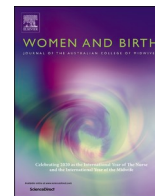




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Review article

Women's experiences of care and support following perinatal death in high burden countries: A metasynthesis

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ABSTRACT

Problem: The experiences of women in low and middle-income countries following perinatal death remains difficult and challenging, thereby increasing their susceptibility to negative psychological impact particularly with insufficient bereavement care and support.

Background: Perinatal death invariably brings intense grief which significantly impacts women, and requires adequate bereavement care to limit negative outcomes in the short and long-term.

Aim: To develop deeper understanding of women's experience of care and support following perinatal death in high burden settings.

Methods: Six electronic databases were searched with relevant terms established using the SPIDER tool, supplemented by hand search of reference lists. Studies were independently screened for inclusion by all authors. Meta-ethnography (Noblit and Hare, 1988) was used to synthesise existing qualitative studies.

Findings: Eight studies conducted in Sub-Saharan African and South Asian countries namely South Africa, Uganda, Ghana, Kenya, India and Malawi were included, and three main themes were identified; mothers' reaction to their baby's death, care and support after perinatal death, and coping strategies in the absence of care and support. Perinatal death was not appropriately acknowledged therefore care and support was inadequate and, in some cases, non-existent. Consequently, mothers resorted to adopting coping strategies as they were unable to express their grief.

Discussion: There is insufficient care and support for women following perinatal death in high burden settings.

Conclusions: Further research is required into the care and support being given by healthcare professionals and families in high burden settings, thereby ultimately aiding the development of guidance on perinatal bereavement care.

Statement of Significance

Problem

Inadequate care and support following perinatal death in high burden settings makes women more susceptible to negative psychological consequences. There is insufficient research into their experiences of care and support.

What is already known about the topic?

Women in high burden settings have poorer psychological and

health outcomes following perinatal death.

What this paper adds

This paper adds that in high burden settings, care and support is inadequate after perinatal death for women from both healthcare professionals and families. Mothers experience negative consequences as a result of perinatal death so they adopt strategies of coping. Thus, there is a need for more research into the experience of care and support of women in high burden settings to help create a better understanding of ways to improve the provisions, and limit negative outcomes.

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1. Introduction

Stillbirth is the death of a foetus of or over 28 weeks prior to or during birth however its classification and definition vary in different countries (World Health Organisation [1]; [2]). Neonatal death is the demise of a baby within the first 28 days of life, subdivided into early and late neonatal death (within first seven (0–6) days and before 28 days of life respectively [3]. Perinatal death is a prevalent issue worldwide, as of 2019, there were 2 million stillbirths per year, and a further 2.4 million deaths within first month of life, 75 % occurred in the first week of life and 1 million newborns died in the first 24 h [4,5]. Low and middle-income countries (LMICs) particularly in Sub-Saharan Africa and South Asia carry the highest percentage of the global burden, 77% of stillbirths, and 81 % of neonatal death [6-12]. The United Nations, and UNICEF and World Health Organisation under the Sustainable Developmental Goals (SDG3) and Every Newborn Action Plan (ENAP) respectively aim for a global reduction of perinatal death to 12 stillbirths or fewer per 1000 live births and 12 neonatal deaths or fewer per 1000 total births in all countries by 2030 respectively [8,13-15].

After the death of a baby, women experience grief, described as complex, unique, and long lasting which is worsened by lack of societal acknowledgement [16,17]. Adequate and effective bereavement care from healthcare services is essential to limiting negative outcomes for women in the short and long-term [18,19]. High-income countries continue to improve bereavement care through health education, interventions, enhancing healthcare professionals' knowledge and approach [19,20]. However, less is known about women's experience of care and support provided following perinatal death in LMICs. Shakespeare et al.'s (2018) metasummary of parents and healthcare professionals' experience of care following stillbirth in LMICs identified that parents' grief was unrecognised by healthcare professionals and communities in these settings. Therefore, negative experiences such as stigma, blame, loss of value and social status are worsened. Thus, this calls for a deeper understanding of the experience of care and support following perinatal death in high burden countries. This metasynthesis aimed to build on existing understanding, with a focus on women's experience of care and support following perinatal death in high burden countries. This understanding will contribute to effort of ensuring appropriate bereavement care is offered to those who experience perinatal death in such settings.

