

Experiences of Perinatal Loss: A Focused Ethnographic Study of Ghanaian Women

By

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A thesis submitted in partial fulfilment of the requirement for the degree of

Doctor of Philosophy

Faculty of Nursing

University of Alberta

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## **Abstract**

There is evidence indicating that grief experiences and support available to women who experience perinatal loss has not been well investigated in Ghana. In particular the emotional and psychological impact of the loss, the ability of women and their family members to flexibly mourn their lost child, and the cultural influence on mourning is less researched. Using focused ethnographic method, the current study explored Ghanaian women experiences of perinatal loss to gain an in depth understanding of the multiple intersecting of cultural influence on this phenomenon. The unique stories of twenty women who had experienced perinatal loss in a tertiary institution in the capital city of Ghana were used to conduct the research.

Findings provided insight into the profound emotional experiences of mothers whose loss brought immense pain. It also indicated that the grief experience of perinatal loss is often underestimated by most people in Ghana including health professionals, and many of the women who go through this loss, experience challenges in grieving the deceased child. Conversations with participants uncovered many themes which improved the understanding of the meaning of losing a child in Ghanaian cultural context.

The recommendations on practice, education, policies and research directions set forth by this study will inform decisions of concerned authorities, the public and other health professionals to support and intervene to provide care that is culturally sensitive and unique to individual parents who have lost children through perinatal loss.

## **Preface**

This dissertation is an original work by Alberta Baffour-Awuah. The research project of which this thesis and manuscripts are part, received ethics approval from the University of Alberta Research Ethics Board, Project Name “Experiences of Perinatal Loss: A Focused Ethnographic Study of Ghanaian Women.” No. Pro00073592 (Renewal), June 7, 2017 –June 6, 2018. Further ethics approval was obtained from the and Ghana Health Service Ethics Review Committee – GHSERC22 /06/17. The four manuscripts enclosed herein were prepared by Alberta Baffour-Awuah. Chapter two of this thesis has been accepted to be published as A. Baffour-Awuah and S. Richter, “Perinatal Loss in sub-Saharan Africa: A Scoping Review”, African Journal of Nursing and Midwifery, A. Baffour-Awuah designed and led drafting and revisions of the manuscript. S. Richter substantially contributed to the design of the study and revisions of the manuscript for intellectual content.

## **Dedication**

This dissertation is dedicated to the women who participated in this study. Thank you for trusting me enough to share your personal life stories and profound pain with me. To my mother Oheneba Dwabeng Serwaah, may your soul continue to rest on peacefully.

## Acknowledgement

I would like to gratefully acknowledge the hard work of the people who provided me with help and support during my doctoral program journey. My supervisor: Dr. Solina Richter! Your directions and motivations provided me with an atmosphere of peace to work things out for myself. Thank you very much!

To my committee members who worked tirelessly to bring me this far, I say thank you! Dr. Pauline Paul, your contributions to my journey of PhD means a lot to me. I appreciate the valuable support and your willingness to be part of my committee when my supervisor reached out to you. Your critical intellectual reviews of each article provided me with great depth of knowledge. I also thank you for your immense support through your quick feedback and most of all those comments of encouragements you leave on my paper when you read them.

I owe a debt of gratitude to Dr. Florence Naab; even though we were far apart, you availed yourself to read my papers. Your rich contributions have enhanced my work. I have benefited from your expertise in Ghanaian cultural norms on childlessness.

My appreciation also goes to my examiners: Dr Margot Jackson, Dr Tanya Park and Dr Shannon Scott. I am very grateful for your support.

I would like to say a big thank you to Dr Vivian Pupilampu. My journey through PhD wouldn't have been possible without your support, mentorship, encouragement and prayers. You were with me through my dire moments and I say thank you and God bless you.

I wish to thank my family and people whose role in my doctoral program made a significant impact. My educational endeavours would not have been possible without the support of my husband and my two daughters—Lawrence, Anna and Wilsonia for their unconditional love, prayers and encouragement throughout this journey. You have been unwavering in your support and I say thank you for all you do for me. My siblings; Kwame, Aniwaa, Kwasi and Ekyem, your support and prayers kept me going.

Oyankronpong Tweedeanpong, de3 wode mabedu yi esom me bo dodo. Agya gye wonhyira, wayeyi ne wonaase. The Omnipresence God, Alpha and Omega! I glorify your name!

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## Chapter One

### Introduction

The introduction to the dissertation begins with a story of which I position myself in the study using personal and participant's narratives. In addition, I provide a background to the study from the literature, state the purpose as well as the research questions and objectives that guide the study.

#### My Story

*I approached my first day at the maternity ward as a senior midwife with mixed feelings. I arrived to meet many unfamiliar faces who were oblivious of my greetings. That concerned me. I wondered if we would get along and be able to work together. I took a deep breath and tried to find my way around, which led me to the admission room of the labour ward. I was greeted by the sounds of a labouring mother with her uncomfortable husband by her side. "Here we go again; this is a 'real' labour ward with its usual noises. Hmm, here I am!" I muttered. I introduced myself and spent some minutes with the couple in labour. I got to know that Amma and Kofi were both university graduates who were working with the bank and had been married for some time.*

*I read Amma's medical file and her records showed she had been married for five years without a child. She has had three miscarriages over the last five years and, fortunately, this pregnancy had progressed beyond what she termed as her "danger zone". Amma and Kofi are finally going to have a child. Her records indicated that there hasn't been any incidence of complications with this pregnancy. Both mother and fetus were in good condition.*

I am very familiar with the experience of perinatal loss because of the personal loss of my own son many years ago. My expertise as a researcher in perinatal loss has developed through my interaction with my work and experience with perinatal loss. As a midwife, my work gives me the opportunity to come into contact with different couples such as those experiencing perinatal loss. My first encounter with perinatal loss before my own was with Kofi and Amma (pseudonyms), a couple who were treated for infertility. They had experienced three miscarriages

over a five-year span and lost each of the pregnancies at approximately eight-month gestational period.

The uniqueness of the story I am about to share, and that of my personal experience, are reflections on the impact of perinatal loss on women. How are they impacted by these experiences and how are they able to manage in a society like Ghana where children are the pinnacle of marriage? How long do they carry these experiences with them? It has been 16 years since my own experience with perinatal loss, but I still remember the day vividly. I believe the tragedy of each loss never eases for women who truly wanted children. Mine never did and I know it will be the same for Amma. Kofi and Amma's experience lives with me.

In the Ghanaian society, women are seen as the bearers of children; men are the providers and have most of the decision-making power in the home. Marriage without children is frowned upon and marital relationships often end in divorce because of childlessness. Infertility and inability to successfully carry pregnancy to term is a major contributing factor for marital instability in Ghana (Kane, 2016; Donkor, Naab & Kussiwaah, 2017). Bearing children places value on women, helps to secure marital ties, and satisfy emotional needs of parents (Jarnkvist, 2019; Nyarko & Amu, 2015). Children are one of the important functions of a marital bond because they continue family lineage (Gyekye, 2003). In Ghana, women who are able to give birth, especially to a male child, receive social and economic security in the family and society (Gyekye, 2003). The husband provides for the household needs including the needs of his wife and children. Similarly, in most cases, male children inherit their father's property, therefore affording the mother security in old age. It is believed that males are nerver, and females are feebler, more emotional and cannot handle stress (Gyekye, 2003). In a polygamous marriage, the wife who has the most children is given the larger portion of what the husband earns (Awumbila,

2006).

Due to the traditional implications and the significance of childbearing, infertility in Ghanaian society is considered a misfortune. Though both men and women can be the source of infertility, women are often the ones blamed for their inability to reproduce. Society and families victimize them, and they experience personal grief, frustration, and social stigma. Social, cultural and familial norms shape the lives of women in Ghana (Clandinin & Connelly, 2000). Women who are not able to live up to the traditional expectations of procreating are made to feel rejected. Having a child soon after marriage is the priority of many couples in Ghana, hence, Kofi and Amma's predicament.

*I left them when the labour ward midwife arrived. Two hours later, Amma delivered a 6-pound asphyxiated baby boy. Regardless of the efforts of the labour ward team including the obstetrician, they were not successful in reviving the baby. Her beautiful son lay dead in the resuscitating room next to the delivery room where Amma was resting. This was their first child, and a son, their parents' first grandson.*

As a midwife, it is emotional when a hard day's work cannot be celebrated. Cases where fetal heartbeats cannot be detected are difficult— we desperately try to find a heartbeat so that we do not have to bear the burden of telling the unexpected news of the death of an unborn or newborn baby. The midwives were familiar with Amma's medical history and found it difficult to break the news of her baby's death to her. With her husband gone to inform the rest of the family about her admission, there was nobody to share the sad news with. I received the news 20 minutes after Amma's delivery and rushed to the delivery room just when Kofi returned. None of the team members felt comfortable telling them about the death of their son. Amma and Kofi needed to know about the outcome, and someone has to give them the news. I gathered courage and informed them.

*Amma's face changed and became distant with no expression. She spoke to herself while asking many questions with tears pouring down her face. Why me? Is it something I*

*should have done differently? Has God abandoned me? Where is He, now that I need Him so much? I stood helplessly by her side and could not answer her. I was lost for words. My heart ached for this mother who just lost her first child, and a Ghanaian dad who lost his first son. My instinct as a mother was to respond immediately. I imagined what I would have done in their situation, so I put my arms around her unyielding body as she wept. I did not feel there were any words I could say at that time. I stayed in this position (by her side with arms around her) at the labour ward for some minutes.*

Amma did not want to move from the ward. The hot, stifling room, the bed with stirrups, and the delivery room noises muddled with baby cries and groans of pain from expectant mothers meant everything to Amma. No matter what her husband and I said, Amma remained unresponsive and did not move.

*Then came the call. That call...Amma's husband excused himself to make a call and as soon as he returned, Amma, with a low shaky voice that barely covered her sobs asked slowly "are your parents angry again?" I sensed so much fear in her voice, fear of going back to the in-laws with empty hands. In my mind I saw a woman who was blaming herself for something that was not her fault. I felt sorry for her because from a medical perspective I knew she was not to blame. That forever changed me and made me realise that this was wrong.*

I explained the meaning of asphyxia (a condition arising when the body is deprived of oxygen, causing unconsciousness or death) to the husband and assured him of how the midwifery team worked hard to resuscitate and save their baby. I asked if they wanted me to visit and explain the cause of the baby's death (asphyxiation) to the other family members. As I spoke with them, I saw Kofi cuddle her, try to comfort and protect her. It was good to observe that Amma had a supportive husband.

*I stayed at work late that day, not wanting to leave Amma until her mother arrived at the hospital, because I knew this young couple would need their family members... Amma would need her mother now.*

*The raw emotion of Amma's grief led me to stay with her and ease her pain. At that stage, Amma was unaware of what was going on around her. She might not remember that I stroked her arm to comfort her as I verbalized her fears. She might not remember me telling her husband to call her mother. She may never know that I went home, climbed into bed and cried for her. She does not know that I am still thinking about her and writing about this so many years later.*

This experience makes me question how a culture with a deeply embedded expectation of procreation shapes perinatal loss. I wonder how a procreation-focused culture supports private and public spaces for the grieving and healing of women, families, and community. Amma's experience with perinatal loss is not a singular story in Ghana. It is a shared, but silenced experience among Ghanaian women; a female experience and a stigmatized loss. Many women in Ghana experience perinatal loss and struggle to cope with it. However, there is dearth of research on Ghanaian women's experience with perinatal loss.

### **Problem Statement**

Perinatal loss is considered a misfortune, and the treatment of this loss leads to the marginalization of bereaved mothers and women. Women feel disenfranchised when they are marginalized, and this type of grief could aggravate parents' experiences of various psychological symptoms that persist after the loss of a child (Heazell et al., 2016). Almost all women who experience perinatal loss, including Ghanaian women, are disenfranchised, exhibit heightened anxiety specifically associated with the loss, and a tendency to develop chronic symptoms of depression (Kint, 2015; Nynas, Narang, Kolikonda, & Lippmann, 2015). The silent grieving and inability to openly discuss their loss leave these women distressed and disenfranchised.

Disenfranchisement of grief during a perinatal loss is common in Ghana, where health professionals and society do not acknowledge bereaved women's grief after the death of their child (Kuti, & Ilesanmi, 2011; Modiba, & Nolte, 2007). African researchers have documented strong cultural beliefs in Africa that do not allow women to express the emotional anguish of their loss, thereby disenfranchising them (Kuti, & Ilesanmi, 2011; Modiba, 2008; Modiba, & Nolte, 2007; Obi, Onah, & Okafor, 2009). Cultural beliefs around perinatal loss are often based



on religious and spiritual beliefs. It is believed that if a woman mourns her deceased child through perinatal loss, she may not be able to conceive again (Attachie, 2013).

Researchers examining the emotions and support of perinatal loss in Africa have concluded that most African women want their grief to be acknowledged, understood, and supported (Kuti, & Ilesanmi, 2011; Modiba, 2008; Modiba, & Nolte, 2007; Obi, Onah, & Okafor, 2009). In addition, the women disclosed a need to bond with their deceased children and have some mementos (Kuti, & Ilesanmi, 2011). Over the last thirty years, research findings on grief disenfranchisement, particularly in developed countries, have been used to improve the care and support given to women who lose their pregnancy or babies during the perinatal period. Nevertheless, there remains a significant gap in support and reduction in disenfranchisement in sub-Saharan Africa, including Ghana. Little is known about the grief experienced, the types of support and care needed, and the effectiveness of support system for Ghanaian women who experience perinatal loss.

## **Purpose**

The purpose of this study was to explore the experience of perinatal loss from the perspective of women within the Ghanaian cultural context and to find out if there are good support systems for women faced with such losses.

## **Research Questions**

Research questions arising from the purpose statement were:

1. What is the extent of research literature available on the experience of perinatal loss in sub-Saharan Africa?
2. What is the grief experience of women who have had a perinatal loss in the Ghanaian cultural context?

3. What are the types of support and care given to grieving women to enable them to cope with their perinatal loss?
4. What do women think about the care they receive or do not receive when they experience perinatal loss?

## **Objectives**

The objectives of the study were to:

- Explore and summarise what is known in the literature about the experiences of perinatal loss in sub-Saharan Africa and support available to couples who experience perinatal loss in Africa.
- Explore and develop a deep understanding of the experiences of perinatal loss within the Ghanaian cultural context.
- Explore what relevant and meaningful support looks like within the Ghanaian cultural context.
- Describe the components of culturally sensitive and inclusive care for women who have experienced perinatal loss within the Ghanaian cultural context.

## **Organization of the Thesis Outline**

The dissertation is presented as a paper-based thesis. In order to accomplish the purpose and objectives of the study and fully understand the research objectives, I organized the thesis into eight chapters. Chapters three, five, six, and seven are stand-alone manuscripts. Chapter one is the introduction to the topic, and also provides justification for conducting the research on Ghanaian women experiences of perinatal loss. It concludes with the purpose statement and objectives of the study.

**Chapter two:** This chapter includes a background introduction to perinatal loss. It includes a reflection on literature on the nature of perinatal loss, the causes and progress on the global level, the emotional impact, support and disenfranchisement of perinatal loss. The chapter concludes with the gaps in the literature on perinatal loss. The literature revealed that very little has been written on experiences of perinatal loss in Africa especially in the sub Saharan Africa and Ghana.

**Chapter Three:** This chapter is presented as a manuscript. It presents the findings of the scoping review that explore and summarise what is known in the literature about the experiences of perinatal loss in sub-Saharan Africa and support available to couples who experience perinatal loss in Africa. I used Arksey and O'Malley (2005) proposed scoping review methodology to acquire an in-depth knowledge of the existing literature. The main themes that emerged from the scoping review were: A) women's experiences of perinatal loss and B) relevant and meaningful support. The subthemes were: i) grief reactions to perinatal and ii) cultural influence on reaction to perinatal loss. This manuscript is a stand-alone paper and it is presented as the first manuscript of the dissertation and has been accepted for publication in the African Journal of Nursing and Midwifery.

