, inadequate data and minimal national and global leadership.[27 28]

Understanding the experiences and perspectives of women who have undergone perinatal loss is crucial to come up with bereavement interventions to support and challenge the stigma that surrounds women. Very few studies have been done on women's lived experiences and perspectives in Kenya, especially Nairobi, where different women from different backgrounds and cultures dwell. Therefore, the objective of this study was to explore the lived experiences and perspectives of women who had experienced perinatal mortality in Nairobi county, Kenya.

METHODS

Study design and setting

This study was conducted as part of a larger research project focusing on assessing the existing support services for women of reproductive age who have experienced perinatal loss in Nairobi, Kenya. The research employed a qualitative research design using a descriptive phenomenological approach. A phenomenological study is a technique that seeks to explore and understand the lived experiences of individuals regarding a particular phenomenon. This method allows the researchers to penetrate and capture the meaning, essence and structure of the

experience of people.[29] The approach is guided by the following assumptions: humans create social networks; humans can describe retrospective and prospective life events; patterns and themes surface through intense study of phenomena. A phenomenological approach to inquiry is consistent with the ideas in health sciences where humanistic understanding is valued.[9] Through Focus Group Discussion (FGD), the researchers sought to understand the impact of perinatal mortality loss, the women's challenges and the opportunities for support and change within the healthcare system and community.

The targeted participants were women of reproductive age between 15 and 49 who had suffered a perinatal loss within the previous 3 years before the study. Participants were recruited from three subcounties within Nairobi county: Kibra, Lang'ata and Kamukunji. Nairobi was selected for the study because the region had posted a significant number of perinatal deaths, accounting for about 12.5% of the total perinatal deaths in the country in the last 3 years before the study.[30] Further, the selected three subcounties were among the top contributors of perinatal deaths within the county. Nairobi also hosts a diverse population comprising individuals from different socioeconomic, ethnic, cultural and religious backgrounds. This allowed for a representative view of the population in the study.

Participants and sampling

Purposive sampling was used to select the study participants. The research team worked closely with the subcounty health management team and the community health workforce, including Community Health Assistants and Community Health Volunteers (CHVs), to recruit women who had experienced perinatal loss. Within the community health system in Kenya, each subcounty is usually divided into Community Health Units (CHUs), with each CHV assigned to manage about 100 households. Therefore, CHVs were instrumental in the recruitment process as they could identify eligible women within their households to participate in the study. The selected participants were invited to participate in face-to-face focus group discussions within the CHU. The sessions were held at Community Health Unit Link health facilities close to participants' residence areas to ensure accessibility. The venues were also carefully selected to guarantee the privacy of all participants while at the same time providing a conducive environment for free and open discussions around their experiences. Only participants who fit within the inclusion criteria were allowed in discussion rooms and to participate in the study.

Before the FGD session, the principal researcher explained the purpose of the study and the reason participants had been selected. Informed consent was sought from each participant, who was provided with a consent form detailing the study's purpose, procedures, potential benefits and risks, confidentiality measures and participants' rights. Participants aged 15–18 years with a child are considered mature minors and did not require parental consent to participate in the study.[31 32] The research team ensured that participants understood the information by explaining it clearly and concisely before allowing them to sign the form. Each FGD was designed to include approximately 7–10 participants. Generally, a sample size of 6–12 is often considered sufficient for FGD in order to achieve information saturation.[33–36] The selected group size also allowed for in-depth discussions while ensuring that every participant had the opportunity to share their perspectives.

Inclusion criteria

Participants had to (1) be a woman of reproductive age[15–47] who has experienced perinatal loss within the 3 years preceding the study and (2) have experienced l loss from 24 gestation weeks or lost a neonate within the first week of life.

Exclusion criteria

Excluded were women who were outside the age range of 15–49 years and those who had not experienced perinatal loss within the 3 years preceding the study. Other exclusions included women who were not at home during the recruitment process and those unable to provide informed consent.