2. Methods

2.1. Search strategy and data sources

The search strategy was informed by an initial scoping search of qualitative studies on women's experience of care and support following perinatal death. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research Type) tool developed by Cooke et al. [21] was used in formulating search terms (Table 1), because of its specificity to qualitative studies [22]. Search terms were combined using Boolean

Table 1
Search Terms.

Spider	Search terms
<i>SAMPLE PHENOMENON OF INTEREST</i>	"Women" or "mothers" or "parent* " or "Famil* " "Perinatal death" or "baby death" or "neonatal death" or "neonatal loss" or "neonatal death" or "death of a baby" or "neonatal bereavement" or "neonatal mortality" or "foetal loss" or "Stillbirth" or "Neonatal bereave* " or "Stillb* "
<i>DESIGN EVALUATION</i>	"qual* " or "qualitative" or "mixed methods" "Experience" or "views" or "perceptions" or "perspectives" or "feelings" or "opinions" or or "Narrative" or "Thoughts"
<i>RESEARCH TYPE</i>	"interpretive" or "descriptive"

operators of "And" and "Or". Truncations were also used for a wider search. Six electronic databases including EMBASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychInfo, Applied Social Sciences Index and Abstracts (ASSIA), and African Journals Online were searched. The search was initiated in July 2019, and repeated in July 2020 to ensure it was up to date. No date limit was applied on the databases because older studies may give valuable insight into changes in care and support provisions following perinatal death and experiences of women over time. Hand searching of reference list was adopted to supplement and enhance database search as applicable terms may not be used in titles and abstracts resulting in relevant studies being missed [23].

2.2. Study selection

Author 1 completed the literature search and imported all references to COVIDENCE software (www.covidence.org), a systematic review management software. All titles, abstracts and full text were screened independently by all authors to ensure rigour in the process [24]. Conflicts were resolved via the COVIDENCE software and a discussion between all authors. A summary of characteristics on included studies is provided in Table 3.

2.3. Inclusion criteria

Primary qualitative studies, in English using descriptive and interpretative methodology, in exploring the experiences of women following perinatal death on the care and support in high burden setting were included. Mixed-method studies were eligible for inclusion if the qualitative data was clearly reported and applicable. Studies including experiences of other family members were also eligible for inclusion if women's experiences could be extracted. The ENAP and SDG3 targets reducing stillbirths to 12 deaths per 1000 live births, and neonatal deaths to 12 deaths per 1000 live births globally by 2030 respectively [1, 11]. Thus, in this metasynthesis, high burden settings were defined as countries with perinatal death rates above the ENAP and SDG3 target rates.

2.4. Exclusion criteria

Studies focused solely on miscarriage (loss of pregnancy before 28 weeks of gestation and termination of pregnancy) were excluded [1]. Grey literature such as thesis were also excluded due to financial and time constraints in retrieving these resources.

2.5. Quality appraisal

Quality was appraised in this review to gain an insight into the strengths and flaws of each study and how they may impact the findings and new interpretation. It was important to appraise the quality of included studies as it contributes to the credibility of a metasynthesis [25]. Walsh and Downe's [26] appraisal tool which evaluates rigour by assessing integrity, transparency and transferability, and Downe et al., [27] grading system were used in quality appraising included studies [25,27]. All three authors independently appraised the included studies, and assigned a grade between 'A' and 'D' according to Downe et al. [27] grading system. A study by author 2 was appraised by authors 1 and 3. Conflicts in grading was resolved in a meeting between authors. No study was excluded on the basis of grade because although a study may be graded as 'poor', it may contain valuable qualitative findings [28].