**Chapter Four:** This chapter describes the methodology used in this thesis research. My goal for the dissertation was to develop an in depth understanding and to provide a comprehensive account of the women's experiences of perinatal loss in their cultural context. The chapter includes a detailed description of the design, justification of using the specific design, researchers' positionality, data collection methods used, data analysis, methodological rigor and ethical considerations.

**Chapter Five:** This chapter is presented as a manuscript and addresses the sociocultural factors (marriage, motherhood and childbearing) that influence the experiences of perinatal loss

in the Ghanaian context. It addresses the following objective: Explore and develop a deep understanding of the experiences of perinatal loss within the Ghanaian cultural context. The focused ethnography design helped with the development of a deeper understanding on how these cultural norms impact Ghanaian women's reactions to the grief they experience after perinatal loss. In this manuscript, I focused on two themes of six themes that emerged from the study. The two themes are: A) beliefs and values surrounding marriage, motherhood and children; and B) Views of childlessness and perinatal loss. Furthermore, I discussed subthemes under each theme. The subthemes for theme (A) are: - i) marriage as an obligation for raising children, ii) motherhood is equated with successful birth and identity, iii) children as gift from God and source of strength; and the subthemes for theme (B) are: - i) attachment, loss and isolation: a response to perinatal loss and ii) childlessness as a failure for women.

**Chapters Six:** This is the third manuscript from the dissertation, and I present the understanding on the experiences of perinatal loss within the Ghanaian cultural context. It also addresses and expand on the objective: Explore and develop a deep understanding of the experiences of perinatal loss within the Ghanaian cultural context. I will be discussing two of the six themes that emerged from the study. The two themes are A) understanding of pregnancy and loss in the context of Ghana, and B) subsequent impacts of perinatal loss on women. The related subthemes for theme (A) are: - i) mothers' attachment to pregnancy and preparation, ii) grief experiences, iii) reflection and a new understanding of loss; and subthemes related to theme (B) are: - i) relationships: before and after perinatal loss, ii) fear of the unknown, iii) disenfranchised grief.

**Chapter Seven** The chapter is also presented as a manuscript and addresses the components of culturally sensitive and inclusive care for women who have experienced perinatal loss within the

Ghanaian cultural context. It addresses the following objectives of the study: Explore what relevant and meaningful support looks like within the Ghanaian cultural context and describe the components of culturally sensitive and inclusive care for women who have experienced perinatal loss within the Ghanaian cultural context. The paper examines the types of support available to the women and emphasis on what the women perceived as a meaningful support. In this manuscript, I will be discussing two of the six themes that emerged from the primary study. The two main themes include, A) support, and B) culturally sensitive care. The related subthemes that emerged under theme (A) are: - i) immediate communication/interactions, ii) support from significant others, iii) seeing and holding iv) being with v) mothers' perceptions of relevant and meaningful care and vi) psychological counselling. The following subthemes emerged under theme B (culturally sensitive care) i) burial and funeral arrangements, ii) creating meaningful memory, and iii) follow up/postpartum care.

**Chapter Eight** is the final chapter and the concluding part of the dissertation. It provides a discussion of important findings from the study and offers suggestions for further investigation. I also discuss the implications and made recommendations for practice, education, policies and research. The chapter concludes with a discussing the limitations of the study and the way forward.

## **Chapter Two**

### **Literature Review on the Nature of Perinatal Loss, Causes and Progress on the Global Level**

This chapter includes a background introduction to perinatal loss. It includes a reflection on literature on the nature of perinatal loss, the causes and progress at the global level, the emotional impact, support and disenfranchisement of perinatal loss. The chapter concludes with the gaps in the literature on perinatal loss.

The literature review includes peer-reviewed articles and doctoral theses to explore the research on the experiences of perinatal loss and support systems available to women. Although there are different views on literature review in qualitative research, the purpose of the literature review in a qualitative approach provide a strong foundation for the proposed study to identify what is known and unknown about the topic (Fulton, Krainaich-Miller, & Cameron, 2018). This study being a focused ethnographic design a review of the literature was considered essential (Knoblauch, 2005; Wall, 2015). The search strategy involved searching through the following electronic databases: ALT Health, Family Studies Abstracts, Medline, SocINDEX with full text, Violence and Abuse Abstract, CINAHL, Eric and Psych Info. The keywords used in the electronic search were pregnancy loss and fetal death (neonatal death, perinatal death, stillbirth, miscarriage, sudden infant death, infant mortality), support systems, pregnancy until 28 days after birth, and grief (bereavement) covering the period of 1997 to 2020. Originally, only articles ranging from 2007 to 2020 were included; however, other older references of particular relevance were added because of their exceptional significance to the study.

The search approach concentrated on content related to experiences of perinatal loss both in Africa and globally. The research articles used were carefully chosen to include peer-reviewed

studies written in English and focused on perinatal loss and support systems for bereaved women. The reference lists of the chosen articles were expanded to identify additional studies relevant to the topic. Articles that were not peer reviewed and/or written in languages other than English language were excluded. Most of the literature retrieved were from the high-income countries (e.g., the United States and Canada) and included topics on the causes, effects and experiences of perinatal loss. Conversely, there was limited information from Africa with those retrieved mostly on the causes of perinatal loss. Few articles were published on the experiences of perinatal loss in Africa. An additional search was organized in the library catalogue to identify relevant book collections on the topic. As well, grey literature such as dissertations and abstracts of qualitative articles, which were relevant to the study, were reviewed. The literature reviewed was organised under the following headings: nature of perinatal loss, emotional discomfort, lack of support from health professionals and support groups, and the gaps in the literature on perinatal loss.

### **Nature of Perinatal Loss**

The term “perinatal” refers to the period before and immediately after birth. The period of perinatal loss is defined in different ways and depending on the classification it includes loss of the pregnancy from the 20th to 28th weeks of gestation until birth and during the 1st to 4th week after birth (Clark, 2006). The WHO (2006) defines perinatal loss as the death of a fetus occurring between 22 completed weeks of gestation to 7 days after birth. Perinatal loss is further described as a non-voluntary ending of pregnancy without reaching term (Clark, 2006). For the purpose of this study, perinatal loss is defined as the loss of a child by stillbirths and neonatal deaths occurring at 22 weeks of gestation to one month after birth.

There are different classifications of perinatal loss, which are commonly classified as miscarriage, stillbirth, or intrauterine fetal death (IUFD) and neonatal or newborn death.

Miscarriage is a pregnancy loss, medically referred to as spontaneous abortion or inevitable abortion, which occurs within 20 weeks of gestation after conception (Prager, Micks, & Dalton, 2019). Stillbirth or IUFD is described as a loss of pregnancy or a newborn with no signs of life after having survived through at least the first 28 weeks of gestation or more, while neonatal death is the loss of a child within the first 28 days of life (Roos & Tall, 2019; WHO, 2006).

Despite improvements in several areas of obstetrics, perinatal loss still occurs in both high and low-income countries.

### **Statistics of Perinatal Loss**

The most vulnerable phase of a child's survival is the neonatal period (the first month or first 28 days of life) and it is a stage where infants are at their highest risk of losing their lives (UNICEF, 2014). Perinatal loss accounts for 44% of under-5 deaths worldwide. Indicators show that every year, more than 2.7 million neonatal deaths and 2.6 million stillbirths occur worldwide (Hug, Alexander, You & Alkema, 2019, UNICEF, 2014). Children face an average global neonatal deaths rate of 18.0 per 1,000 live births (UNICEF, 2014). Evidence shows that one million of the 2.7 million yearly neonatal deaths occur on the first day of life, another million die within the next six days, and approximately 7,000 die daily (Liu et al., 2016). However, there is a global improvement of a 50% decrease in neonatal mortality (from 5.0 to 2.5 million) from 1990 to 2017. Nonetheless, there is a clear difference in mortality among regions and countries. Sub-Saharan Africa and South Asia had the highest mortality rate of 27 deaths per 1,000 live births in 2017. The probability of a child dying in the first month of birth in sub-Saharan Africa or South Asia is nine times more likely than those delivered in high-income countries (Blencowe et al.,



2016). Additional work is needed to achieve the 2030 Sustainable Development Goals in these regions (Hug et al., 2019).

The highest phase of risk of children dying through stillbirth is the intrapartum period (WHO, 2016). An estimated ninety eight percent (98%) of the 2.6 stillbirths occur in the low and middle-income countries; and 77% of the 98% occur in the sub Saharan Africa and south Asia. Comparatively, only 2% occur in developed countries (Blencowe et al., 2016; WHO, 2016). Further investigations indicate that the stillbirth rate in low-income countries is 10 times higher than in high-income countries (WHO, 2016). In 2000, the rate of stillbirths was projected at 24.7 per 1,000 live birth; however, records show that for every 1,000 births in 2015, 18.4 infants were stillborn representing a 19% decrease between 2000 and 2015 and indicating an annual rate decrease of 2% (Blencowe et al., 2016). The progress of reducing stillbirths is slower than the neonatal mortality rate, therefore, stillbirth should also be set as a priority on the global health agenda (WHO, 2016, Blencowe et al., 2016).

**Disparity in statistics on high- and low-income countries.** According to Bhutta and Black (2013) between 2000 and 2008, the rate of perinatal loss in Norway was at 2.2 per 1000 births for pregnancies at 28 weeks pregnancy or more, while that of the UK was 3.8 stillbirths per 1,000 births. Similarly, in the US, analysis of perinatal death rates by gestational age indicated that the risk of losing a baby during the third trimester (especially from 28 weeks' gestation and more) was less than losing the pregnancy during the first two trimesters (Flenady et al., 2011). The overall rate of perinatal loss in the US was estimated at 5.96 per 1000 births as of 2013; however, the rate of loss at 28 weeks improved and stayed relatively unchanged compared to that of 20 to 27 weeks of pregnancy, which declined by 3% from 2012 to 2013 (Bhutta & Black, 2013). Another significant concern in the US is the high rate of perinatal loss occurring

among the lower-income and minority groups such as black women, who experience perinatal losses more than twice (10.53 per 1000 births) that of white women (4.88 per 1000 births) (Bhutta & Black, 2013). In contrast, Canada had an increase in perinatal loss rate from 5.9 to 6.7 per 1,000 births between 2001 and 2010 (Irvine, Dzakpasu & Leon, 2015). Analysis shows that the death rate among fetuses weighing 500 g or less at birth were 5.1 and 3.7 per 1000 total births. The report added that during the period of 2000 and 2009, the perinatal loss varied between 4.9 and 5.4 per 1000 live births (Irvine et al., 2015).

The UNICEF 2012 report correspondingly asserts that perinatal losses occur in higher rates in the sub-Saharan Africa where poverty is high with weak institutions and progresses for reduction of the incidence rate is slow (Kujala, et.al., 2017). According to the Ghana Demographic and Health Survey of 2017, the rate of perinatal loss in the country is approximately 25 per 1000 live births (Ghana Statistical Service, 2018). The report revealed that infant mortality (child dying before the first birthday) decreased from 64 per 1,000 births in 2003 to 41 per 1,000 in 2014. Very little was mentioned about neonatal mortality rate (children dying within the first month of life), whilst nothing was said about the loss of pregnancy before birth. The causes of these losses were not mentioned in the survey. Although perinatal loss in high-income countries needs further reduction, there are still vast differences between these countries and low-income counterparts.

### **Anticipated Causes of Perinatal loss and Progress Made in Addressing the Problem**

Most of the causes of perinatal loss are unknown but many of them are treatable and preventable (WHO, 2016). There are many common causes and determinants for stillbirths and neonatal deaths (perinatal loss). While a number of variables are predicted to cause perinatal loss worldwide, it is projected that about 80% of perinatal losses that occur globally are due to

preventable causes like intrapartum-related deaths such as asphyxia, preterm birth complications, and neonatal infections (sepsis, pneumonia) (Liu et al., 2012; Pinar & Carpenter, 2010; WHO, 2014). According to WHO, premature rupture of membranes during labour causes bacteria to enter the uterus from the vagina, which causes infection to the foetus (WHO, 2016). It is estimated that 26% of all neonatal deaths are due to infections that occur during labour and delivery. However, compared with mothers, babies are more predisposed to infection, which is also difficult to detect around this time (WHO, 2016). In addition, infections such as HIV and syphilis can break through the placental barrier and affect the fetus, causing the death of the infant soon after birth. Other related causes are birth defects (chromosomal disorders), prematurity, fetal malpresentation, and fetal growth restrictions (Aminu et. al., 2014; Frøen et al., 2011). Obstetric complications compounding these deaths are cervical disproportion, placenta praevia, and cord prolapse (Adere, Mulu, & Temesgen, 2020).

In addition to the mentioned causes, reports attribute the high perinatal loss rate in sub-Saharan Africa, including Ghana, to poor maternal health and fetal health, inadequate reserves and equipment in hospitals, lack of skilled professionals, poor management of antenatal and postnatal care, and limited or lack of birthing facilities (Lawn, Blencowe & Waiswa, 2016; WHO, 2016). Other challenges including bad roads and lack of emergency transportation often prevent mothers from getting the needed services, hence causing the lives of their infants.

A United Nations International Children's Emergency Fund (UNICEF) (2008) report discloses that while there is consistent documentation of perinatal loss in high income countries, there is less data reported from low income countries, partly because some deliveries are performed in homes by traditional birth attendants (Liu et al., 2016). Recording and documenting data on birth and death and their causes are significant in health care and government policies

and planning. Additionally, it has been noted that accurate records and classification of the causes of perinatal loss is a massive task in amassing information to reducing these types of deaths (Allanson et al., 2016). Compared to the high-income countries, the quality of services rendered by health professionals in Ghana is inadequate, and there is inefficient expert care for expectant mothers and their newborns during labour and delivery (Ghana Millennium Development Goals, 2015).

The progress made in reducing stillbirths and newborn deaths (perinatal loss) is closely associated with a country's economic income because it requires the availability of essential supplies and educated and skilled health professionals (Flenady et. al., 2014; WHO, 2014). Several high-income countries have been able to accomplish significant progress in reducing the rate of perinatal loss through comprehensive documentation and strict measures (Flenady et al., 2014). In countries such as the United Kingdom (UK), the United States (US), and Canada, the rate of perinatal loss has dramatically decreased from 45 per 1000 births occurring during the third trimester in 1940 to five per 1000 births in 2000 (Flenady et al., 2011; Farrant, Stanley, Hardelid & Shepherd, 2016). The decrease in loss is attributed mainly to improvements in the provision of obstetric care during pregnancy, highly trained and efficient health care workers, the expansion of better hospital facilities, improvements in maternity care, and skilled birth attendance in hospital settings (Munabi-Babigumira, et al., 2019; Flenady et al., 2011). According to Flenady and colleagues (2011), the trend of perinatal loss in these countries showed improvements depending on the gestational age of the pregnancy. However, for the past two and a half decades, the rate of reduction has decreased as per the trimester of pregnancy (Farrant et al., 2016). Greece, Turkey, Belarus, Oman, and Estonia have been able to reduce their death rate by 50% between 2000 and 2010 (Lawn, et al., 2012).

Presently, the global progress of reducing the rates of perinatal loss is slow and deficient to meet the United Nations proposed target for the global Every Newborn Action Plan (ENAP) and Sustainable Development Goals Three (SDG3). Specifically, the decreasing rate of stillbirths is slower than that of neonatal deaths, as stillbirths were not sufficiently addressed during the period of Millennium Development Goals (Blencowe et al., 2016). WHO is keenly working with global partners in the health ministries to advance and improve on the lives of newborn babies within the first month of life, expand quality of antenatal and postnatal care, and train health personnel (WHO, 2016). While the majority of perinatal losses occur in sub-Saharan Africa, they have achieved the least progress of success, with no significant change in reducing perinatal loss.

**United Nation's goals on perinatal loss.** World leaders at a United Nations (UN) summit agreed upon the Millennium Development Goals (MDGs) in 2000. The MDGs had eight targeted goals with deadlines for member countries to improve on the health of deprived groups of people in their countries by 2015 (United Nations, 2015). The expectations were for low-and middle-income countries like Ghana and other African countries to reduce the incidence of perinatal loss by two-thirds by 2015. Specifically, goal number four (MDG 4) included improving and reducing neonatal mortality. However, records show that stillbirth is largely excluded, received less investment, and was not tracked under the global goals of improving mortality and morbidity (Blencowe et al., 2016; Qureshi et al., 2015).