Data collection

Data was collected primarily through focus group discussions of about seven to eight participants. The principal researcher facilitated the sessions using a focus group discussion guide that the researchers developed. Alongside the principal researcher (who is female) were two female research assistants due to the nature of the study. The sessions were conducted in the Swahili language, familiar to all the participants. Each session took 45–60 min, which falls within the ideal recommended time for an FGD.[37 38] Before the commencement of discussions, the principal researcher introduced herself and requested the participants to do the same. Participants were allowed to narrate their personal experiences; where need be, the women were given moral support or counsel by the research team. This allowed the participants to discuss their experiences and perspectives freely. The discussions stopped when all participants were heard, and no new information was forthcoming. All sessions were audio-recorded and transcribed in the original language (Swahili). Manual notetaking was undertaken during the field session, which was a backup to the recorded audio files.

Researcher's reflexivity

The principal researcher holds a master's in health system management and was pursuing a PhD in Reproductive Health Sciences at the time of research. The study was motivated by the researcher's personal experiences and desire to shed light on an issue that has remained largely overlooked. Recognising the potential for personal bias, the principal researcher regularly engaged with the

research team and coauthors to examine assumptions and perspectives. To ensure credibility, a rigorous methodology was outlined before the commencement of the study to ensure that the data collected accurately represented the realities on the ground.

During the data collection process, efforts were made to remain open-minded and non-judgemental to allow participants to freely share their experiences during the FGDs. The transcription, translation and coding process involved multiple independent team members. The involved parties then came together to obtain a general consensus on the agreed codes and themes. This process aimed to let the themes emerge from data rather than be informed by the principal researcher's biases. Peer debriefing and member checking were also regularly employed to enhance credibility.

Data analysis

The study used thematic analysis, a qualitative data analysis technique designed to identify patterns and themes within a qualitative data set. Prior to data analysis, audio records from the FGDs were transcribed, first in the original Swahili language, then followed by a line-to-line translation in the English language so as not to lose the original meaning. Each transcript underwent a cross-checking process with the audio record to ensure the accuracy, consistency and completeness of the data collected. After translation, the data analysis team, composed of two members proceeded with an in-depth examination of the transcripts to familiarise themselves with the data. The team then independently conducted data coding, which involved identifying and labelling key segments of the transcripts. The two data analysts and the principal researcher held discussions to compare the individual codes and reconcile any discrepancies or differences in interpretation. Similar codes were then grouped into broader categories, forming the preliminary themes and subthemes. Refinements to the themes and subthemes were then made through further discussions and iterative revisions. Triangulation was then done per thematic area to allow for a deeper understanding of the experiences and perceptions of the study participants.

Translation of Swahili personal pronouns

In Swahili there are three types of personal pronouns (Viwakilishi-nafsi): First person pronoun (singular-mimi (I), plural-sisi (we)); second person pronoun (singular-wewe (you), plural-nyinyi (you, plural)); and third person pronoun (singular-yeye (he/she/it), plural wao) (them). In Swahili, there are no gender-specific pronouns. For instance, the third-person singular pronoun 'yeye' is used for both male and female subjects. So, for example, the following phrase 'She told me' and 'he told me' could be directly translated to 'Yeye aliniambia' in Swahili. However, pronouns are often integrated within the verb or action. Instead of using the full pronoun 'yeye' in a sentence, the verb is modified to convey the intended meaning. For example, instead of saying 'Yeye aliniambia,' which directly translates to 'She/or he told me,' Swahili speakers would typically use the verb 'aliniambia' alone. Similar for the second person 'You told me' will translated as either 'uliniambia' (single) or 'waliniambia' (plural).

Ethical considerations

All team members were trained in ethical research practices, respecting participants' rights to privacy, voluntary consent and confidentiality. Written informed consent was obtained from all participants, and the risks and benefits of the study were fully explained. To ensure the privacy and anonymity of respondents, no identifiable information was collected and participants were assigned unique identifier codes. Additionally, all the research team members were also made to sign data confidentiality agreement forms.