2.6. Data extraction and synthesis

The researcher read and re-read included studies for understanding and immersion in the data. Data was extracted under the categories of study aim, participants, study and recruitment setting, methodology,

method of analysis and findings. These categories also informed description of study characteristics (Table 3). Noblit and Hare's [29] meta-ethnography was adopted in analysing the data. Five steps were followed; analysis commenced with author 1 reading and re-reading each study to identify key concepts and themes within the findings. Key concepts in the included studies were highlighted, and written out by hand, cut out and arranged on a large paper. The concepts and themes were organised, along with the first and second order constructs (direct quotes of participants and interpretation of original research authors respectively) identified from each study to preserve their original contexts [30]. These findings were synthesised by comparing the themes and concepts to identify similarities (reciprocal findings), and highlight the conflicts (refutational findings). The reciprocal and refutational findings were converged from which a line of argument was developed. This approach advocates that synthesis should be interpretive not just descriptive, and its steps aid the development of interpretation of women's experiences of care and support following perinatal death [31].

2.7. Reflexivity

The authors ensured that interpretations remained very close to findings by using words and quotes that express the original participants' experiences. The authors are qualified nurses (authors 1 and 3) and midwife (author 2) with experience in various settings, general and mental health nursing, and midwifery which enhances the quality of this metasynthesis, as each person brings their knowledge and expertise. Furthermore, two of the authors have extensive experience of conducting and supervising research in global mental health, and perinatal death, but not limited to these.

3. Findings

3.1. Search outcome

A total of 1882 studies was retrieved from the database search of which 744 duplicates were removed. After title and abstract screening of 1138 studies, 177 studies moved to full text review and 940 papers were excluded as they did not meet the inclusion criteria. At full text review, of the 177 studies, 7 were eligible for inclusion in the metasynthesis from the database search. 2 studies were retrieved from hand search of reference lists, of which 1 study was eligible for inclusion. Of the 170 studies that were excluded, 20 were not retrievable due to either pay-wall restrictions or not being available, 7 were dissertations, 9 were not focused on women, 1 was not in English, 48 were not of qualitative or mixed method design, 85 were from low burden settings. Overall, a total of 8 studies was included in this metasynthesis (Refer to PRISMA diagram below for the database search). (Fig. 1).

3.2. Characteristics of included studies

The eight (8) included studies were of interpretive, descriptive and grounded theory qualitative methodology, except one which was mixed-methods. Studies were undertaken in Uganda (1), South Africa (2), Ghana (2), India (1), Malawi (1), and Kenya (1) (Table 3 for characteristics of studies), all high burden settings in Sub-Saharan Africa and South Asia, and were conducted between 2007 and 2020. The sample sizes ranged from 8 to 134 participants. All of the studies focused on women's experiences of care and support following stillbirth and/or neonatal death but some included other participants such as partners [33,34], grandparents and traditional birth attendants [33]. All the studies utilised interviews as their data collection method. In relation to the quality appraisal, four studies [33-36] were graded B, three [37-39] were graded C and one [40] was graded a D (Table 3).

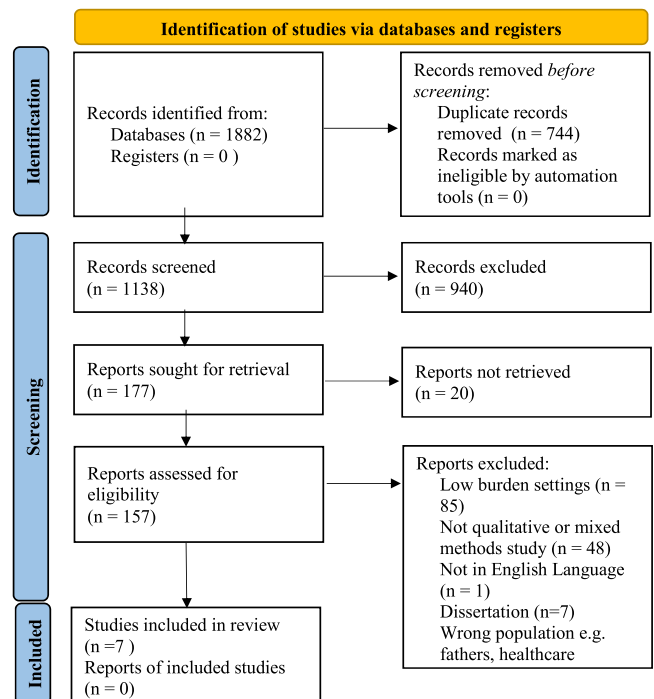


Fig. 1. PRISMA Diagram of database search. From: Page et al. [32].