Findings again imply that progress towards achieving the goals was not consistent; almost all the high-and middle-income member countries achieved the goals, leaving the African continent (mostly the sub-Saharan region) struggling to accomplish their targets. The available statistics (WHO, 2016) indicate that sub-Saharan Africa countries including Ghana have not reached expectations in attaining the health outcomes established in the MDGs (Ghana

Millennium Development Goal, 2015). To further improve on the newborn survival rates, the UN reviewed the progress in 2010 and adopted the SDGs to follow on the MDGs in 2016 (de Bernis et al., 2016). The Sustainable Development Goals focus on supporting countries to lower neonatal deaths to 12 per 1,000 live births by 2030.

With the emergence of SDG in 2015, most of the sub-Saharan African countries were confronted with the unaccomplished MGD goals, especially stillbirths and newborn health. Ghana's plan is to merge some of the targets of the MDG 4 with the SDG 3 and address in that context (Ghana Millennium Development Goal, 2015). The new SDG 3 focuses on health and well-being at every stage of life. The SDG 3-3.2 aims to "reduce neonatal mortality to at least as low as 12 per 1,000 live births" (Sustainable Development Goal, 2015 p.14). Notwithstanding the efforts by world leaders and that of Ghanaian leaders, perinatal loss remains a prominent issue, causing psychological and emotional distress for families.

The UN additionally launched the Global Strategy for Women's and Children's Health and the global Every Woman Every Child movement in 2010; A Promise Renewed commitment to child survival in 2012; and the global Every Newborn Action Plan in 2014 to further enhance the chances of survival of the newborn (Hug et al., 2019). The UN, in response to countries' demand, developed the ENAP initiative during a consultation process (WHO, 2014; de Bernis et al., 2016). The ENAP's main goals are ending preventable newborn deaths and ending preventable stillbirths by 2035. Furthermore, ENAP's additional goals are to address the quality of care around the time of delivery and to generate information for decision making (Roos & Tall, 2019).

The ENAP is a global multi-partner campaign that demands solutions to end preventable deaths and keep newborns alive (WHO, 2014). Through this campaign, the UN urgently appeals

to health professionals, policymakers, and families to provide better solutions to improve newborn health and prevent stillbirths by 2030. The recommended target for this initiative is to have a national stillbirth rate of 12 or fewer stillbirths per 1,000 births in every country by 2035 to address inconsistencies (Blencowe et al., 2016). Three million children could be saved every year if these targets were effectively achieved (WHO, 2014).

### **Emotional Impact of Perinatal Loss**

Documented as a grief-inducing event, perinatal loss causes a natural grief response (Kersting & Wagner, 2012). The natural grief response can be triggered by the death of a loved one or an emotional breakup from someone or something cherished. Rando (1993) recognizes this type of loss as a symbolic loss, a loss that generates feelings that require processing. Luby (1977) and Lang et.al., (2015) disclose that when an adult die, the family loses their past but when a child dies, it is a loss of the future, a loss of wondering about what the child would have become. This makes the death of a child or perinatal loss particularly difficult for most mothers because mothers often imagine an entire lifetime for their children “from the moment of confirmation of the pregnancy” to becoming an adult (van Aerde, 2001, p. 470).

Understanding the emotional distress of perinatal loss has been a gradual process. Many people do not understand the extent of pain mothers experience during and after a perinatal loss. Until the early 1970s, health professionals, who were women’s first point of contact during this loss, were oblivious to this pain (Kersting & Wagner, 2012). Kennell, Slyter and Klaus (1970) conducted one of the first studies on perinatal attachment and identified the grieving patterns of mothers’ deep emotional pain after the loss of a child. A follow-up study by Peppers and Knapp (1980) investigated the effects of perinatal loss and revealed the profound emotions mothers experience when they lose their children. More research studies followed and explored all

dimensions of perinatal loss (Kersting & Wagner, 2012) including the mother's experience and the relationship between the mother and spouses and family members, as well as the causes and support systems available to them, to mention a few.

Several researchers from high-income countries have extensively investigated and identified perinatal loss as an experience accompanied by different emotional changes and adaptations (Cacciatore, Blood & Kurker, 2018; Marwah, Gaikwad & Mittal, 2019; Sereshti et al., 2016). The emotion and adaptation to perinatal loss begins with shock and numbness, a realization of a sense of loss, anger, guilt, and emptiness (Howarth, 2011). The emotions of perinatal loss have also been described as overwhelming, heartbreaking, and emotionally traumatizing and complemented by shock, intense confusion, restlessness, anxiety, and hopelessness (Cacciatore, Blood & Kurker, 2018; Human et.al. 2014; Marwah, Gaikwad & Mittal, 2019). It is an unsettling and stressful experience (Farren et al., 2016). These emotions can prolong grief and have adverse effects on the grieving woman and can lead to physical, psychological, and mental disorders (Kersting & Wagner, 2012). Women are at increased risk for significant depression and anxiety for a long time, depending on the type of loss they experience (Kersting & Wagner, 2012). Sell-Smith and Lax (2013) reveal that women experiencing perinatal loss look for ways to have a better understanding of their experience. There is evidence in the literature that 4.2 million women globally suffer depression following the loss of infants through perinatal loss (Roos & Tall, 2019).

Perinatal loss also has effects on relationships; it is seen as a factor in breaking up marriages (Gold, Sen, & Hayward, 2010). Women who experience stillbirth have an increased risk of divorce; those who have had a previous stillbirth are four times more likely to experience



divorce (Shreffler, Hill & Cacciatore, 2012). Continuous loss of children easily leads to spouses divorcing or getting another partner (Kuti, & Ilesanmi, 2011).

Furthermore, it has been noted that stigma and taboo following perinatal loss further complicate grief (Roos & Tall, 2019). Research on perinatal loss in Africa has shown that strong cultural practices and norms prevent women who experience perinatal loss from expressing their emotions and mourning their loss as in the death of an older person (Kuti, & Ilesanmi, 2011). It is believed that mourning a child who did not live long may prevent the next pregnancy (Attachie, 2013). These beliefs and cultural attachments have influenced the perception, reaction, and support given to women who experience perinatal loss in sub-Saharan African societies.

### **Support from Health Professionals**

Findings from the literature reveal that perinatal loss affects women for many years (Watson, Simmonds, La Fontaine, & Fockler, 2019). Support from friends, families, and professionals during emotional discomfort are memories people appreciate and remember even after an event is passed. Encouraging words such as ‘you are in my thoughts and prayers’ and ‘I am so sorry for your loss’, or even a hug without saying anything show genuine and caring presence. The primary goal and intention of supporting and counselling couples is to alleviate the intense emotional reactions to perinatal loss. Support, whether moral or emotional, plays a vital role in helping those experiencing perinatal loss to come to terms with losing a child. Health professionals at the global level have moved from disenfranchising women to supporting and helping them bond with their deceased babies (Kersting & Wagner, 2012). Although there is support in high-income countries, women are still not satisfied with the approach of care by the health professionals and therefore recommend that professionals take specific actions, including good quality photos and collecting mementos carefully (Sereshti et. al., 2016).

In sub-Saharan Africa, especially Ghana, there is lack of support from health workers to couples experiencing perinatal loss which could be due to many factors including a shortage of nurses and staff burnout (Aminu et al., 2014). Although the Ghana Health Service's set target was one nurse to 900 patients, the rate of nurse to patient worsened from 1,240 per nurse in 2011 to 1,251 in 2012 (Ghana Health Service, 2013). Heavy workload, lethargy, and lack of resources are seen as the causes of indifference and unsupportive attitudes of health professionals towards their patients (Ageyi-Baffour et al., 2013). More studies in this region continue to confirm inadequate care, lack of communication, and lack of interest in the well-being of mothers experiencing perinatal loss (Modiba & Nolte, 2007). Most women who experience perinatal loss feel they do not receive adequate support from health professionals and struggle to cope with their loss. These women desire understanding and acknowledgment from health professionals and find it difficult to approach them and express their psychological and physical emotions (Kersting & Wagner, 2012; Kuti, & Ilesanmi, 2011). It is important for nurses and midwives to recognize that a grieving woman needs a truthful and open conversation about why her baby died (Hasanpour, Sadeghi & Heidarzadeh, 2016). Equally important is to answer questions of why the death occurred and provide suggestions on how to move forward (Cacciatore, Blood & Kurker, 2018). Giving a factual and credible overview of the loss will build trust between women and health care providers. Midwives are often the first to come into contact with expecting parents, they are often involved during the whole experience, and their support extends beyond reducing stress to giving comfort. The unique role of health professionals is to support women and their families to work through the grief process. It would be helpful for nurses and health care providers to show complete understanding and communicate openly with women.

## **Social Support/Support Groups**

*I don't want you to hear my story and say, "my own suffering is less significant." I want you to hear my story and say, "if she can do it, then so can I."— Dr. Edith Eger*

Support groups are helpful in coping with the emotional pain associated with perinatal loss (Kinsey et al., 2015). There are social support groups in high-income countries to help women work through the emotional burden of losing a pregnancy and expected child. Most women find they cope better when they share their experiences with people who have had similar experiences. Women who have previously experienced perinatal loss are the most suitable to connect with because they understand their pain and concerns (Kinsey et al., 2015). Constant interactions with people who share the same experiences help to address the emotional feelings of depressed women and support them to achieve a sense of purpose (Cacciatore et al., 2018). Attending social support groups where they can be heard and share their experiences contributes to reduce stress and feelings of loneliness and assists individuals to adjust and cope better (Kint, 2015). The region in the world with the highest incidence of perinatal loss, sub-Saharan Africa and particularly Ghana, has limited evidence of community social support groups to help couples who have experienced a perinatal loss. There is dearth of literature and research on perinatal social support groups in Ghana even though there is strong familial support for women during perinatal loss.

## **Disenfranchised Loss a Contributing Factor to Inadequate Support for Patients**

Disenfranchisement is a phrase first created by Doka in 1989. According to Doka (1989), disenfranchised grief is when society disregards a loss or emotion as irrelevant and therefore does not publicly acknowledge the pain of the individuals affected. It is a loss in which the best time or place for individuals to mourn is decided by people of power and authority. However,

Barney and Yoshimura (2020) describes disenfranchised as a societal failure of empathy and an abuse of power that limits people's options of grieving. Society disregards this loss or emotion as irrelevant and therefore does not recognize the pain of the individuals affected. An example is the loss of a loved one through perinatal loss in Ghana. Before the 1980s, mothers who experienced perinatal loss in hospitals in western countries were also disenfranchised (Watson et al., 2019). Research has significantly reduced the harmful psychological practices of disenfranchisement in high-income countries such as the United Kingdom, Canada, and the United States, where women are no longer deprived of the right to see or bond with their deceased children (Obst, Due, Oxlad, & Middleton, 2020). Furthermore, research findings on perinatal loss in these developed countries have led to improvements in the practices of hospitals by providing modern facilities and trained health professionals to deliver services that support women who experience perinatal loss (Shakespeare et. al., 2019). Literature shows more improvements at the international level, where bereaved couples are given the opportunity to bond with their deceased children, take photographs, and make their own private preparations for burial (Leigh, 2016).

Disenfranchisement, however, still persists in sub-Saharan Africa. Culturally, the people of sub-Saharan Africa, such as in Ghana, have different ways of mourning the dead and perinatal loss is the least recognized (Oppong, Antwi & Waeness, 2009). The deaths of adults such as parents, spouses, and chiefs who led a productive life and were beneficial to society are culturally mourned for one year after death. However, the deaths of younger persons—young unmarried adults and teenagers—are mourned after the burial for only a few months (Oppong, Antwi & Waeness, 2009). In order of significance, losing a child through perinatal loss is the least mourned and recognized. Most African society including Ghana perceives the loss of a

child as insignificant because the child neither lived long nor served any purpose to society (Okechi, 2017). Therefore, physical and emotional grieving and performance of necessary funeral rites for perinatal loss are not encouraged or allowed. Family members, in their endeavour to protect the bereaved, restrict people from offering condolences and avoid discussing the issue at home, all to prevent more grieving (Hutti et. al., 2016).

Family members unknowingly cause disenfranchisement through these kinds of protections and reassurances, using indifferent statements like “God gives and He takes away”; “You’re young, you can have another”; “You have your other children”; “Well, it happens in life”; and “If you cry over it, you may not be able to have another one” (Nichols, 1989, p. 117). These words cause fear and suppress women’s’ feelings, which can lead to emotional complications. In the hospitals, decisions are left to male partners, who exclude the mothers from any decision regarding handling and burial as well as any other arrangements related to the deceased child (Kuti & Ilesanmi, 2011). Health professionals, including midwives, do not encourage the bereaved parents to bond, hold, or be with the deceased child and they thereby disenfranchise couples of the right to be with their deceased child and to collect mementos like photographs, hair, and nails (Kuti & Ilesanmi, 2011).

Perinatal loss disenfranchisement does not only affect women but also their spouses. In most countries in sub-Saharan Africa, husbands “had different expectations about how to react, how to behave and what [is] an appropriate length of time to grieve” (Lang et al., 2011 p.121). Furthermore, African culture prevents men from grieving openly, given their traditionally gendered roles as heads of families who must always appear stoic and strong in public. When grieving is not legitimately recognized, distressed fathers inadvertently feel ignored and deserted, and this can be emotionally, physically, and psychologically harmful (Lang et al., 2011).

Perinatal loss in Ghana reduces self-worth, especially for women who truly desire children. Compounding this reaction is the lack of recognition from Ghanaian society and disenfranchisement, which increase the women's reaction to this loss and contributes to isolation (Leon, 2008). Recognizing, accepting, and supporting their loss can help women adjust to their situation, promote a sense of belonging, and reduce feelings of social isolation. Governments and health professionals need, and look forward to, research findings to inform decisions and practice related to the support of women who have experienced perinatal loss. In this research, I intend to generate knowledge to address critical gaps and help improve the health of women; another intent is to improve the clinical practice of health care workers to understand and appreciate the experiences of women dealing with perinatal loss and thereby be able to offer appropriate support. I believe the findings will offer insights into a better understanding of women's emotional experiences, will allow Ghanaian women to openly grieve, and will change social practices about perinatal loss in Ghana.

### **Gaps in the Literature on Perinatal Loss**

From the background literature review, it is evident that sub-Saharan Africa is among the continents that report the highest incidence of perinatal loss. However, little research was found on the support provided to couples experiencing perinatal loss which precipitated a scoping review focusing on the experience of perinatal loss in sub-Saharan Africa and support available to couples who experience perinatal loss in the region. I proceeded with a focussed scoping review to explore the extent of literature on the experiences of perinatal loss in sub-Saharan Africa.

## **Chapter Three**

### **Perinatal Loss in sub-Saharan Africa: A Scoping Review**

This chapter is presented as a manuscript. I present the findings of the scoping review that specifically examined the extent of literature on grief experiences of perinatal loss and support available to couples in sub-Saharan Africa.

#### **Abstract**

Estimates from the World Health Organization reveal that perinatal loss is a threat in the sub-Saharan Africa region. The region has the highest levels of perinatal loss in the world. It is established that half of all stillbirths and neonatal deaths occur around the period of the onset of labour to the delivery of the baby (WHO, 2019). Approximately 75% of these deaths occur in sub-Saharan Africa. There are limited studies investigating the experiences and support of women who experience perinatal loss. The aim of this scoping review is to explore and summarise what is known in the literature about the experiences of perinatal loss among couples in sub-Saharan Africa and to identify the relevant and meaningful support given by health professionals and the community to improve the well-being of parents going through perinatal loss. The study followed the framework of Arksey and O'Malley's (2005) methodology of scoping reviews. Electronic databases were used to comprehensively search for peer-reviewed articles and grey literature between 2005 to 2019. Two independent reviewers screened and analysed the data of the selected articles through data charting procedure. Eight articles on experiences and support of perinatal loss met the inclusion criteria for this study. These articles were all qualitative studies; seven of them were peer-reviewed articles and one was a master's thesis paper. The findings of the studies reviewed were categorized under the following two themes: emotional experiences of perinatal loss among sub-Saharan African women and support systems available for the women. This review

highlights the limited research and lack of literature about the emotional experiences and support available to couples who experience perinatal loss in sub-Saharan Africa. The literature further reveals that couples would like more support during the event of loss to reduce psychological trauma. The findings of the study demonstrate the need for more research in this area to enhance understanding and improve services provided to the couples and their families.