RESULTS

The findings are structured around three key themes and seven subthemes that emerged from the narratives of the participants.

Participants demographic profile

A total of 22 women aged between 15 and 49 were involved in the study with none dropping out of the study. Out of the 22 women who participated in the FGD, 8 were from the Kibra subcounty, 7 from the Langa'ta subcounty and 7 from the Kamukunji subcounty. Age wise, 12 were aged between 20 and 29 years, 7 between 30 and 39 years and 3 between 41–49 years as illustrated in table 1.

Theme 1: psychosocial challenges of perinatal loss

Emotional trauma and grief

According to women who participated in the study, the period after perinatal loss was often marked by emotional trauma and grief, with the psychological impact of the loss extending beyond the aftermath of the loss and often affecting women's mental health and overall well-being. From the narratives provided, the trauma itself manifested in several ways ranging from feelings of isolation to intense and prolonged grief. In some cases, the women who had experienced multiple losses felt discouraged to attempt to get pregnant again. In some instances, discouragement came from the community itself including family friends.

> From my experience, you can go through it, because I have a friend I have grown up with since our childhood. She told me something that really hit me; she said M-6, why do you keep having children, and they keep dying? Why don't you stop? (M-6)

Multiple losses and reproductive pressure

Some women disclosed experiencing multiple losses, often within a short time. In some cases, this was brought about by the pressure from the community to have children immediately after loss.

Table 1 Respondent demographic characteristics

Participant (M)	Subcounty	Age
M-1	Kibra	29
M-2	Kibra	30
M-3	Kibra	21
M-4	Kibra	36
M-5	Kibra	23
M-6	Kibra	42
M-7	Kibra	36
M-8	Kibra	25
M-9	Langata	39
M-10	Langata	22
M-11	Langata	38
M-12	Langata	49
M-13	Langata	26
M-14	Langata	33
M-15	Langata	28
M-16	Kamkunji	25
M-17	Kamkunji	24
M-18	Kamkunji	27
M-19	Kamkunji	26
M-20	Kamkunji	34
M-21	Kamkunji	23
M-22	Kamkunji	48

> …you know, in Luo (ethnic group in Kenya), if you cannot bear a kid is something else; they say she gives birth to children and they die I do not know why; that is just a lot of stress and that pressure from the family, and still the children are dying…. can you see all that pressure, so I gave birth and when my husband took me to the hospital, he left me there, and they had already married him another wife. (M-14)

The findings revealed low awareness of family planning practices, especially among young women. A woman narrated how she would end up getting pregnant shortly after experiencing loss due to a lack of awareness of family planning.

> So, I didn't have parents or someone who could tell me to take it easy, or there's something like family planning. I did not have someone who could be like a parent to me, and the mother-in-law was too harsh. So, I found myself with my husband, and no one has ever told him about something like family planning, and I ended up getting pregnant again. (M-10)

Broken relationships

From the findings, perinatal loss often led to strained relationships between partners, leading to disagreements, abandonments and in some instance divorces. Some of the women explained that they had on more than one occasion had their marriages fail due to experiencing multiple losses.

> … I lost my first marriage because I was losing babies and was married to my second husband, and I got pregnant. After nine months and two weeks, I gave birth and the baby cried, they cleaned me, and I put the baby to sleep, and I took a rest after waking up my baby was dead. I was like my first marriage broke now this one has started, I questioned God. The in-law to my second husband told the man she was chased away there (in her first marriage) because her babies were dying now, she lost yours do you think marriage will work? I was like I do not have a mother and my children keep on dying, I lost my first marriage and now the second one I wanted to commit suicide, but I always thank God. (M-6)

In the cases where the marriages did not end divorce or separation, the women still went through emotional neglect from their partners who would sometimes bring in another woman into the relationship.