3.3. Themes

Three main themes (with 6 subthemes) emerged from the synthesis which includes; *mothers' reaction to their baby's death, care and support following perinatal death, coping strategies in the absence of care and support*. These themes are explained and discussed below.

4. Mothers' reactions to their baby's death

"The baby died, I embarked on a wasted journey it's my fault"

The anticipation of welcoming a living baby was dashed by their death causing mothers to experience a range of negative emotions including guilt, heartbreak, confusion, sadness, numbness, emptiness, lack of fulfilment and emotional pain which were worsened by different factors [33,40,35,36,39].

"I just felt confused. I could not cry, I really felt empty ... When a child is born dead, there is nothing. The world remembers nothing and the gap in the womb is replaced by an emptiness in your arms. You are not recording a birth or a death." [40].

Women described the experience of perinatal death as having embarked on a pregnancy journey with its accompanying emotional and physical demands in vain without a reward of a living baby [34,40,39].

"I felt very sorry for myself because it was as if I had worked for nothing." [39]

The feeling of guilt was heightened when others such as healthcare professional or family inferred that mothers were responsible, and they also blamed themselves for their baby's death due to actions they may have or not taken whilst pregnant or during labour [38,40,35,36,39].

"I felt myself it was my fault. I felt it was something wrong with me...I feel it's my body rejecting the baby". I think really I am blaming myself for going into labour, for getting out of bed. If only I had stayed in bed that extra day, would it have made any difference?" [40].

Table 2
Themes, subthemes and core concepts.

Subthemes	Relevant Studies	Main Themes	Example Quotes	Core Concept
My baby died, I embarked on a wasted journey it's my fault	Kiguli et al.,[33], Simwaka et al., [39], Modiba and Nolte,[40], Roberts et al.,[36], Onaolapo et al., [35], Mills et al.,[34], Meyer et al., [38]	Mothers' reaction to their baby's death	<i>I was filled with sorrow because I was expecting something, I was eagerly waiting, and I was also happy that I would have a baby. I was heart-broken... I become depressed</i> [39].	Perinatal death causes a range of emotions in mothers, particularly feelings of guilt which is compounded when others blame them for the loss. There is an understanding amongst mothers that the absence of a living baby makes them of less concern to healthcare professional. Family and communities contribute to the grief due to lack of support. Consequently, coping strategies are adopted by women to help in managing their experience of perinatal death and its impact. There is a need for appropriate bereavement support for mothers.
I don't have a live baby so staff don't care	Simwaka et al.,[39], Modiba and Nolte,[40], Roberts et al.,[36], Onaolapo et al.,[35], Mills et al., [34], Meyer et al.,[38], Conry and Prinsloo,[37]	Care and support following perinatal death	<i>"nurses ... should try hard to comfort patients. They should try hard to look at the other person's problem, try to comfort her the way they have been taught, and according to their capability, because most of the time, at home there is no time for this" ... "The doctor avoided me, and when I pressured him, he said: "These things happen and you should try to put that behind you". He really offered no support, he was so cold". Modiba and Nolte</i> [40]	
Lack of support from partners, family and community	Kiguli et al.,[33], Modiba and Nolte,[40], Roberts et al.,[36], Onaolapo et al.,[35], Mills et al., [34], Meyer et al.,[38]		<i>"they all acted as if I intentionally killed the baby myself. People's attitude sometimes can make someone's situation worse"</i> [35]	
Stoicism and acceptance	Onaolapo et al.,[35], Meyer et al., [38]	Coping strategies in the absence of care and support	<i>Because I knew that, actually, the baby is gone and there's nothing that I can do. So there's no need for me to cry and scream and shout for people to know. Meyer et al.,</i> [38].	
Living children and faith as a protective factor	Kiguli et al.,[33], Mills et al.,[34], Meyer et al.,[38], Onaolapo et al., [35]		<i>"I think I have to concentrate on how to help raise my children to get to somewhere in life than to think of bringing another one into the world."</i> [38]	
Avoidance	Kiguli et al.,[33], Meyer et al.,[38]		<i>"I believe God has a purpose for everything, he allowed this to happen for a reason"</i> [35] <i>"even the pictures we took of the baby have been seized by my uncles, in a bid to help me not talk or remember the event, to prevent me from crying or being sad...They [my family] said if I talk or think about it so much, I will be so depressed and also that chances of having another baby will be so slim"</i> [38]	