**Keywords:** Community, experiences, family, perinatal loss and support, sub-Saharan Africa

This article has been accepted to be published in the African Journal of Nursing and Midwifery



## **Introduction**

The term “perinatal” refers to the period before and immediately after birth. The World Health Organization (2019) defines the perinatal period as commencing at 22 completed weeks of gestation and ending seven completed days after birth. Depending on the classification, it may include loss of the pregnancy or the fetus from the twentieth to the twenty-eighth week of gestation until birth and during the first to the fourth week after birth (Shiel, nd.). There are different classifications of perinatal loss, but it is commonly classified as stillbirth or intrauterine fetal death (IUFD) and neonatal or newborn death. Stillbirth or IUFD is described as a fetus born with no signs of life at or after 28 weeks’ gestation and neonatal death is the death of a child within the first twenty-eight days of life (UNICEF, 2018).

In the sub-Saharan African community, a significant amount of cultural importance is attached to fertility and childbirth. Much is expected from women of childbearing age or soon after marriage to have children, and failure leads to stigmatization. The biological birth of a child in an African clan is the greatest honour conferred by any woman on her family. Pregnancy and delivery are natural physiological processes but occasionally are accompanied by complications that expose expectant mothers and their developing infants to various health risks (Rosenberg & Trevathan, 2018). Most women naturally assume that the outcome of pregnancy produces positive results of a healthy child and therefore perinatal loss is not thought about. However, the World Health Organization reports that perinatal loss (death) is very common and a threat in the sub-Saharan Africa region (WHO, 2016)

## **Background**

Evidence from the World Health Organization (WHO) has established that half of all stillbirths and neonatal deaths are preventable deaths occurring around the period of the onset of

labour to the delivery of the baby (WHO, 2019). The report further states that worldwide 133 million children are born alive every year; out of this, 2.8 million die during the first week of life. Improving perinatal mortality has been the agenda for global communities and governments of countries. To achieve the target, *WHO's Every Newborn Action Plan* and *UNICEF's A Promise Renewed* are part of the initiatives set up to specifically reduce under-five and neonatal mortality (Hug, Alexander, You & Alkema, 2019). These are replicated targets in the United Nations Sustainable Development Goals (SDGs) advocating for reducing both preventable deaths in children under five years and of neonatal deaths by 2030 (Hug et al., 2019; De Bernis et al., 2016). The main target of neonatal deaths in the SDGs is for all countries to set a target and reduce neonatal deaths to lower than or equal to 12 per 1000 live births by the year 2035 (Tekelab, Chojenta, Smith, & Loxton 2019).

Current statistics show a decline in perinatal deaths on the global level especially in high-income countries due to the provision of quality health care facilities and obstetric care. Between 1990 to 2017 respectively, neonatal death rates have decreased in high-income countries by 51%, from 36.6 to 18.0 deaths per 1000 live births and the number of neonatal mortalities also dropped from 5.0 million deaths to 2.5 million (Hug et al., 2019). Additionally, between the same years, stillbirths revealed an average rate of 18.4 stillbirths per 1000 live births, and nearly 2.6 million deaths (Reinebrant et al., 2017; UNICEF, 2017).

In high-income countries such as Japan, Norway, South Korea, and others consistent records, provision of quality and accessible health care facilities, and professional obstetric care have contributed to improvements in perinatal mortality and stillbirth rates (Flenady et al., 2016). However, data show very little improvement in sub-Saharan Africa. The neonatal mortality rate in sub-Saharan African and South Asia compared to the average world record is high. It ranged

between 30.2 to 26.9 deaths per 1000 confirming WHO's 2019 report stating that progress to reduce the rates of perinatal loss is slow in low- and middle-income countries (Hug et al., 2019). This is due to poor facilities, inadequate staff training, and poor management (Lawn et al., 2014). In 2015, 94 countries, mainly high- and middle-income, already met the target to decrease neonatal mortalities (Millennium development goal); at least 56 countries including many in Africa, need to improve their current practices to reach that goal (de Bernis et al., 2016).

Further evidence has established that sub-Saharan Africa has the highest perinatal death rates on the African continent (WHO, 2016). Reasons include inadequate equipment, fewer hospital facilities, and poor documentation practices (WHO, 2016). Additionally, UNICEF's report asserts that more perinatal deaths are unaccounted for given the low documentation of data relating to perinatal loss in sub-Saharan African countries (UNICEF, 2008). In these countries, due to limited access to health care facilities, traditional birth attendants perform many deliveries at home (Engmann et al., 2012). This contributes to inaccurate or no documentation and reporting of statistics on live births and losses (Liu et al., 2016).

The grief of perinatal loss often follows stages of denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969). These stages do not always occur in chronological order. They may begin with denial when the bereaved couple perceives what has happened as a mistake and continues to think it could change. When denial stops, a physiological response of anger sets in and couples are frustrated and ask questions like, "Why me?" and, "Why not any other person but me?" Bargaining commences with hope—a hope to be given another chance to replace what has been lost. Once couples' prospects of getting what they want fails, depression and acceptance set in (Kubler-Ross, 1969). The experience of perinatal loss presents a substantial life crisis for most couples and can bring about suspicion, uncertainty, lack of self-confidence, and prolonged grieving

(Lang, Fleischer, Duhamel, Sword, Gilbert, & Corsini-Munt, 2011). Moreover, a number of researchers have documented that couples who have experienced perinatal loss often live with depression and abandon the hope of becoming a parent and this further intensifies emotional trauma (Leon, 2008; Fenstermacher, 2014).

The burden of perinatal loss does not only affect couples: the stress also extends to family members and society as a whole. Yet, perinatal loss remains concealed in many cultures in sub-Saharan Africa and is not openly talked about. Many research studies have been written on causes of perinatal mortality in sub-Saharan Africa, however, very little has been written in relation to the experiences of women, cultural beliefs, the accompanying emotional trauma, and the support system available for women (Kuti & Ilesanmi, 2011, Modiba & Nolte, 2007; Obi, Onah & Okafor, 2009). The research questions for this scoping review are: 1. What is currently known about the experiences of perinatal loss in sub-Saharan Africa? 2. What sociocultural factors influence the experience of perinatal loss and support? The objective of this scoping review is to explore and summarise what is known in the literature about the experiences of perinatal loss among couples in sub-Saharan Africa and to identify the relevant and meaningful support given by health professionals and the community to improve the well-being of parents going through perinatal loss.

### **Method**

A scoping review aims to summarize and identify the gaps in the existing literature as well as to disseminate research findings (Arksey & O'Malley, 2005). This review follows Arksey and O'Malley's (2005) framework, which includes the following five steps: 1. identifying the research question; 2. identifying relevant literature; 3. selecting research articles; 4. charting the data; 5. collating, summarising, and reporting results; and 6. consultation of stakeholders.

### **Identifying the research question**

In line with Arksey and O'Malley's (2005) framework, the following questions guided the conduct of the review: (1) What is currently known about the experiences of perinatal loss in sub-Saharan Africa? (2) What sociocultural factors influence the experience of perinatal loss and support?

### **Identifying relevant literature**

To identify relevant articles, a research librarian assisted with conducting a comprehensive search in the following databases: MEDLINE (Ovid), CINAHL, PubMed, EMBASE, Scopus, Alt Healthwatch, Family Studies Abstracts, Sociology Index with full text, and Violence and Abuse Abstracts. The results of the database search were complemented with a grey literature search in Google and Google Scholar, allowing for the retrieval of non-peer papers, including grey reports and dissertations. The database and grey literature search utilized the following keywords and Boolean operators: parent\*, mother\*, father\*, grief\*, experience\*, fetal death\*, pregnancy loss, infant death, bereavement, infant mortality, and neonatal death\*. The reference lists of the selected records were hand-searched for additional relevant papers (Lisy, Peters, Riitano, Jordan, & Aromataris, 2016).

The search yielded a total of 1471 records (1449 from the database search and 22 from the grey literature search). The search results were exported into RefWorks, where duplicated records were identified and eliminated.

### **Selecting Articles**

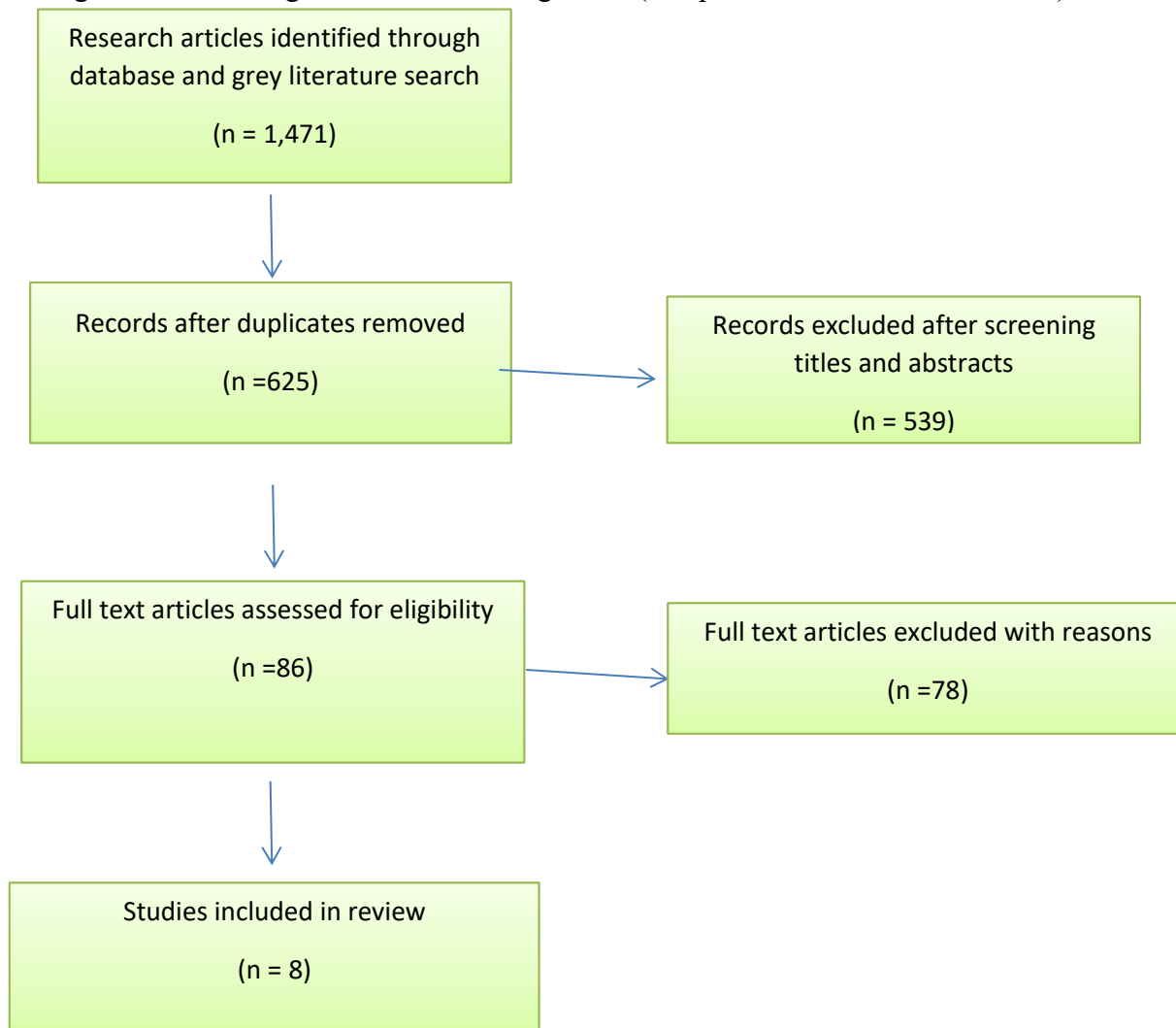
Given the large number of records identified in step two, an eligibility/inclusion criterion was applied to select articles that were relevant to the research topic under review. Peer-reviewed

articles and grey reports (e.g. dissertations and conference abstracts) were considered for inclusion if they met the following selection criteria:

- (i) Investigated the experiences of women and couples who have gone through perinatal loss from 22 weeks of gestation to 28 days after delivery;
- (ii) Described coping strategies and support systems available to women and couples during perinatal loss (e.g. stillbirth, newborn death, and early infant loss);
- (iii) Were written in English and published between 2005 and 2019, coinciding with a period where very little research had been published on emotional experiences and support on perinatal loss in sub-Saharan Africa.

In this regard, papers published in languages other than English and on topics unrelated to perinatal loss in sub-Saharan Africa were excluded. To ensure consistency and quality in the selection of articles, two independent reviewers were involved (Levac, Colquhoun, & O'Brien, 2010). They met at the beginning, midpoint, and final stages of the review to discuss selection decisions and challenges of the screening process (Levac et al, 2010). The reviewers independently screened titles and abstracts and then subsequently screened full texts of the identified records. First, 625 records were screened by title and abstract, resulting in the exclusion of 539 records. Full text screening of the remaining records (n = 86) resulted in the exclusion of 78 records. Thus, a total of eight articles were included in the review. In situations of differences in opinion between the two reviewers, discussion was the key to reaching a consensus.

Figure 1: Flow Diagram for Data Management (Adapted from Moher et al., 2009)



### Charting the data

Data extraction helps to summarize studies in a common format and to facilitate coherent synthesis of research findings (Munn, Tufanaru, & Aromataris, 2014). Data from each selected article was extracted into a data charting template. This template captured information about the authors, year of publication, study purpose/objective, study design, countries where study was conducted, sample size, and findings. The extraction form was created based on the information needed to address the research questions. One reviewer independently extracted the findings of the

included articles. To ensure quality in the data extraction, the second reviewer reviewed and provided feedback.

### **Collating, summarizing, and reporting of results**

As Arskey and O'Malley (2005) recommended, thematic analysis was performed to identify the experiences and support systems associated with perinatal loss in sub-Saharan Africa. This analytic process involved comparing findings and identifying patterns of meaning across all the included studies. The study findings were articulated using the identified themes and linked with the objective of the study (Levac et al., 2010). They were discussed and finalized with experts in the field of maternal and child health. These themes are presented in the results section as follows.

## **Results**

### **Study Characteristics**

The literature search yielded a total of 1471 records of abstracts, full text studies, and grey literature. About 846 of the articles were found irrelevant to the study and were eliminated. The remaining 625 were assessed and screened for eligibility and duplication, and 539 were further excluded. Subsequently, 86 fulfilled the eligibility criteria as included in Figure 1. Only eight met the full inclusion criteria and were fully read and quality assessed. The eight included studies were conducted in four different sub-Saharan Africa countries (Ghana, Nigeria, South Africa, and Malawi) and were published between a period of 12 years, from 2007 to 2019. While all the articles were written in English, they varied in purpose and used different qualitative methodologies. The geographical distribution of the studies by individual countries on the experiences and support of perinatal loss was Ghana (1), Malawi, (1), Nigeria (2), and South Africa (4). All studies were peer-reviewed except one, a master's thesis publication in Ghana.



Data extracted for the narrative description included the author, year, country, purpose, design, and findings. Two themes were identified from the review of the eight articles (See Table 2). The themes centered on emotional experiences during perinatal loss and support systems for couples in sub-Saharan Africa.