> Sometimes, if men don't grant a divorce, they look for another wife. They might console you, saying you will find someone else, but they have already brought another woman. So, they are not very interested in you; they are more focused on the new wife who is giving birth. You find that the attention is on the woman who is giving birth, and you feel unloved by the family. Even the love from your husband decreases; even though he still loves you, certain things diminish. (M-16)

Violence and abuse

In one case, a woman, after experiencing loss, was physically assaulted by her father, who believed that she had intentionally undergone an abortion because she did not want to give birth.

> … but there was someone who left and told my father that I had an abortion. My father came with the whip in the evening, and he started whipping me, saying you prostitute, come, you are the one who knows how to abort; you see that you aborted the five-month pregnancy. I'm telling you I was beaten by my father. (M-11)

Violence and abuse were not only restricted within the household, but on multiple occasions, women were also victims of verbal and physical abuse from the community, neighbours and family members. These mainly stemmed from misconceptions and cultural beliefs that wrongly placed blame on these women for the loss of their children.

> We are viewed as bad luck; some community members call us witches and they say we are sacrificing our babies to get money. (M-20)

Familial stigmatisation

Most of the women described how they were often subjected to judgement, blame and isolation which further compounded the emotional burden they had already been dealing with. Some women shared that they felt blamed or held responsible for the loss by their family

members. For instance, one participant mentioned that her parents suggested that her lifestyle choices had caused her perinatal loss, exacerbating her guilt and shame. In another case, a woman explained how she was abandoned and left at the hospital by her husband whom his family had pressured to do so. She stated that.

> They left me there (at the hospital), they told him (her husband) to leave that woman, her children are always dying. (M-6)

Theme 2: healthcare experiences

The participants highlighted their experiences where they believed negligence on the part of healthcare providers contributed to their tragic outcomes. These cases included slow response, lack of attention, care or basic medical support during labour and delivery. In one case, a woman in labour was not attended to, and she eventually had to deliver her child on the floor of a healthcare facility which was undignified and unhygienic. The healthcare workers remained unsympathetic, and the child later developed complications and passed away.

> … After they told me I would be taken to the theatre for an operation, I started walking, and after a short while, the water broke. I went to the doctors, and they told me the baby's way (cervix) had not opened, so I should go and walk far. I tried to talk and plead with them to help me, but they chased me, saying that I was disturbing them; when the time for me to deliver, I sat on the floor and pushed until the baby came out… (M-19)

Cases of misdiagnosis, especially during the early stages of pregnancies, were also reported by the women.

> I was given drugs to treat cysts, then after some time, I started bleeding only to be told I had ectopic pregnancy. (M-4)

Women also reported encountering mistreatment and abuse from healthcare workers, leading to traumatic experiences. Women also decried that many health workers lacked sensitivity in dealing with women who had experienced loss. For instance, in one of the facilities, it was reported that women had to stay with their dead babies until the next round when morgue attendants would come to pick up the bodies. This is the same ward where other mothers who gave birth to live babies are admitted.

> The one who has given birth normally is here, and the one whose child has passed away is there beside her with the deceased baby placed in a box next to her on the ground. They come to collect it later in a box. Before being discharged, they will ask you whether the baby should be buried or disposed of, as many people tend to say they should be disposed of, and many leave them. (M-18)

Additionally, women with disability were not spared by the health workers.

> When I lost my baby, the doctor said even God did something good to allow your baby to die because how would you bring up a baby when you are disabled. (M-7)

Counselling was also lacking in most of the health facilities. Participants who said they were counselled had to pay an extra cost to do so. In most cases after the loss, they were treated and discharged without anyone talking to them.

> At the facilities let them introduce counsellors so that the woman can know she is not alone, and these things are normal. Currently, we just leave the hospital without any form of counseling.

At the community level, although the participants said some CHVs were good and supportive, most of the women did not trust them enough to disclose their perinatal loss to the CHVs because of fear of stigma or being tagged as HIV-positive.