5. Care and support after perinatal death

"I don't have a live baby so staff don't care"

The care from healthcare professionals (staff) had a direct impact on mother's grief experience. The level and quality of interaction and communication from healthcare professional were perceived as inadequate, limited and in some instances absent particularly from doctors. The included studies show that most mothers had an understanding that they were not appropriately cared for and supported by healthcare professional due to the absence of a living baby [38,34,40,39].

"Nurses don't communicate with you". "Doctors don't have time for the patients. Just a few. But they don't have time for the patients! Most of them don't have time for the patients." [40].

Consequently, many mothers were left to construct their own explanation of the reasons and circumstances leading to their baby's death which contributed to their grief [38,34,40,35,39]. Some of which included; medical negligence, partners' infidelity, witchcraft.

"I think it is the nurse's negligence because if she had attended to me a way could have been found to save my baby." [39].

Some meaningful interactions were reported where healthcare professional offered verbal encouragement and sensitive approach to care such as nursing bereaved mothers on separate wards to those with living babies [37,38,34,36,39].

"She [healthcare professional] said I should not worry too much because that is how God planned it, He gives and takes away so maybe God will give me another gift at a later time" [39]

However, healthcare professional were mostly unsupportive of mothers as they did not provide opportunities for discussion, were insensitive, absent, rude, unapproachable, lacking in compassion, warmth, and enthusiasm in their care duties [37,34,40,35,39]. This is reflected in an example of healthcare professional's conversation as narrated by a mother;

"What do you want us to help you with? Your thing has already died, for us we save those who are still alive, if your baby was still alive, we could have saved him. So, on that note, help yourself because we also have no way of saving you." [34].

The grief experienced by mothers was further compounded as it appears that there was no consideration of their desires or emotional impacts of certain actions such as preventing seeing and holding their babies, and nursing them on the same wards as those with living babies.

Table 3
Characteristics of Included Studies.