**Table 2:** Summary of the studies on the experience of perinatal loss

Author	Year	Country	Purpose	Design	Findings
Attachie, I. T.	2013	Ghana	The study investigated the experiences of mothers who have experienced stillbirth, and the support available to them in Ghana.	Qualitative exploratory design	Experiences of perinatal loss  Support system
Human, M., Groenewald, C., Odendaal, H. J., Green, S., Goldstein, R. D., & Kinney, H. C.	2014	South Africa	The study had two objectives: first, to understand the psychological effects of stillbirth on mothers and their family members and second, to establish if the crisis intervention is effective to work with bereaved mothers.	Exploratory, descriptive design	Experiences of perinatal loss  Relevant and meaningful support
Kuti, O., & Ilesanmi, C. E	2011	Nigeria	To determine the type of care Nigerian women find appropriate after experiencing stillbirth.	Interviewer-administered questionnaires	Relevant and meaningful support
Modiba, L.M.	2008a	South Africa	An investigation into the type of support program necessary to assist health professionals to give care and support to mothers with pregnancy loss.	Exploratory descriptive design	Relevant and meaningful support
Modiba, L.M.	2008b	South Africa	The aim was to explore and describe midwives' and doctors' experiences when caring for mothers who have experienced pregnancy loss.	Analytical, descriptive	Experiences of perinatal loss
Modiba, L., & Nolte, A., G. W	2007	South Africa	The objective was to investigate and describe the experiences of mothers who have lost their children during pregnancy in a hospital in South Africa.	Exploratory descriptive design	Experiences of perinatal loss
Obi, S.N., Onah, H.E., & Okafor, I.I.	2009	Nigeria	This article seeks to demonstrate the level of depression Nigerian women experience after pregnancy loss and the kind of coping strategies they use.	Questionnaire survey method	Experiences of perinatal loss and support
Simwaka A.N., de Kok, B., & Chilemba, W	2014	Malawi	An exploration of women's perceptions of nursing care received following stillbirth and neonatal death in Malawi	Semi-structured interview	Relevant and meaningful support

## **Findings**

Of the eight included studies, three specifically investigated women's experiences of perinatal loss (Modiba, & Nolte, 2007; Modiba, 2008b; Obi, Onah, & Okafor, 2009). While two of the studies reported on both experiences and the type of support relevant to the women (Attachie, 2013; Human, Groenewald, Odendaal, Green, Goldstein, & Kinney, 2014), studies by Kuti and Ilesanmi (2011), Mobila (2008a) and Simwaka, de Kok, and Chilemba (2014) focused on support rendered by health professionals and family members. None of the studies used scoping review as a method. Below is a presentation of the themes from the scoping review. The findings are presented under the following themes: experiences of perinatal loss and relevant and meaningful support.

### **Experiences of perinatal loss**

All eight of the articles suggested that perinatal loss is accompanied by grief. The subthemes were categorized as grief reactions to loss and cultural influence on loss.

#### **Grief reactions to loss**

Among the included studies, the Obi et al., 2009 study critically spoke about grief and depression associated with child loss. The authors point out that there are deep emotions associated with perinatal loss and wonder why these emotional experiences have not been sufficiently documented. Using a questionnaire survey method, Obi, Onah, and Okafor, 2009 seek to find answers by exploring the level of depression in Nigerian women after the loss of a fetus and the types of coping strategies used. The article reports that almost all the 202 women who participated in the study experienced depression ranging from mild to severe after the pregnancy loss. Basing their argument on documented literature, the authors contended that factors like marriage, loss of a male fetus, no living child, previous pregnancy loss, and gestational age of the fetus impact on the emotional state of women who have experienced perinatal loss. Other studies also reported that

parents who experience perinatal loss in sub-Saharan Africa have diverse emotional changes due to the expectations from society on childbearing and described the emotions as profound, heartbreaking, overwhelming, shocking, an experience of intense confusion, and depressing (Attachie, 2013; Human et al., 2014; Modiba, & Nolte, 2007; Simwaka et al., 2014). However, the studies did not discuss interventions for relief of the grief.

The majority of the studies that reported on the grief response of the experience of perinatal loss found that most women suppress feelings of grief which aggravates pain and often leads to various psychological symptoms. Comparing the women to those from higher-income countries where grief of pregnancy loss has been recognized as an important aspect of loss, Obi, Onah, and Okafor (2009); Simwaka et al., (2014), and Attachie (2013) note that the cultural norms and beliefs in some African countries discourage women from discussing their emotional experiences. The authors listed some helpful coping strategies such as support and presence of family members and friends and engaging in religious activities. The authors also identified communication as an important tool to prevent emotional trauma and psychological complications. Participants identified loneliness and lack of social activities as the factors contributing to worsening their symptoms.

### **Cultural influence on reaction of perinatal loss**

Commonly reported findings on experiences of perinatal loss were cultural norms and beliefs and their influence on reactions to perinatal loss in the sub-Saharan African context (Kuti & Ilesanmi 2009; Attachie, 2013; Obi et al, 2009). The findings significantly showed that culture plays an important role in the way women express grief when a baby is lost through perinatal loss (Kuti & Ilesanmi 2009; Attachie, 2013).

A cultural influence is the importance of childbearing in Africa, which intensifies grieving

when a mother loses a child (Simwaka et al., 2014). Some societies have the habitual tendency of condemning women when couples fail to have a child, which contributes to intensified grief and psychological trauma during perinatal loss (Obi et al., 2009). African women are not only afraid of what society might do, but they also feel at risk of losing their marriages (Obi et al., 2009). The authors noted that among traditions in Nigeria and Ghana, women are encouraged to put their grief on hold (or hold their grief) and consider the child as ‘water’ that has passed and which certainly could be replaced while they (women) are still alive (Attachie, 2013; Obi et al., 2009; Kuti & Ilesanmi 2009). Further explanation alleges that African tradition discourages women from mourning in order to not affect their chances of getting pregnant (Kuti & Ilesanmi, 2009). Instead of words of encouragement, some couples’ grief is constantly subdued by certain comments and beliefs from family members, friends, and religious groups (Obi et al., 2009). Religion is a key component of African society and bereaved couples are often reassured with spiritual statements such as “God has his reasons for permitting certain things to happen”, “God has the authority to give and take any time he deems fit”, and “You are young so you will get pregnant again” (Modiba & Nolte, 2007).

### **Relevant and meaningful support**

Many of the included studies discovered that support from close relations like husbands, children, and the extended family plays an important role in the recovery of loss (Attachie, 2013; Human et al., 2014; Kuti & Ilesanmi, 2011). Six studies considered support as the basis of well-being, relaxation, and strength for bereaved couples (Kuti & Illimani 2011; Attachie, 2013; Modiba, 2008a; Simwaka et al, 2014; Human et al 2014; Obi et al, 2009). Support was perceived as that which functions to lessen a couple’s grief during the desperate time of bereavement (Modiba, 2008 a). Support, compassion, and information from health professionals were identified

as the care needed to help participants who were emotionally unstable (Modiba, 2008a). Supporting their argument with literature, Modiba and Nolte (2007) maintained that the inability of health professionals to provide information and support to women experiencing perinatal loss escalates emotion and potentially could lead to psychiatric illness.

While in the African context, community support is often delivered by the family, community, and religious bodies, family support is the most important (Obi et al., 2009). More evidence from two studies report that the support grieving couples receive from family members, including parents, children, and grandparents, plays a vital role in alleviating pain and facilitating the healing of perinatal loss. Regular visits from extended family and religious groups have proven to be useful and have an impact on how couples cope and accept the reality of perinatal death (Obi et al., 2009). Participants in a study (Attachie, 2013) acknowledged that support in the form of advice and the company of siblings, friends, and members of the community contributed significantly to reduce stress and promote faster recovery.

A recurring challenge is the lack of support from health professionals, which is portrayed as the most desired by couples who experienced perinatal loss (Obi et al., 2009). Accordingly, studies in this review established that women of Africa expected health professionals to acknowledge their loss, be with them, give them a listening ear, and be emotionally supportive (Modiba & Nolte, 2007; Kuti & Ilesanmi, 2009). Women recruited in a study in Malawi expressed disappointment with the services provided by the health professionals and described the nurses as unsupportive professionals who offered no emotional support (Simwaka et al., 2014).

A Nigerian study revealed that only 53.3% of the participants had the advantage of seeing the body of the child (Kuti & Ilesanmi, 2009). None of the couples reported being provided the opportunity to hold or take photographs of their babies. Additionally, grieving couples are often

not allowed sufficient time to decide what to do with the remains of the fetus. The decision is often made on their behalf by professional health workers or heads of their families (Kuti & Ilesanmi, 2009).

### **Consultation of stakeholders**

In this study, stakeholders are health care professionals (doctors, nurses, midwives, paramedics, and students) and traditional birth attendants in sub-Saharan Africa who work with women who experience perinatal loss, policy makers, and members of the public. None of the stakeholders have been involved in the conduct of this scoping review. The researcher believes the study findings, which will be included in multiple dissemination activities, will be relevant to the stakeholders.

### **Dissemination**

A dissemination matrix for implementation of results of research involves getting clear and relevant information to the right people, through suitable and multiple channels, and taking into account the setting in which the message is received (CRD, 2009). Raising awareness about the experiences of perinatal loss and the type of care and support systems available in sub-Saharan Africa either by health professionals and/or significant others is critical.

The findings of this review will be implemented using different communication/multimedia channels and a variety of knowledge translation strategies to suit the different audiences. Distribution of knowledge is a key step in making findings from research and other knowledge endeavors accessible to stakeholders. The objective of disseminating these findings is to give the best evidence-based results to inform stakeholders who make daily decisions for families experiencing perinatal loss in Africa.

**Table 2. Dissemination plan for stakeholders**

Stakeholders	Dissemination Objectives	Dissemination Channels
Health Ministry/Administrators	To provide training for midwives and nurses to provide better care	Presentation Research Paper
Health professionals	To provide support for caregivers	Presentation In-service training Research paper
General Public	For better understanding and acceptance of perinatal loss	Flyers, education on public communication systems like radio and television

### **Discussion**

The paper explored and summarised what is known in the literature regarding the experiences of perinatal loss among couples in sub-Saharan Africa and offered a step to new understanding. Findings revealed different experiences of couples and the support systems available to them. For instance, the findings demonstrated that religion and culture strongly influence and impact the grief response of affected parents in this part of the world; people use their spiritual beliefs as a source of hope to overcome emotions. The review further established that many people who encounter perinatal loss encounter numerous challenges; and these challenges are related to disenfranchisement, isolation, and the reactions of family members and society.

Several factors emerged to offer explanations for how parents experience perinatal loss. Many of the included studies' findings revealed that perinatal loss triggers deep emotional changes such as anxiety, hopelessness, despair, and numbness for the couple involved (Kuti & Ilesanmi, 2009; Modiba & Nolte, 2007; Simwaka et al., 2014). These emotional reactions resonate with



other research findings on perinatal loss conducted outside sub-Saharan Africa. For example, Gold, Boggs, Muzik, and Sen (2014) found that there are adverse effects of psychological trauma and mental disorder on the well-being and health of grieving parents. Other researchers believe that women emotionally respond to perinatal loss because they are searching for meaning in their experiences (McCreight, 2008). However, the emotional state of most parents in the study was based on fear of not delivering a healthy baby, of losing their marriage, and on cultural pressures to have a biological child.

Losing a loved one calls for emotional and physical support. More than half of the included studies reported on the lack of support for bereaved parents and their families. However, good support systems have been found to reduce emotional trauma. Findings from the scoping review indicated that most of the grieving women wanted and yearned for the support of health professionals. The findings of studies by Arnold and Buschman (2008) and Lee (2012) revealed that parents grieve for their loss and appeal to society and health professionals to be compassionate and acknowledge that loss. However, health professionals (doctors, midwives, and nurses) have been found to lack training in perinatal support to assist bereaved couples (Modiba, 2008 a). The inability to offer the needed care to these women and the lack of proper policy on management of perinatal loss deepen the traumatic experience and contribute to an increased risk of postpartum depression or puerperal psychosis (Frøen et al., 2011). Incidence of perinatal losses are higher in sub-Saharan Africa; to help curb this menace, it is important for health care providers to be efficiently trained to have better knowledge in the management and support of these people.

Research records from other countries indicate that most women find it resourceful and cope better when they share experiences with people in the same emotional state (Fenstermacher, 2014; Kersting & Wagner, 2012). There are advanced and recognized social organizations and

associations in developed countries helping couples to work through the emotional burden of losing a pregnancy and the expected child (Killeen, 2015). These support groups comprised of women who have experienced perinatal loss and are therefore able to assist bereaved couples to find meaning in their own experience through the sharing of stories. The groups also offer confidence and enable people to withstand the pain. This resonates with existing literature which asserts that constant interactions with people who share the same experience can be beneficial to the women and help them achieve a sense of well-being (Kersting & Wagner, 2012). Attending social clubs where couples can openly voice and share their grief contributes to reducing stress and feelings of loneliness, and also assists individuals to adjust and cope well (Flenady et al., 2014). Reports from this study indicate that there are limited or no such groups in the sub-Saharan African countries; however, none reported on parents' preparedness to join a social club.

Sub-Saharan Africa has limited evidence of social support groups where families can receive support and share their emotions (Simwaka et al., 2014). Since sub-Saharan Africa is the region with the highest incidence of perinatal loss, the establishment of systems to provide support and care to parents experiencing perinatal loss is crucial in preventing psychological and mental complications (Kersting & Wagner, 2012).

### **Implications for clinical practice, research, and policy**

This scoping review contributes to the existing literature regarding couples' emotional experiences and support on perinatal loss in sub-Saharan Africa. As well, it provides evidence that there is a strong connection between grief recovery and the support received from health care professionals. The implications for health professionals, especially nurses and midwives, are that they should be aware of the need for support of couples experiencing perinatal loss and should understand the grief experiences during this vulnerable time. Helping couples to address the

challenges and suggesting coping strategies can help them to deal with this overwhelming and sad time.

Nurses should encourage couples to bond with their deceased child. Continued education of health professionals is needed in relation to bereavement counselling. Given the limited literature available, especially for sub-Saharan Africa, further research will need to be undertaken to determine the kind of support needed by couples experiencing perinatal loss and related interventions for better care. There is a need to develop clinical guidelines for health care providers on caring for patients during bereavement.

Additionally, findings from this review could contribute to and inform the design of protocols and formulation of culturally sensitive care and policy change on perinatal loss within hospitals. Besides that, this paper also has the potential to influence other advocacy and support groups, such as women and gender ministries, to embark on education programs to inform the public on the experiences of perinatal loss. Policy makers in government can formulate policies that provide funding and encourage the formation of counselling and social groups at the community level.

### **Limitation**

A major limitation in this study was that only peer-reviewed articles written in the English language were included, thus potentially excluding significant studies published in other languages and in grey literature.

### **Conclusion**

This scoping review explored couples' experiences and support of perinatal loss in sub-Saharan Africa. Findings from the literature highlighted the profound emotional impact and lack of support (especially professional and societal support) parents experience during perinatal loss.

Many parents reported lacking professional and societal support. The high rate of perinatal losses in the sub-Saharan region is a concern to governments and global communities and while measures are being put in place to reduce the rate of losses, there should also be some interest in the health and mental state of those individuals who experience this loss to prevent and reduce mental illnesses and psychological trauma.

Finally, the paper improves knowledge on the understanding of the experiences of perinatal loss in sub-Saharan Africa. Knowledge from the studies regarding the nature of emotions women experience after loss could be a foundation for developing a new approach to perinatal bereavement practices and providing better individual patient-centred care.

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## **Chapter Four**

In this chapter I discuss focused ethnography as the methodology of choice for the dissertation. I begin this chapter with a brief account of focused ethnography, its key features and justification for selecting focused ethnography as a methodology. I continue discussing the ontological and epistemological assumptions and my positionality as a researcher. In addition, I provide a comprehensive description of the recruitment and sampling process. Furthermore, data collection procedures and data analysis are outlined, and process of rigor are also discussed.

### **Methodology**

#### **Research Design**

Focused ethnography was the design of this study. Focused ethnography is appropriate because it allows inquiry within a particular context or among a subgroup of people to inform decision making regarding a distinct problem (Mayan, 2009). As a type of ethnography design, focused ethnography studies culture and the shared beliefs and practices of a group of people (Aldiabat & Le Navenec, 2011). Focused ethnography is considered an applied research methodology that is fast gaining popularity and is used in many disciplines such as nursing and sociology to study the cultural perspectives of a subgroup of people (Cruz & Higginbottom, 2013; Knoblauch 2005). This type of ethnography is used to examine a particular phenomenon in a specific group of people in their natural environment (Cruz & Higginbottom, 2013). Focused ethnography is a methodology that is context-specific, problem-focused, and focuses on a particular group of individuals or participants that share some features (Cruz & Higginbottom, 2013; Sawford, Vollman & Stephen, 2012).