> You will get a good CHV who can keep secret, here in our community, especially Kibra, we know that if a CHV enters a house, that lady is taking drugs (Meaning ARVs) (M-3)…

> CHV don't come unless you are close friends from the past, CHV know but in the slum if CHV come to comfort you and to support they come out with your secrets and they take them to out. (M-5)

During the discussion, the women reported that they were often taken through a complex referral system which led to significant delays in attending to them, especially during emergencies. As local facilities often did not possess the capacity to handle pregnancy complications, this often resulted in multiple referrals between facilities before one could obtain the required services. These came with additional financial costs to the women, further adding to delays in seeking services. A woman shared her ordeal of going to multiple hospitals before finally accessing the necessary health services. She narrates her case as follows:

> When I gave birth, the baby was healthy at first. However, after a while, the baby's condition started to deteriorate. I took the baby to a nearby private hospital, and when the doctor saw the baby, they wrote me a referral letter instructing me to go to the county hospital. Upon reaching the recommended health facility, they examined me and advised me to go to the referral hospital, where they had the necessary equipment. I went back home because I did not have the money needed. After three days, the baby's condition worsened, and I was rushed to a private hospital. The doctors there said they could not help, and it was already late at night, around seven o'clock. We took an ambulance and went to a second referral Health facility. When we arrived there, they took me to the emergency room, and another doctor examined the baby. He looked at me with sadness in his eyes and said, 'I am sorry, the baby is already gone'. (M-3)

Long waiting time was also an issue, especially in public hospitals. There were cases where women could be forced to wait longer than a week to be attended to even when the fetus had died inside the womb.

> I was told to wait for 24 hours with a dead baby in my womb. (M-22)

where I was admitted there were some (pregnant women) before me who had stayed for one week with dead babies in the stomach. Imagine children dead in the stomach and nobody is attending to you. I was like I will also stay for another one week without anyone attending to me by at least they treated me but later everyone (pregnant mothers who had stayed for a week) started creating chaos. (M-16)

Women also had to endure lengthy periods times before procedures, especially after loss which further amplified the trauma and emotional distress especially when these women had to be mixed with those who had had successful deliveries. At the health facilities, women who have lost their babies were mixed with those who had successful deliveries thus adding to their trauma and stigma.

After my loss, I was admitted in the same ward with women who had given birth to live babies. It was very traumatic when the new-borns cried. I cried day and night I could not stop asking God why my baby passed away. (M-13)

Theme 3: stigma and cultural influences

Societal stigmatisation

In many instances, the women were often blamed for their loss, with some communities believing they had either intentionally caused the loss (through abortion) or lifestyle choices. As one of the bereaved women stated.

There is also a lot of stigmas, as people do not understand what you feel about your loss. Especially when there is more than one loss people start thinking that it is your fault. (M-7)

In some extreme cases, the stigma often led to women being ostracised by the community. Many of the women explained how neighbours tended to avoid them and their families after their loss. In one case, a woman narrated how she was not allowed to hang her laundry within the community hanging line with neighbours, fearing that their misfortune might be contagious. In another case, a woman narrated her case as follows:

Later, friends came to visit me, but one of them had a baby at one point, and I went to visit her. However, she forbade me from holding her child, saying that I had experienced a loss, and it was inappropriate for me to hold her baby. (M-10)

The stigmatisation often resulted in avoidance and isolation, blame and self-doubt and a generally negative impact on their mental health. Most of the women who had experienced perinatal loss explained that they often felt that they were abandoned during their time of great need.

…you feel abandoned by your neighbors, after arriving at home like this (from the hospital), everyone will tell you not to visit their house because you are bleeding. (M-2)

Many of them also questioned themselves and their role in the perinatal loss leading to self-doubt and guilt as they tended to absorb the blame projected onto them by the community.

… this person (bereaved woman) should enter her house and stay there she is bereaved; she should stay in one place, and I don't know where that thing (belief) comes from saying that a bereaved mother should not meet or stay with people. (M-8)

Cultural perception and norms surrounding perinatal loss

Cultural perceptions and practices significantly influenced the community's response to perinatal loss. Oftentimes, both the victims and their communities attributed such losses to witchcraft and curses, leading victims to consult traditional healers rather than seeking medical assistance.