Authors, Date, Country	Aim	Methodology	Sampling Strategy	Recruitment setting	Data Collection Method	Data Analysis Approach	Quality Assessment Grade
Conry and Prinsloo, [37], South Africa	To explore access of bereaved mothers to services following perinatal death.	Exploratory study	Purposive sampling (n = 15) 15 women	Hospital	Interviews	Mixed methods (dominant/less dominant approach).	C
Kiguli et al. [33], Uganda	To explore local definitions and perceived causes of stillbirths as well as coping mechanisms used by families affected by stillbirth in rural eastern Uganda.	Interpretive phenomenological research	Convenience sampling (n = 29) 14 women (who experienced stillbirth) 6 men (husbands of women who experienced stillbirth) 4 Grandmothers 1 Grandfather 4 Traditional Birth Attendants	Hospital maternity ward register, and village community leaders.	In-depth interviews and observation	Content analysis using Granheim and Lundman approach	B
Modiba and Nolte [40], South Africa	To describe the experience of mothers with the loss of a baby during pregnancy (stillbirth included) and the professional care received during the time.	Interpretive phenomenological research	Purposive sampling (n = 10) 10 women who had experienced perinatal death.	Maternity ward in a hospital.	In-depth unstructured interviews	Tesch's data approach.	D
Meyer et al. [38], Ghana	To further understand the notion that suggests that women in sub-Saharan Africa are discouraged from publicly mourning a perinatal death and discussing their loss for fear of social ramifications such as stigma, gossip and blame.	Mixed methods	Convenience sampling (n = 8) 8 women	Mother and baby Unit in a hospital	Interview and quantitative survey for demographics.	Content Analysis	C
Mills et al., [34], Nairobi, Western Kenya, Kampala and Central Uganda.	To explore the lived experience of care and support following stillbirth in urban and rural health facilities.	Qualitative interpretative design (Heideggerian phenomenology)	Purposive sampling (n = 134) 75 women and 59 men	Hospital and postnatal clinics	Interviews	Van Manen's reflexive approach	B
Onaolapo et al. [35], Ghana	To explore experiences, coping strategies and support systems available for perinatally bereaved mothers.	Descriptive phenomenological design	Purposive sampling (n = 12) 12 women	Hospital	Interviews	Thematic analysis using Colaizzi's approach	B
Roberts et al. [36], India	To explore how poor, rural central Indian women perceive and cope with stillbirths.	Grounded theory	Snowballing sampling (n = 33) 17 women 16 healthcare professionals and hospital staff	General hospital	Interviews and focus groups	Standard qualitative data analysis	B
Simwaka et al., [39], Malawi	To explore women's perceptions of and satisfaction with nursing care they received following stillbirth and neonatal death.	Qualitative exploratory study	Purposive and snowballing sampling (n = 20) 20 women	Villages around the community hospital	Interviews	Thematic analysis using Colaizzi's approach	C

"then after that delivery[sic] and the incident of losing my child I was being put in the same room with other women holding their baby. I felt very bad because I too wanted to hold mine and feel like them." [34]

"I have the most amazing and supportive husband in the whole world...he did not let me feel bad. He is so funny and dramatic that all his dramatic acts in the house make me forget my loss" [35].

5.1. Lack of support from partners, family and community

Relationships between women, partners and families and with the community were impacted either positively and negatively by perinatal death. Many reported that the bond with their partners was strengthened as they lived through and coped with the grief jointly [33,34,36]. The sustenance of relationships was in some cases reliant on its quality prior to perinatal death [33].

However, breakdown in relationships occurred as perinatal death caused strife and sadness for some couples thereby drawing them apart. This was also precipitated in a few cases where mothers were blamed by partners, and extended family members for the baby's death. Thus, mothers experienced marital strife, separation, emotional and verbal abuse from partners, family members including co-wives and stigmatisation in and by communities [33,38,34,40,35,36].

"I had a previous [perinatal] loss, and this again! At a point my husband started frustrating me, coming back home late at night...he even threatened to bring in another woman as a wife" [35].

The family and community particularly stigmatised mothers in the case of repeated perinatal death, often accusing them of witchcraft or being possessed by demons [33,38]. They withdrew their care and support for mothers as they were seen as responsible for their baby's death. This reinforced sense of guilt carried by most mothers. Mothers responded by isolating themselves, enduring the blame and ill-treatment due to lack of understanding of their grief experience, and support from their families and communities [38,34,36].

6. Coping strategies in the absence of care and support

6.1. Stoicism and acceptance

Perinatal death was not adequately acknowledged in communities and by families, majority of mothers were unable to openly express their grief. Therefore, the absence of care and support led to the adoption of personal coping strategies to manage their experiences. Stoicism was described as "being strong for themselves" by some mothers who endured the emotional pain and impact with an assurance that they will live through the grief [35,38].

"All mothers have to be strong for themselves especially during their loss because whatever loss or pain or tragedy we are experiencing we would always get through it. I know it hurts but my Allah will do another one, I know" [35].

6.2. Living children and faith as protective factors

Older living children were a protective factor to a few mothers who were grateful to be alive to care for and see them grow [33,38,34].