Focused ethnography is similar to other types of ethnographies. For instance, there is the use of different methods of data collection and an in-depth description of the culture of interest. The difference between ethnography and focused ethnography is that in ethnography researchers encounter strangeness because they are unfamiliar and lack understanding of the basics of the general culture being investigated (Knoblauch, 2005). Alternatively, in focused ethnography the researcher often enters the field with knowledge or has reviewed the literature to gain in-depth knowledge to help understand the diverse views of the group they intend to investigate (Knoblauch, 2005).

Focused ethnography is also characterized by the investigator paying short visits to the field rather than engaging in longer durations of field stay. The research questions of focused ethnography are narrower in scope and, ultimately, the researcher's goal is to describe and interpret the phenomenon under study (Sawford, Vollman & Stephen, 2012; Knoblauch, 2005). A criticism against focused ethnography is the short duration for data collection and less observation in the field (Sawford, Vollman & Stephen, 2012). However, Knoblauch (2005) argued that the in-depth data collection in focused ethnography could produce a huge data set within a short period by using various methods such as audio-visual recordings and photo-cameras to supplement human observation.

Focused ethnographers may have an interest in acquiring cultural knowledge, although cultural knowledge cannot be directly observed. Rather, it is learned using implicit and explicit methods over a period of time (Reeves, Peller, Goldman, & Kitto, 2013). Focused ethnography also aims to study a particular aspect of knowledge, belief systems, and practices of a group of people. Likewise, the ontological and epistemological stances and the essence of data collection are also explained

## **Justification for Selecting Focused Ethnography**

My experiences as a professional midwife and a woman who has suffered perinatal loss have shaped my outlook on life and the nursing profession as well as offered me an in-depth knowledge that will shape the data generation (Knoublach, 2005; Wall, 2015). My strong interest in the experiences of perinatal loss, the quest to understand my own experience of loss which position me as an insider, and my desire to listen to the stories of other women who have experienced the same struggles led me to select focused ethnography as the methodological design. Although I have an insider knowledge on the topic, my experience may differ from other women which position me in the outsider role to discover new knowledge on the topic and justify the use of focused ethnography for this study (Knoublach, 2005; Wall, 2015). Most families who lose their children through perinatal loss experience an exceptional sense of grief.

In Ghana, this significant loss is frequently disregarded and treated as though nothing has happened (Van-Otoo & Adusei-Poku, 2010). Coming from the same culture as these women, where it is the expectation for a married couple to bring forth children and where failure to do so promotes stigmatization (Obiyo, 2016), I feel a deep sense of responsibility to understand the meaning of the experiences of these women and give voice to them through my dissemination of the research findings. Hence, focused ethnography was appropriate to use in this study.

Focused ethnography is a qualitative research method that allows inquiry within a particular context or among a subgroup of people to gain an in-depth understanding and inform decision making regarding a distinct problem (Cruz & Higginbottom, 2013). My research questions were focused and narrow, and therefore suitable for a focused ethnographic design. Being a Ghanaian and speaking the most common dialect (Akan), I was considered relatable and

gained insight into participants' perspectives on perinatal loss. This promoted my exploration of the topic.

### **Ontological and Epistemological Assumptions of Ethnography**

Since Focused ethnography is a type of ethnography, it shares some similar ontological and epistemological assumptions with ethnographic research. Researchers, especially ethnographers, need to understand the ontological and epistemological assumptions guiding a design in order to accurately describe the nature of knowledge (ontology) and how knowledge can be known (epistemology) in that design (Bradshaw, Atkinson, & Doody, 2017). Ontology involves asking a question about the nature of a phenomenon, for example, what is the nature of reality (Bradshaw, Atkinson, & Doody, 2017). The ontological assumption in ethnography is that multiple realities of cultural knowledge exist, which are socially constructed and can be known through symbolic interactionism (SI) (Aldiabat & Le Navenec, 2011). In ethnography, reality is socially constructed and one way of understanding the culture of a group is through Symbolic Interactionism (Reeves et al., 2013).

Symbolic Interactionism (SI) is the exploration of symbols, practices, and customs of a group of people in order to gain an insider's view of the culture and describe their subjective world (Aldiabat & Le Navenec 2011). Through SI, an ethnographer acquires knowledge or tries to understand a concept by making inferences from the group's actions, artifacts, and verbal communications (Reeves et al., 2013). In this way, ethnographic researchers strive to develop knowledge and understand the social relationships among the cultural group being studied and their sequences of interaction (Wall, 2015). In other words, it is important for ethnographers to have an idea of the culture and value its true meaning and interpretation and, in addition, to know

about the social and psychological relationships shared among the people in their natural setting (Cruz & Higginbottom, 2013).

Epistemology seeks to understand how truth can be arrived at through research by studying the relationship between the knower (the participant), what can be known (the phenomenon of interest to the researcher), and the would-be knower (the researcher) (Bradshaw et al., 2017). Ethnographers always endeavour to understand the meanings people give to their beliefs, events, and artifacts using both emic (insider) and etic (outsider) approaches (Agar, 1996). To access this knowledge, the researcher spends longer periods in the participants' natural environment and uses different methods to access that knowledge (Speziale & Carpenter, 2007).

### **Positionality**

Since cultural knowledge is implicit, ethnographers agree that both emic and etic approaches can be used in order to acquire cultural knowledge (Fetterman, 1998; Naaeke et al., 2011). This qualitative research sought to offer meaning to Ghanaian women's voices on perinatal loss. It is essential to remember that the procedure and understanding of an investigation can be influenced by the researcher's emic (insider) and etic (outsider) positionality. As a researcher, I have come to acknowledge the significance of a researcher's positionality in a research study. Merriam et al., (2010) defined positionality as the status of researchers in relation to the participants. The personality of the researcher is culturally defined and associated with education, religion, socioeconomic status, and language spoken (Naaeke et al., 2011).

In this research, I considered myself both an insider (emic) and an outsider (etic) in terms of my culture and class. I was born and raised in Ghana and am of Ashanti heritage. I share

similar ethnic and linguistic characteristics and possess an in-depth knowledge of a section of the Ghanaian society. This offers me an understanding that is difficult for an outsider to appreciate. I also became an insider as a mother who had experienced a perinatal loss. My emic positionality helped me to recognize and identify the perspectives from which the cultural narratives of Ghana arise and the tacit messages in these cultures.

These differences between the researcher, the participants, and others involved in the research can create power imbalances and present a challenge to gaining access to the community and participants. Depending on my experience and background, the participants in the study can consider me as either an insider or an outsider. As I embarked on negotiations with health professionals to recruit participants, I became aware of what defined me as an outsider. My background as a researcher, doctoral student (academic) studying abroad, and midwife who has not practiced on the unit for a long time made me an outsider to my colleague midwives and the participants. My 'etic' identity as a researcher also led the participants to treat me differently than they treated the attending midwives; they considered them more of a friend than me. As I moved along with the investigation, I had both opportunities and challenges of being both an insider and an outsider which are discussed later in the chapter.

### **Study Context**

The study site was a tertiary hospital located fifteen miles outside Accra, the capital city of Ghana. The facility is the largest public health institution in the metropolis and serves a population of about one million people. It is the only referral centre in the district and has ten wards with a bed capacity of two hundred and eighty. The neighbouring districts refer their cases to this hospital. The hospital has approximately 680 staff, comprised of 304 nurses/midwives, 10 specialists, and 35 general practice physicians; the rest are paramedical staff. The setting

provides services, including pediatrics, obstetrics and gynecology, dental care, eye care, internal medicine, and general surgery.

It is a busy referral hospital with an average bed occupancy of eighty percent and an outpatient attendance of at least 650 patients daily. The setting for the collection of data included the outpatient unit, the labour ward, and the obstetric ward. The outpatient clinic of the obstetric and gynecologic department provides services to over 203 patients a day. The labour ward of this hospital is one of the most active maternity units in the Greater Accra Region of Ghana (Baffour-Awuah, Mwini-Nyaledzigbor, & Richter, 2015).

## **Recruitment**

Given the close-knit culture and the norms of Ghana that do not allow family or community members to talk about or identify couples who have experienced perinatal loss, it was difficult to recruit participants directly from communities (McAreavey & Das, 2013). Hence, I used intermediaries—the midwives—who also acted as recruiters. Using midwives as recruiters was a challenge because of their commitment to patients' confidentiality; their commitment to protecting vulnerable women; and my outsider position of being a student studying abroad. Trusting me with patient information was questioned. I built trust by volunteering and connecting with the midwives at the maternity unit; re-established my relationship as a colleague; and equalized the differences that could have created a power imbalance, thus gaining access to the community. I had many interactions with them and convinced them of the credibility and usefulness of the research. I attended and participated in postnatal visits and continuously made them aware of the significance of my research through conversations with them as both a group and, occasionally, individually.



My previous status as a professional and colleague midwife who had worked with most of the nurse managers of the proposed study setting also helped me to gain access. The recruiters (midwives) considered the importance of the study and its significance to Ghanaian women and nursing service and supported me throughout the process. They assisted in recruiting participants faster and sped up the process, which helped me to save time and resources (McAreavey & Das, 2013).

Subject to the midwives' schedules, I met them regularly to explain the recruitment strategy and the importance of conducting this research. The midwives understood the process and handed out information letters (Appendix A) to potential participants. Women who were interested in participating completed the consent to contact forms (see Appendix D) and handed them to the midwives, who in turn forwarded them to me. After receiving the consent to contact forms, each participant was contacted personally and confirmed meeting days and places for further information about the research and data collection.

### **Purposive Sampling**

Focused ethnography primarily uses purposive sampling because of the emphasis on culture and the need to recruit participants who have knowledge on the research topic (Aldiabat & Le Navenec, 2011). Purposive sampling techniques were used to identify and select women who have rich information for proper utilization (Benoot, Hannes & Bilsen, 2016). The women who were recruited to participate in the study were Ghanaians who have had a specific experience in a particular setting. They also served as sensitive informants who enriched the data collection of the phenomenon and added to the general understanding of experiences of perinatal loss (Benoot, Hannes & Bilsen, 2016).

**Inclusion and exclusion criteria.** Eligibility for the study included:

- Bereaved women who have experienced perinatal loss from 22 weeks' gestation up to 28 days after birth and who consented to share their experiences for the purposes of this research;
- Women who delivered at the research setting and lost a child—either a newborn death or stillbirth; and
- Women who completed the consent to contact form.

### **Sample Size**

All the participants had experienced perinatal loss and were of reproductive age between 20-42 years. Thirty participants were recruited and referred to me through the midwives. However, two dropped out without signing the consent form and an additional four who signed the form later declined to take part in the interview because their spouses did not agree to their participation. Additionally, during other interviews, four participants discontinued due to recollection of painful memory (recall) and requested their information not be included in the study. The researcher respected their privacy and therefore abided with their requests. Out of the 30 women initially recruited, only 20 women participated in the study.

### **Data Collection Methods**

Data collection occurred over a period of four months, from July to November 2017. Guided by the principles of the methodology (focused ethnography), I interviewed my participants using a semi structured interview guide as the main tool for my data collection. I developed this semi structured interview guide prior to my data collection to ensure all participants are guided through the same questions. It was made up of open-ended questions with

probes to seek clarifications and attain a rich account of information. The questions were developed to investigate women's experiences of perinatal loss in the Ghanaian cultural context and they were relevant to the objective of the study. It was supplemented with participants observation and fieldnotes. I conducted face-to-face interviews at a convenient time for the participants' schedule. The interviews ranged from 60 to 90 minutes.

**Interviews.** As it was imperative for the participants to feel relaxed and comfortable, all appointments were scheduled at each participant's convenience and place of choice. I made sure I was available at all times to provide flexibility. I, the researcher and doctoral student introduced myself at the beginning of each interview, stated the purpose of the study, and described the anticipated use of data. I also showed respect and appreciation for their contribution. I answered any questions that arose as clearly as possible. I took every opportunity my participants offered me to interview them and to hear more about their stories. Of the 20 participants interviewed, thirteen were conducted in participants home and seven in an office and church premises at the request of the participants. The interviews were conducted between three weeks to six months after the loss. While there is no set time for conducting interviews, researchers propose a range between three months to two years after the perinatal loss for effective recall (Garenne & Fontaine, 1990; Kint, 2015; Sereshti et al., 2016).

As a midwife, I have attended workshops on providing emotional support to grieving patients and their families. My journey as a graduate student has offered me many opportunities to be trained to interview different kinds of participants for varieties of research studies. In addition to having a degree in nursing with psychology, one of the courses I recently took in my PhD course work was on grieving and hope which further prepared me to conduct the research on this sensitive topic. Furthermore, participants were made aware that they could stop at any

point during the interview if they were uncomfortable and they would be provided with resources on counseling in the hospital and community if they chose to explore this service.

I used semi-structured interviews to collect data. Each interview began with an open question such as “Tell me about the loss of your pregnancy/child?” and “When did you experience perinatal loss?” Starting with such open questions engaged the women to freely talk about their losses, admission experiences, support, and care received from health professionals and family members. The semi-structured interview guide presented the possibility to probe further with follow-up questions and, as a result, paved the way for more information from the participating women (Nicholls, 2009). Probing questions such as “Can you explain more?” and “Is there anything concerning your loss you would like to tell me?” were used to further explore the phenomenon and clarify participants’ ideas and emotions to gain a deeper understanding of the research phenomenon (Mayan, 2009). See Appendix C for the interview guide.

The interviews were conducted with the study purpose and the scope of the research question in mind. Although English remains the official language, the widely spoken language in Ghana is Akan, the dialect I speak, and all the participants were able to communicate in Akan during the interview. Consistent with focused ethnography method and with the consent of the participants, each interview was audio recorded. Permission for audio recording was granted by all participants. Behaviours and certain mannerisms that could not be captured by the recorder were jotted in the field notes.

Participants’ perception of researchers as insiders or outsiders can either afford researchers the power to move the study ahead or present a challenge that impedes the progress of the research (Merriam et al., 2010). From the beginning of the interview, I sensed I was being marginalized by some of the participants; it was clear from their body responses that most

considered me an outsider because of my social position as a researcher. Although I had no initial intention of revealing my experience of perinatal loss, the process of the interview and the emotional discourse of participants brought about the disclosure of my experiences to most of them. Sharing my experience with participants significantly enhanced my acceptance and encouraged them to talk openly.

Nonetheless, I had some challenges with my emic position of being a Ghanaian of similar cultural background and as a bereaved mother who shares the same experience of loss. From this stand, a number of the participants assumed I already had answers to their experiences because of my position. Some of their answers began with “You already know”. My etic position as a researcher probed and asked questions like “what is your opinion?” or “what is your experience on that?”. My insider’s view as a woman who has experienced perinatal loss and shared the same experiences helped me to bond with the participants and access detailed information. This situation also put me in the position of becoming biased, and to prevent this I cognitively avoided leading questions and biased comments. I maintained my relationship with participants and focused on the research purpose to achieve my objectives of the research topic.

**Field Observation.** In the Ghanaian and African cultures, observation is seen to be a primary source of knowledge (Oppong et al., 2009). The field observations in this study began with the recruitment of the participants and lasted to the end of data collection, stretching over a four-month period. Upon entering the field (after participants signed the consent form), I developed relationships with each participant to be studied in order to gain their trust and be accepted.

The beginning of most of my interviews was spent observing the environment of the participant and the participant’s interactions with the environment and her family, as well as

observing artifacts such as photos and clothing, using symbolic interaction to generate meaning of the culture. I mostly stayed where I could observe the surroundings: paintings, walls, gardens, and trees. I observed the participants and their relationships with their family members, the midwives, and sometimes with community members. Additionally, I endeavoured to understand the experiences of these individuals and tried to capture their behaviours within the respective cultural contexts (Morgan-Trimmer & Wood, 2016). I also took on the role of a learner and used the opportunity to learn about the differences in the multiple Ghanaian cultures; this enhanced the quality of my data (Aldiabat & Le Navenec, 2011).