… I went somewhere, and I heard that this woman(me) and her children (neonates)keep on dying, sorry to say this, something has grown down there, and she should be examined by the villagers because something has grown inside the vagina, and it is killing the children. So, you are sent to an elderly lady to look and wipe or do other things. (M-5)

It was mentioned that the caesarian section was forbidden in some cultures and religions as a method of delivery which meant women had to undergo natural labour even during high-risk pregnancies which could lead to further complications for both the mother and the child.

I was telling the doctor to take me to theatre, and the doctor told me, M-17, you are from the Islamic religion; do you know something called Kadar? Kadar is something that God has written, and nobody can erase it. So, you hold on until you deliver the baby… (M-17)

Furthermore, cultural beliefs played a pivotal role in shaping how communities treated women who had suffered these losses, determining whether they received essential support or encountered stigmatisation. As one woman articulated:

…the person next to you has a different tradition; this one is mourning and can't hold a child; this one is mourning and should not walk and meet someone breastfeeding; this one is mourning, if you meet them, you should step aside, if it is a toilet, let them enter, and when they come out, then I can go in. You shouldn't cross paths; this person is mourning, and their shadow shouldn't meet that one's shadow with a child. (M-1)

DISCUSSION

The study identified themes based on the data collected on women's experiences and perspectives after perinatal loss. A majority of the participants had traumatising experiences that had an impact not only on their mental health but also on their social life. Mothers expressed their gratitude to the research team as they thought for the first time someone had remembered them and were ready to listen to their predicaments. They stated that they needed support groups where they could talk about

their experiences and receive assistance from counsellors and other women who had also experienced loss.

Women who took part in the study reported that the time following perinatal loss was frequently characterised by emotional trauma and grief. The psychological effects of the loss often went beyond the immediate aftermath and had an impact on the mental health and general well-being of the women. These findings resonated with other studies that parents experiencing perinatal loss have feelings of shock, denial, anger, hopelessness and despair.[39–41] Apart from their psychological state, prolonged grief coupled with multiple losses, women had pressure to give birth immediately after loss because of familial/societal expectations. These feelings were also expressed in the works of Paudel,[42] and women had repeated births with the hope that they would have a live baby to secure their marriage.[41]

Consistent with other research, the participants stated that they faced stigma at family, community and societal levels. Women described how they were often subjected to judgement, blame and isolation, which further compounded the emotional burden they had already been dealing with. Studies show that grieving parents continue to face stigma, social shame and marginalisation from community members, including friends, family, colleagues and, in some cases, even medical providers.[43] Despite the prevalence of perinatal mortality, perinatal loss grieving is rarely recognised or socially legitimated in many countries.[43] Common explanations frequently serve to promote stigma, which is the result of people being labelled and stereotyped and experiencing discrimination, exclusion and status loss.[44–47]

Some of the women reported that they were verbally and physically abused after the loss. Their mental health problems and psychological suffering grew as a result. This finding agrees with other studies carried out in Ethiopia that reported cases of intimate partner violence.[20 48–50] Verbal abuse did not only come from the family but also from the community and health workforce.

Women were also reported to have been abandoned in hospitals by their spouses, and others said that their spouses married a second wife into their relationship (polygamy). This was a recipe for further distress that can cause the breaking of marital relationships and or women abandonment of mothers who had experienced perinatal death,[46] as family and husbands' attention were geared towards the new wife who could bear children.

Serious concerns were raised about the quality of care, the competence of healthcare personnel and overall management of health services. These cases included slow response, lack of attention, care or basic medical support during labour and delivery. Research shows that barriers still exist that prevent the effective provision of support and bereavement care. These include insufficient training and experience of healthcare workers, lack of clear care pathways and limited availability of support system and structures for parents.[46] Studies further found that most nursing professionals felt unprepared and lacked the confidence to provide perinatal bereavement care. Healthcare workers, especially midwives, also find caring for bereaved families stressful and emotionally challenging.[20 51]

Additionally, women had to endure lengthy waiting times after miscarriage before procedures, which further amplified the trauma and emotional distress, especially when these women had to be mixed with those who had had successful deliveries. The trauma of having to endure being admitted to the same ward as those with live babies was rampant among the women who had losses. Some explained that they cried and questioned their womanhood.