"Do I even have the time [to dwell on the death of the baby]? Look at the children around me. If I lost one, will I not get on my feet to support the rest that are alive?." [38]

There was a reliance on religious belief as a few mothers accepted their baby's death as the will of God/Allah who will provide a living baby for them in the future [33,38,34,35].

"I believe God has a purpose for everything, he allowed this to happen for a reason" [35].

6.3. Avoidance

Avoidance was used as coping strategy by mothers but this was not always by choice rather enforced by others such as family or as a result of cultural beliefs. Certain cultures discourage mothers speaking or thinking about a deceased baby as it is believed to be an effective method of coping and preventing future fertility issues [38]. Consequently, mothers avoided thinking or speaking about their baby's death by placing focus on others things or engaging in activities, although some longed to speak about it.

"even the pictures we took of the baby have been seized by my uncles, in a bid to help me not talk or remember the event, to prevent me from crying or being sad...They [my family] said if I talk or think about it so much, I will be so depressed and also that chances of having another baby will be so slim" [38].

6.3.1. Line of argument synthesis

After the death of their baby, mothers in high burden settings were isolated in their loss. The experience of perinatal death was perceived as a 'fruitless journey'. This invoked a range of emotions such as sadness,

emptiness, lack of fulfilment, which was compounded by the feelings of guilt and responsibility for their baby's death. There were expectations of understanding of the impact of their loss and support in managing their grief from healthcare professional, family and community. However, there was mostly a lack of communication, supportive interactions, and care from healthcare professional who were insensitive, unapproachable and lacking in compassion. Relationships between mothers and their partners were strained, and families also stigmatised them, as they were often regarded as responsible for the loss. Thus, mothers were reliant on their own coping strategies in managing their emotions and grief.

7. Discussion

7.1. Main findings

This metasynthesis aimed to increase the understanding on women's lived experience of care and support following perinatal death by synthesising the findings of existing studies in high burden settings. In this review, there was a perception amongst mothers that they had embarked on a journey to motherhood without a positive outcome. This experience of perinatal death was characterised by intense grief which manifested in negative emotions such as anger, emptiness, and lack of fulfilment. There was a sense of guilt in mothers which was further worsened when blamed by others such as healthcare professional, families and communities as responsible for the death. There was an expectation of care and support from healthcare professional, families and communities which some mothers received. However, most mothers expressed dissatisfaction as they had a negative experience with healthcare professionals who were thought to place them as less of a priority due to the absence of a living baby. Mothers reported negative experiences following perinatal death such as blame, stigmatisation, relationship breakdown, and lack of avenue to express their emotions from healthcare professional, family and the society which worsened their grief responses. Family members and the community lacked understanding of support needs of mothers; they were driven by cultural beliefs in their approach. Family members were a concern for mothers as they blamed them and contributed to the breakdown of their relationships/marriages, experience of abuse and ostracization. Thus, many felt unsupported and left to cope with their experience of perinatal death alone. Consequently, in this synthesis, mothers sought other ways of coping and managing their grief. They utilised caring for their other children, and isolating themselves from others, avoidance, acceptance and faith as there is often no opportunity to express their grief.

7.2. Interpretation

This metasynthesis highlighted that the experience of care and support following perinatal death in mothers is shaped by the response of the healthcare setting, partners, family and community. The response stems from a lack of understanding on acknowledgment of perinatal death, recognition of deceased babies and cultural norms thereby leading to disenfranchised grief [41,42]. Mothers were affected by negative responses thus can be said that they experienced multiple losses; of their baby, relationships, family and also social status [43,44]. They yearned for opportunities to express their grief experience, but were hindered by the response of others, and cultural beliefs and practices. Healthcare professionals' approach was inadequate as there was a lack of communication, attention and sensitivity in interactions following perinatal death. A high level of expectation was placed by mothers on healthcare professional in being physically and emotionally supportive and present but this was not the case, which worsened their experience and its accompanying grief. Support and ongoing encouragement from healthcare professional is often of paramount importance to bereaved mothers [20,45,46]. Healthcare professionals are to support mothers by having consideration for their feelings, helping relieve their

negative emotions and feelings of guilt [47,48]. However, it will be beneficial to understand from the perspective of healthcare professionals the rationale behind their approach of care and support towards bereaved mothers in high burden settings following perinatal death.