Field observation is part of the learning of both explicit and tacit cultural knowledge, and a way of gaining an insider view into some aspects of the everyday life of participants (Higginbottom, Pillay & Boadu, 2013). The opportunity to observe the relationships between what the women said and did helped me to gain a better understanding of the women's actions in relation to the phenomenon of interest (Berg & Lune, 2012; Higginbottom, Pillay & Boadu, 2013). Evidence also shows that researchers' presence and observations can be obtrusive and psychologically disturbing for some participants under study (Cruz & Higginbottom, 2013). Every time I sought permission to conduct the interview, the women and their family members were given a detailed explanation of the study and the type of design. I made sure our conversations mainly focused on the reason for my visit (on the research topic) and tried to be as tactful as possible. I used unstructured observation as part of my interviews and communicated to the participants that they should notify me if my presence caused any discomfort to them or their family members. They were further reminded of the option to discontinue the session whenever they felt uncomfortable (Nightingale, Sinha & Swallow, 2014).

**Field Notes:** An equally significant tool is the field notes written by the researcher during fieldwork to record behaviours, events, and activities observed during interviews. Field notes are referred to as the “brick and mortar” of the research and mainly consist of conversations and observations (Fetterman, 1998, p.114). Field notes are raw data and written evidence that are read by the researcher after each day’s fieldwork to produce meaning and a better understanding of the phenomenon being studied (Wall, 2015). Field notes comprise of shared artifacts and documentations of daily observations, mannerisms, and unclear questions that need to be answered but were not captured by the audio recorder. Human memory declines with time and therefore information gained, if not recorded or jotted down, will be overshadowed by subsequent proceedings. As an important written observation, field notes helped to obtain the bulk of implicit data of most participants. Observations on the field were written as soon as they were noted (Fetterman, 1998). In order to get detailed descriptions of the women’s experiences, all observations of the participants, including emotional reactions, mannerisms, facial gestures, and other behaviours were recorded in the field notes. Equally important were the written notes of interactions and relationships between the women and their family members, the community, and the midwives. Accounts from the field notes were used as a self-reflection guide about the research process. I reflected on my role and the possible influence I had on the data collection at the end of every interview/ observation (Sutton & Austin, 2015).

**Document Analysis.** This is a way ethnographer access valuable documents and interpret them to give meaning and add to data collection (Bowen, 2009). Document analysis is a useful source of data that helps to strengthen, and support data generated through observations and interviews. In addition, document analysis provides general background information relating to the management of perinatal loss (Kutsyuruba, 2017). I gathered documents such as obstetric

procedural guidelines, protocols, and policies related to the management of perinatal loss.

Accessing these documents provided me with extra information that informed the objectives of the study. Moreover, information gained through these documents prompted me to be watchful of particular situations and ask appropriate questions (O’Leary, 2014). Document analysis was conducted concurrently with field observation, the sharing of physical symbols and artifacts, and interviews, and was a means of triangulation to provide rigor (O’Leary, 2014).

### **Data Analysis**

Data analysis commenced with different electronic folders created in a Microsoft Office Word 2014 processing program. There were files within each folder to group the data and store aspects of the study such as transcribed interviews, demographic data, and the audit trail. Thorne (2008) encouraged “engagement in the transcription process” as a first step in making sense of data (p.144). I transcribed all the audio-recorded interviews verbatim from Akan into English language since I am schooling in Canada and the preferred language is English. My cultural background as a Ghanaian, the in-depth knowledge of the society, and the major language I speak helped me to have a better cultural interpretation and understanding of the meaning conveyed in statements recorded and also their facial expression, tone of voice and silence (Strandas, Wackerhausen & Bondas, 2019).

My aim was to learn, interpret, and understand in detail the information I had received. Therefore, during transcription, I played the audio recorded interviews back several times to understand the meaning of what was said, confirm accuracy, and crosscheck transcripts for any errors. I was able to type in the omissions and correct all the typographical mistakes I had made. Reviewing the transcripts helped me to gain the principal interpretation of the data and gave me the opportunity to go back to the participants and ask more questions to clarify and verify unclear



statements discussed during the interview and to pose fresh and new questions in my next interviews (Spradley, 1979). Transcribed data including fieldnotes were read and reread several times to obtain a general view of all the data before coding and analysis began. This helped me to gain an in-depth understanding of the participants shared story and their experience.

Data analysis is the systematic way of identifying, organizing, and sorting out significant parts of data into themes, ideas, and categories. In qualitative research such as focused ethnography data analysis involves searching for patterns in the data to uncover an in-depth description of the cultural experiences of the research topic and what it means (Berg & Lune, 2012). Using Roper and Shapira (2000) approach for ethnographic data analysis, each participant's transcript was analyzed in detail to identify common themes. Roper and Shapira (2000) described the stages of data analysis to include coding for descriptive labels, sorting for similar phrases, identifying outliers and generalizing constructs, memoing and reflecting on identified themes. Roper and Shapira (2000) approach to analyzing qualitative data was employed because of its clarity and applicability to focused ethnography.

Coding is about analysing and assigning labels to ideas in the transcript (Roper & Shapira, 2000; Wall, 2015). It is the foundation of developing analysis in research. The overall approach to coding for descriptive labels included reading through the transcripts to interpret and make meaning of what had been said. After the first reading of the transcripts, I started the coding by labeling ideas in the transcripts. During the coding, I tried to ask myself questions like "What is this participant saying?", "What does it represent?", "Why are these statements and actions taken for granted by society, families and professionals?", and "How can they be supported?" (Roper & Shapira, 2000). This process of questioning the data helped me to gain a full understanding of the experience of perinatal loss from the women's own cultural perspective

and identify common phrases as well as outliers (Roper & Shapira, 2000). In addition, the initial transcripts were shared with participants who could read if their experiences have been accurately captured. The significant and common elements of the data (phrases) were identified and brought together as descriptive labels during the second reading. Using each interview question as a guide, each participant's transcript was analyzed in detail as well as across the individual transcripts in order to organize, compare and contrast to identify patterns (Mayan, 2009; Roper & Shapira, 2000).

Sorting for patterns was achieved through a second reading to group the descriptive labels into smaller sets and then develop themes from these categories (Sangasubana, 2011). The next thing was identifying outliers where situations and responses from the data which clearly differed from the rest were identified and used to test findings.

Memoing or reflective remarks are ideas, notes or minutes written as a reminder for the research to fall on when need be. During the analysis and writing of my research findings, I used the notes and ideas I had jotted in my field notes as a reminder for further clarifications; this helped me to check on my assumptions, opinions and my biases throughout the research process. Additional subthemes were also developed from each theme. The themes and subthemes were compared with the memo I created during the data analysis and to the evidence in the literature. I reflected on the themes and subthemes as well as met frequently with my supervisory committee to discuss and negotiate for consensus on the evolving themes. At the end of the data analysis, the broad themes that emerged from the Ghanaian women experiences of perinatal loss were: a) beliefs and values surrounding marriage, motherhood and children; b) views of childlessness and perinatal loss, c) understanding of pregnancy and loss in the context of Ghana, d) subsequent

impacts of perinatal loss on women, e) support, f) culturally sensitive care. Each theme came up with subthemes. They are as follows:

- a) Beliefs and values surrounding marriage, motherhood and children
  - i. Marriage as an obligation for raising children,
  - ii. Motherhood is equated with successful birth and identity,
  - iii. Children as gift from God and source of strength
- b) Views of childlessness and perinatal loss
  - i. Attachment, loss and isolation: a response to perinatal loss
  - ii. Childlessness as a failure for women
- c) Understanding of pregnancy and loss in the context of Ghana,
  - i. Mothers attachment to pregnancy and preparation,
  - ii. Grief reactions,
  - iii. Reflection and a new understanding of loss
- d) Subsequent impacts of perinatal loss on women
  - i. Relationship before and after perinatal loss,
  - ii. Fear of the unknown (Divorce),
  - iii. Disenfranchised grief
- e) Support
  - i. Immediate communication and interactions,
  - ii. Support from significant others,
  - iii. Seeing and holding,
  - iv. Being with
  - v. Mothers' perceptions of relevant and meaningful care

- vi. Psychological counselling
- f) Culturally sensitive care
  - i. Burial and funeral arrangements,
  - ii. Creating meaningful memory,
  - iii. Follow up/postpartum care

These themes and subthemes will be discussed in detail in chapters five to seven.

### **Rigor and Trustworthiness**

Maintaining rigor or trustworthiness is very important in qualitative study because it is used to determine the accuracy and validity of the research. In most qualitative studies, the quality of the research is influenced by the researcher's imagination, insight, and skill in using verification strategies (Bradshaw et al., 2017). Rigor is the term used to describe reliability and validity in qualitative research in order to ensure the quality of the study (Morse et al., 2002). Rigor involves activities implemented during the conduct of a study to ensure that the findings accurately represent the reality of the participants (Bradshaw et al., 2017). In this study, rigor relied on the credibility and dependability of the findings (Strandas, Wackerhausen & Bondas, 2019). Considering the sensitive nature of my topic and how it is rooted in the Ghanaian cultural context, Meleis (1996) criteria for the development of cultural knowledge and achieving trustworthiness in qualitative research was adopted for the current study on women experiences of perinatal loss in Ghana. Meleis highlights the significance of developing culturally competent knowledge and came up with eight criteria of assessing rigor and credibility. These include: contextuality, relevance, communication, awareness of identity and power differentials, disclosure, reciprocation, empowerment, and time. These criteria for ensuring rigor were

appropriate for this research because the research was culturally based and the participants in the research were vulnerable and marginalized.

**Contextuality.** Contextuality is acquiring knowledge of history or participants' lifestyles and socio-cultural conditions that impact their well-being and can inform understanding of the problem the researcher is interested in studying. Contextuality comprises the sensitivity of structural conditions that add to participants' responses as well as to the interpretations and understanding of the situations informed by their experiences. Meleis (1996) argued that researchers should situate their study in the context of the participant in order to avoid biased assumptions about the participants. As a Ghanaian who has lived and worked in Ghana, I am well immersed in the Ghanaian cultural context. Moreover, I am a mother and a midwife who has lost a child and who has shared the experiences of perinatal loss with patients. I have personal and professional knowledge of the experiences of perinatal loss, the Ghanaian culture, and the societal norms such as the expectation to have children after marriage. Hence, I have the cultural knowledge and experience to be sensitive to participants as well as to situate the study in the appropriate context to increase understanding of the phenomenon. My understanding of the context assisted me in reflecting on the data and correctly describing the participants' experiences in the themes that emerged from the data such as "beliefs and values surrounding marriage, motherhood and children", "Views of childlessness and perinatal loss", and others.

**Relevance.** Relevance refers to the ability of a research question to resolve participant's issues and improve their lives (Meleis, 1996). It is about making sure that the topic being investigated is acceptable and worth exploring. Researchers have emphasized that the relevance of a research is an essential component of a cultural research (Mill & Ogilvie, 2003). To make the participants and stakeholders recognize the significance of the study as an important issue for their well-

being, I explained the research questions and significance of the study to them and answered their probing questions. I further explained the importance of the knowledge that will be generated from the research in contributing to the understanding and management of women experiencing perinatal loss and the support they would like to receive. Furthermore, the identified themes from the study reflect information that is relevant to Ghanaian women who have experienced perinatal loss.

**Communication styles.** Communication styles are the researcher's understanding of the nuances in the communication of research participants, especially those marginalized and vulnerable; it is a way of providing evidence of rigor in culturally competent scholarship as well as understanding of the metaphors used in communication (Meleis, 1996; Mill & Ogilvie, 2002). It is the researcher's ability to understand, the participants language, interact and respond to their questions and concerns. It involves acknowledging the participants grief and being sensitive and compassionate to questioning and verifying information to ensure validity (Morse et al., 2002). Being a Ghanaian, a midwife, and someone who has experienced perinatal loss, I had adequate understanding of the different forms of languages or communication used in the Ghanaian culture in relation to perinatal loss and this informed the quality of the interviews and the development of the themes and sub-themes that emerged from the data. I also used triangulations of methods to collect data (interviewing, field notes, observation) to obtain credible and dependable information.

My insider's view of the Ghanaian culture became an advantage in enhancing the process of communication with participants and their family members. I followed the Ghanaian cultural norms as "one of their own", especially when the interview was held in a participant's home. In Ghana, authority is mainly bestowed to males who are considered heads of the families. Heads of

families possess power, especially when it comes to sharing family information... “to tell or not to tell, who to tell, and how to tell it”. The decisions of the husband for their wives to participate was respected and four (4) of the participants decided not to participate because of their husband’s decision. During my data collection, I continuously communicated with my supervisor throughout, for guidance and improved on the approach of questioning to maintain consistency in aspects of the interview that was unclear. My supervisor guided me through some of transcripts and assisted me to follow up on unclear answers that needed follow up questions to validate accuracy. Additionally, my emic insider’s position as a Ghanaian speaking the same dialect as the participants gave me an advantage of translating all the interviews from the Ghanaian local language into English language. I also reread each transcript for a better understanding and hired an independent translator who is an expert in Ghanaian languages from a reputable university in Ghana to audit the final interviews (Mill & Ogilvie, 2002).

**Awareness of identity and power differentials.** In research, there is often a power differential between the participant and researcher, which is a concern in various fields of research (Meleis, 1996). Meleis warns researchers to be cognisant of the influence of power disparities, make efforts to establish horizontal rather than vertical relationships, and develop shared authority and ownership of the data. Although that power imbalance did not reduce completely, it did help me to establish how best to address those potential harm and discomfort the participants could encounter (Saltus, 2006). Awareness of identity and power differentials were attained by addressing discomfort and accepting and respecting the views, practices, and beliefs of the participants. During interviews/conversations, I tried to create an environment where participants could freely express their experiences without intimidation so that we could all work as equal partners. I conducted more than one interview with seven participants to allow the building of a

trust relationship and an openness to share experiences in order to develop and in depth understanding of their experiences.

**Disclosure.** Disclosure is making known what is regarded as a secret or confidential and building trust with participants. It is the ability of the researcher to recognize matters concerning trust, confidentiality and privacy. Meleis believes that the validity of research participants comments may have, at times, been compromised by their unwillingness to share. People who have similar and confidential experiences but are marginalized and vulnerable do not feel comfortable expressing themselves (Meleis, 1996). The reluctance of participants to discuss their story may be due to the fact that in Ghana, perinatal loss is disenfranchised, and women are discouraged to mourn for fear of not conceiving again. The pain of suppressing their emotions makes women who have experienced perinatal loss vulnerable and marginalized. Sharing my own experience of loss created a strong relationship conducive to sharing sensitive information together (Saltus, 2006). Participants felt confident and freely answered all the questions they felt comfortable with (Meleis, 1996). Their in-depth narratives provided a rich account of data and evidence of trust in me as a researcher. Similarly, some of them ignored or refused to answer questions they felt uncomfortable or emotional about. All interviews and conversations were conducted in an interactive manner. Some participants completed the interview over two sessions (Read, 2018). All of the women were assured of confidentiality.

**Reciprocation.** This is the researcher's and participant's achievement and desired goals from participating in the research and from the research outcome (Meleis, 1996; Saltus, 2006). For example, my goal as the researcher was to acquire an in-depth comprehension of the phenomenon while the participant's goal could be to have some of their concerns about the topic addressed (Meleis, 1996). Reciprocity is obtained when the goal of each party in the study is



achieved. Participants reported feelings of relief after sharing their stories and I gained a profound knowledge of the different levels of cultural experiences of perinatal loss. I have become increasingly aware of what marriage and motherhood mean to women in the cultural context of Ghana. In addition to that I also gained useful information as identified by the participants to assist healthcare practice in the management of perinatal loss. Immediate reciprocity is that I gave the participants the support and a listening ear to share their long-time suppressed grief which gave them some relieve; my long-term reciprocity is to present my findings in conference in Ghana in future and invite the participants to attend the conference.