The complexity of the referral process often led to significant delays in attending to women in an emergency. As local facilities may not have the capacity to handle pregnancy complications, this often results in multiple referrals between facilities before one is able to obtain the required services. These referrals meant a waste of critical time and the chances of losing the pregnancy or neonates increased with every second. This also came with additional financial costs to the women, further adding to delays in seeking services.

Cultural perceptions and practices significantly influenced the community's response to perinatal loss. Oftentimes, both the victims and their communities attributed such losses to witchcraft and curses and bad omens.[52] This agreed with another study that showed that stillbirths were widely associated with witchcraft, bad omens and such women who have experienced multiple losses are rejected and abandoned by not only their husbands but also their families.[53] Other studies outlined beliefs that perinatal loss occurred because the woman was possessed by bad spirits, curses or refusing to take herbal medications.[25]

However, some of the participants said that they received support from their family members including mothers, spouses and moral support from their friends. Also, the CHVs played a key role in giving the mothers health education materials during pregnancy, counselling and referral services. Some of the CHVs also visited them for moral support. At the facility, a participant reported that a health worker bailed her out of the hospital because she had stayed in the hospital for too long because they could not afford.

Strengths and limitation

The study was conducted in Nairobi county, which as the capital city of the country offered a diverse population comprising individuals from various socioeconomic, ethnic, cultural and religious backgrounds was a significant strength. This enabled the study to capture a wide range of perspectives and experiences across different cultural and social contexts. Moreover, the collaboration between the researchers and the community health workforce allowed the researchers to leverage existing networks to facilitate the recruitment process. Their

involvement was also vital to foster trust between the researchers and participants.

However, the researchers acknowledge that while efforts had been made to ensure representativeness, the study's use of purposive sampling may have introduced bias into the sample selection process. Additionally, the participants recruited through community health volunteers may not fully represent the diverse experiences within the target population which could potentially limit the generalisability of the study. The study's use of FGDs while valuable for generating group dynamics and shared experiences may also not have captured the full range of individual perspectives and nuances that could emerge from other methods of data collection such as in-depth interviews.

CONCLUSION

Perinatal loss is a unique type of loss, it is a silent pain that only the parent understands. Most of the time women experience discrimination, stigma, abuse and trauma. This is because it is believed that women are to blame for the perinatal loss. Thus, there is a need to establish a trauma management programme to support the mothers. Additionally, these women should get together in support groups so they can socialise, engage in shared interests and exchange their experiences. In addition, health professionals should receive ongoing training and sensitisation so that they can support and compassionately interact with women who have had perinatal loss and provide some kind of counselling. Also, creating awareness and promoting health education are essential ways to make community members more aware of the concerns of perinatal loss. Lastly, there is a need for another qualitative study that not only interacts with mothers but also other family and community members including the healthcare providers to understand their own perspectives on perinatal loss.

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Patient and public involvement The researchers worked closely with the Nairobi County Community Health Department and involved the public in the recruitment of research assistants. The researchers will collaborate with community leaders to organise meetings where the results of the study will be presented, discussed and explained in simple language. Copies of the study will also be shared with the community members, the community health workforce and other relevant stakeholders.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by University of Ibadan Research and Ethics Board (REF: NHREC/05/01/2008a). AMREF Health Africa Ethics and Scientific Review Committee (ESRC) (REF: AMREF P1386/2023). National Commission of Science Technology and Innovation (NACOSTI) (REF: 424316). Nairobi City County- County Health Research Ethics Committee (Ref: NCG/HWN/REC/360). Participants gave informed consent to participate in the study before taking part.

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