On the other hand, mothers also had negative responses from family and the community thus they had no source of support leading to adopting other ways of coping with their experience of perinatal death. This has been reported to be more prevalent in high burden in contrast to low burden settings [49]. These negative responses stemmed from cultural beliefs and practices held by families and communities such as not being allowed to hold or see the deceased baby to avoid future fertility issues. In addition, perinatal death impacts on the relationship of mothers and their partners positively and negatively, and thus not limited to high burden settings as also found in studies in low burden settings by Gausia et al. [50] and Fernandez-Sola et al. [16]. However, the quality of relationship prior to perinatal death has been reported to determine the sustenance following perinatal death. Some bereaved mothers reported a strengthened bond with partners but others experienced more friction between themselves. Educating communities and families on the causes and impact of perinatal death on bereaved mothers will be beneficial in limiting the negative responses such as blame, and relationship breakdown in high burden settings. However, this links back to healthcare professionals who are best placed to provide adequate medical explanations to mothers and families about the cause of perinatal death. Thus, there is a need for adequate explanations when perinatal death occurs to bereaved mothers and families [51]. This will contribute to increasing the acceptance of bereaved mothers by family and communities as individuals who experienced rather than caused a loss.

7.3. Strength and weaknesses

This is the first metasynthesis exploring the experience of care and support following perinatal death in high burden settings. Shakespeare et al. [19]'s study provided key foundational understanding for this review. However, Shakespeare et al. [19] conducted a metasummary which is the quantitatively-oriented approach to aggregating frequency and intensity effect of qualitative findings [52]. This review is inductive as it utilised metasynthesis which takes a broader approach towards synthesising qualitative studies through integration and interpretation rather than amalgamation of findings to uncover deeper insight into the phenomenon of interest [52,53]. Although metasynthesis has been criticised for producing interpretations three times removed from the original owners of an experience (participants), its findings remain firmly grounded in the primary studies [54,53,55]. Another strength of this metasynthesis is its use of meta-ethnography in analysing and synthesising study findings which is very efficient at generating new interpretation in a rigorous and systematic manner [29,56]. The expertise and experience of each author also contributes to the strengths of this metasynthesis. Although authors brought differing views based on their expertise which can be challenging, it worked positively as it opened up channels of allowing each open their minds to new angles from the data. Furthermore, the processes in undertaking this metasynthesis was rigorous with numerous discussions between the authors thus creating confidence that the interpretations are reliable.

A majority of included studies in this review (6) were conducted in Uganda, South Africa and Ghana, and the rest were India and Malawi. One of the studies was conducted in two countries, Uganda and Kenya. This reflects continuing gaps in research in perinatal death in high burden countries. The studies were also mostly conducted in rural areas, meaning experiences of women in urban areas in these countries were less represented. Furthermore, the studies had some commonalities in cultural responses to perinatal death from family and communities but practices differ within healthcare settings even in, the same and, different countries. Cultural beliefs and healthcare practices often vary

widely between and within high burden countries, which have to be individually understood [57].

8. Conclusion

This metasynthesis has shown that mothers experienced a range of emotions due to perinatal death. However, these emotions are worsened by negative responses from healthcare professionals, partners, families and communities in high burden settings. Thus, mothers rely on their own ways of coping the absence of care and support from healthcare professionals and family.

8.1. Implication for research

Overall, there is a need for further qualitative studies into the lived-experiences of care and support following perinatal death in high burden settings. The findings of these studies would create an in-depth understanding which would shape healthcare professionals' view on the bereavement care that they provide. This evidence could contribute to underpinning the development of interventions and novel care approaches for women who experienced perinatal death. This understanding will be valuable in improving the care and support provided following perinatal death particularly from healthcare professionals such as nurses and midwives. It will also help in improving the response from families and communities towards bereaved mothers via increased education but further research is required in this area.

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