**Empowerment.** Empowerment is about research participants receiving some lasting sense of control and satisfaction when their contributions to research yield results that are beneficial to society (Meleis, 1996). Meleis explained that the participants must feel connected to the study and develop interest and understanding to lead to empowerment. Throughout the interviews/conversations, the participants were made aware of the importance of the study and how their contributions would not only help inspire other women to talk about their experiences of perinatal loss but would also help to develop systems to support other women who experience perinatal loss.

**Time.** According to Meleis (1996), time flexibility permits researchers to create trust, identify reciprocal goals, and complete the research process. Meleis discussed that appreciation of time varies in every culture and researchers need to be aware of the meaning of time in the culture being studied. I interviewed participants at their convenience. Interview times and places were scheduled for the comfort of all participants at their homes and places they felt comfortable being interviewed such as the church and office premises. I, therefore, adjusted the duration of the interview time based on the length of time the participants could be with me and their ability

to focus. With my cultural knowledge of time in the Ghanaian context, I was flexible with participants in terms of keeping time and appointments as well as the duration of the interviews. All interviews lasted 60 to 90 minutes. Some of the interviews were cancelled, but we rescheduled the time and met again. Seven participants were rescheduled due to emotional breakdown during the interviews. Rearrangement of interviews was between two weeks to one month. I inquired if they wanted to be referred to a psychologist and five participants agreed but wanted to consult their spouses before giving their consent. They later declined with the explanation that their husbands were not in favour of consulting a psychologist. The other two participants also declined with the explanation of having their own psychologist.

**Reflexivity.** It is a way how researchers handle their biases and prejudice during data collection (Higginbottom et al., 2013). Reflexivity is a strategy for ensuring confirmability in qualitative research. It is a significant part of focused ethnography and a process whereby researchers place themselves in the inquiry and consciously disclose their personal beliefs, assumptions, and biases and how they will reduce their influence on the research (Higginbottom et al., 2013). Because of its significance, it is necessary for a researcher to acknowledge and describe the beliefs and biases early in the research process to allow readers to understand their positions and then to bracket or suspend biases as the study proceeds (Tufford & Newman, 2010). I clearly described my positionality in this research project. I shared my loss and how relatable I am to their experiences. I consciously documented my experience and knowledge on the topic so that it did not influence the generation of data (Wall, 2015). To ensure that my experiences and assumptions did not affect my data collection, I avoided asking leading questions and allowed my participants to freely share their stories, however, I asked probing questions to clarify the answers to obtain a deeper understanding.

**Researcher's bias.** One of the characteristics of a focused ethnographic research is the role of the researcher as an instrument. The researcher as an instrument involves the immersion of the researcher in the field to gain an insider's view of the culture and generate data on the phenomenon being studied (Speziale & Carpenter, 2003). As a researcher, my experiences, values, and knowledge were likely to influence my observation, analysis, and writing of the findings. Therefore, I used reflexive practice to consciously acknowledge my biases—such as, for example, my assumption of how a woman should react or respond after the loss of a child—and prevent these from influencing the research process and the ensuing findings (Wall, 2015).

Member checking, which involves sending transcribed data and emerging themes to participants for clarification and validation, was implemented by allowing participants to read the transcription of their recorded interviews. For those who could not read and write due to their educational level, I explained the transcribed data to them and played the recorded conversation back for validation. I also implemented triangulation using different data collection methods such as observation and interviews to generate data (Wall, 2015). I tried not to let my own emotional experience and my values affect how I conducted the research and the interpretation of results.

In addition, I worked extensively with my supervisory team to ensure rigor in the study. My primary supervisor had knowledge about the Ghanaian culture through her research and various educational visits to Ghana. One of my supervisory committee members is a native Ghanaian whose research focuses on maternal health, specifically infertility in women, which is an aspect of loss related to womanhood in the Ghanaian culture. They have been helpful in ensuring development of the research context and a rigorous interpretation of data. The constant contact with my supervisory team enabled me to reflect and manage challenges related to

conducting the focused ethnography research. I also made available to supervisory committee an audit trail of transcribed interviews, fieldnotes and coding schemes for review (Morse et al., 2002).

### **Ethical Considerations**

Ethical procedures are fundamental to all research (Lincoln & Guba, 1985); therefore, there is a need for researchers to pay particular attention to ethical concerns regarding participants. This study adhered to the ethical standards set forward by the ethical boards of the University of Alberta and Ghana Health Service Ethics Review Committee.

Ethics approval was acquired from two institutional ethics boards: The University of Alberta Ethics Board with approval number Pro00073592 and Ghana Health Service Ethics Review Committee—GHSERC22/06/17. Permission was sought to conduct the study and access participants. Additional approval was obtained from the hospital administrators and the chief nurse managers to permit the researcher to access midwives who assisted in recruiting the study participants. The advantage of being an insider to access easy passage was not absolute with the ethics board in Ghana. I went through the process with the same strictness as other researchers. Access to this field (Ghana Health Service Ethics Review Committee) was very difficult to obtain; and time consuming.

The nature of qualitative research often raises several ethical concerns. In this study, I was very much aware of the sensitive nature the topic and knowing that the outcome of the interaction between myself and the participants could be unpredictable and could bring back an emotional recall; ethical issues like informed consent, beneficence, respect for persons, confidentiality, autonomy, and psychological harm and benefits were thoroughly adhered to in this study.

During the study, I was constantly aware of the sensitive nature of my research topic and one of my strong ethical concern was not to create emotional discomfort for any of the participants. My top concern was to ensure that the participants felt very comfortable in sharing their stories. Therefore, the following ethical procedures were adhered to in order to avoid causing harm to my participants. Participants were provided with an information sheet that described the purpose of the study and the potential risks and benefits and stated the voluntary nature of participation. Participants who agreed to take part signed a consent form (Appendix B). Voluntary participation in this study was ensured by the researcher having a face-to-face interaction with each participant and thoroughly explaining the study using the information sheet (Appendix A). During the explanation, participants were informed of their right to withdraw from the study at any point without fear of any negative action or harm. They were also informed of their rights to refuse to answer uncomfortable questions. Participation in the study was free and fair and participants were made aware of that. None of the participants was manipulated into being interviewed without her consent. All the women willingly participated without any pressure for the sake of research and their stories to be heard by other women. However, there were situations where participants needed a break during their interviews; I continuously acknowledged their grief and remained sensitive to their needs throughout the interviews, especially in heightened emotions and they needed to stop.

Arrangements were made for counselling services prior to the interview of participants. This arrangement was for cases where participants became emotional during the conversations. A clinical psychologist was contacted before the data collection began so that participants had access to consultation if needed. Participants were made aware that they would not pay for these psychological services should they be referred to the psychologist. Those who experienced

emotional discomfort were offered counseling and professional services available in Ghana, but they all refused and discussed that they will access the services of their private counsellors. Participants used religious leaders and/or family members as their support systems which is common practice in Ghana. None of the final twenty participants withdrew from the study; hence, there was no need for recruiting new participants.

**Informed Consent (see Appendix B).** A key ethical issue in research is the process of obtaining permission from the participants. Informed consent was established to protect research participants from exploitation and harm (Nandra, Brockie & Hussain, 2020). In this research, there was the possibility of psychological harm from the sensitive nature of the topic, therefore it was necessary to describe the risks and benefits of the study to the participants through the informed consent to help them make an informed decision either to take part in the research or not (Bolderston, 2012). I had a face-to-face interaction with participants to explain the process thoroughly to ensure they understood the information before they decided to participate. The participants were accurately informed and made to understand the purpose of obtaining valid informed consent and that consent was voluntary (Nandra, Brockie & Hussain, 2020). Participants were routinely asked to complete a consent form (Appendix B) before the interview commenced.

Informed consent is grounded on the ethical values of respect for the self-esteem and value of every human being and their right to self-determination (Schrems, 2014). Respect for persons is a central ethical principle that values the autonomy and independence of people to make choices (Schrems, 2014). The decisions of the participants were respected throughout the investigation. Participant consent to participate when she is satisfied with the all the information and answers to her questions. They are also informed about their rights to withdraw or stop

participating when they feel uncomfortable to do, to refuse to answer emotional questions and withdraw information volunteered.

**Withdrawal of Participants.** Experiences of death within every cultural and social context are always sensitive because of the associated emotions and anxiety. In the case of this study, and because of the type of method selected, discussions generated an emotional response. Perinatal loss comes with many emotions for women. This can have adverse effects on data, because the participant may withdraw when they become emotionally affected and effectively create a void in the data and the analysis (Gertz, 2008; Mehlman et al., 2014). One of the fundamental principles of ethics is the right of the participant to withdraw. Thus, during the data collection, research participants at all times had the right to withdraw their consent and were free to leave the study at any time or at any stage of the study (Mehlman et al., 2014). Ten out of the initial 30 participants withdrew their consent before or during the interview.

**Maintaining confidentiality and anonymity:** According to the British Sociology Association (BSA) (2004), the concept of confidentiality is strengthened by the code of respect for autonomy. Confidentiality implies that all observed and verbal communications among participants must be safeguarded and remain closely protected by the research team. This means pledging and assuring that conversations will be kept confidential and anonymity will be guaranteed (Saunders, Kitzinger & Kitzinger, 2015). Participants were informed about how the data will be used and shared. All information and paper documents related to this study are held in confidence. Participants were made aware that the data will be kept secured in a locked cabinet and the key will be kept by me. All electronic information including transcripts and digital recordings of interviews will be stored on a password-protected computer within

password-protected files for five (5) years following the completion of the study. Only members of the supervisory team will have access to the documents.

I shared with participants that information collected for this study would be analyzed and summarized into reports and papers for publication. These will be made available to other students, faculty, deans, university administrators, and anyone that will have access to the report and/or publications. Any study subsequent to the results of this research would be considered a new study for which fresh ethical clearance and consent would have to be obtained.

Pseudonyms or codes were assigned to protect all identifying information in the transcripts and ensured participants' privacy and anonymity. Participants' names are not used in any story or publication related to the research. Additionally, pseudonyms are given for both locations and names that came up during the interviews. All other identifying information was removed. To further ensure protection and privacy, only the researcher conducted transcriptions of all the interviews.

**Psychological Harm/Risk.** Psychological harm is described as unintentional pain generated in the participants during the interview without the knowledge of the researcher (British Psychological Society, 2010). The researcher did not directly cause harm; however, the sensitive nature of the topic had the potential to cause emotional discomfort during conversations and participants could become uncomfortable because of the sensitive nature of the topic (Schrems, 2014). Participants who experienced discomfort during conversations were given the option to discontinue as well as the choice to reschedule and complete at a later time. More than half of the participants experienced some sort of emotional distress but refused to discontinue and seven participants rescheduled their appointments. However, it took one to three weeks to arrange the follow-up interview. I persistently asked participants if they wanted a referral to a



support person including a clinical psychologist, religious leader(s), and/or family member(s). Some refused immediately and others said they were already seeing a psychologist. The women were informed that they could withdraw from the study without repercussions.

In order to reduce emotional breakdown, sensitive questions that could cause distress to participants were reduced by discussing interview questions with my supervisory team. As a trained midwife and doctoral student, I closely observed participants' facial expression during conversations to identify those who were having intense psychological stress in order to refer them to psychiatrists, psychologists, counsellors, or priests for counselling. Recommended guidelines by both ethics' boards were strictly adhered to throughout the research.

**Benefits.** The opportunity for the women to participate in the study provided space or voice for participants to tell their stories to be relieved of their grieving. Although some participants may not directly benefit from the study, the knowledge generated from their narratives could help generate public compassion and understanding of the subject of perinatal loss. In addition, the findings from the study can assist stakeholders like health administrators, Ghana Health Service, and the Ministry of Health to develop guidelines for the training of nurses and other medical staff in the provision of support and effective management of other clients who may experience perinatal loss. The study also brings value and contributes knowledge to improve the care of women experiencing perinatal loss. Health professionals, health administrators, and policymakers can use knowledge obtained from this study to make decisions on health care interventions to enhance maternal and child health.

## **Knowledge Translation**

Knowledge translation is a dynamic and efficient way of making all evidence-based research findings available to a targeted audience for implementation (Mallidou et al. 2018). Knowledge transfer includes synthesis, dissemination, and exchange of knowledge to advance better health outcomes of patients through the provision of effective health services (Centre for Reviews and Dissemination (CRD), 2009). According to CRD, a dissemination framework for implementation of results of research involves getting clear and relevant information to the right people, through proper and multiple channels, and taking into account the setting in which the message is received. The research explored the experience of perinatal loss from the perspective of women within the Ghanaian cultural context. The findings have the potential to contribute to knowledge on cultural practices related to care and support available to Ghanaian women who experience perinatal loss. Furthermore, the findings from this study can enhance the work of stakeholders by making informed decisions. My target audiences comprise health care professionals (physicians, nurses, midwives, paramedical staff and students), hospital administrators, and traditional birth attendants. Furthermore, policymakers (such as. ministers), non-governmental organizations, and community leaders/members who make daily decisions for people will be targeted in the knowledge dissemination activities.

The knowledge transmission activities will involve sharing information from the study through publications, workshops, conferences, and web-based activities. My objective for disseminating these findings is to generate knowledge to inform people especially health professionals who make daily decisions for women experiencing perinatal loss in Ghana.

Research has shown that communication of research findings does not translate to behaviour change. Unrelenting efforts need to be made to implement the review findings through briefing notes and other knowledge translation interventions like flyers and posters. Briefing notes are straight to the point and they quickly and efficiently inform decision makers about issues. It is also important for the points to progress in a logical order, short and straight to the point, using plain, simple language. The information and recommendations must be easy to follow. Thus, readers will know what to do with the information and will be more likely to apply the information.

### **Conclusion**

Perinatal loss is one of the top health concerns in Ghana. With the sustainable development goal in progress, Ghana has the challenge of meeting the targeted goal of 12 deaths per 1000 births suggested by the UN by 2030 due to the lack of resources/ facilities to meet this target. There is dearth of literature on experiences of Ghanaian women with perinatal loss and the care as well as the support they receive. It is my goal to gain a better understanding of experiences of perinatal loss among Ghanaian women and the type of support they receive from society and health professionals using focused ethnographic approach. Focused ethnography became my methodology of choice because of my insider's knowledge on the topic and the effectiveness of the design in capturing and describing the interactions and realities of a specific group of people from their own perspectives.

## **Chapter Five**

### **Ghanaian Women's Views on Marriage, Childbearing and Motherhood Within the Context of Perinatal Loss**

#### **Abstract**

In Africa, women are considered mothers after they conceive and have children. Childbearing is important as children add to the social status and emotional fulfilment of African families. Childless couples are labelled as infertile with the women bearing the brunt of the stigma. Couples who are not able to conceive or are unable to carry the pregnancy to term are both perceived as not fulfilling their role within the family. In the Ghanaian society, childlessness produces multiple stressors for women and their families. A considerable number of women in Ghana are unable to carry their pregnancy to term, yet, research in this area rarely focuses on the impact of these losses on the women. In this paper, I discuss Ghanaian women's views and positions on marriage, motherhood, and childbearing within the context of perinatal loss.

A focused ethnographic design was employed. Twenty participants were recruited and interviewed. The interviews were inductively analysed. Two themes developed: beliefs and values surrounding marriage, motherhood and children; and views of childlessness and perinatal loss. Findings indicated that childbearing is an important part of marriage in Ghana. Participants recounted their experiences of perinatal loss as a tragedy and that their rights to make decisions were suppressed by the cultural norms of the family. The study highlights the challenging nature of cultural norms on marriage, motherhood, childbearing and perinatal loss. It informs health

care professionals on the provision of care and support to bereaved mothers. The study informs the need for support systems for affected women and their families.

**Key words:** perinatal loss, motherhood, Ghanaian women, opinion on marriage, childbearing

## **Introduction**

Ghana is a society where respect and authority are associated with accomplishments such as age, life experiences (wisdom), social status, and wealth. Additional respect is gained when couples or mature individuals are able to have children. Childbearing has a significant impact on the stability and quality of a marriage, socialization and mental health of women (Fledderjohann, 2012). Irrespective of their accomplishments or achievements, Ghanaian women of childbearing-age are expected to have children and raise a family; this is of great importance and revered within the culture.

## **Background**

Ghana stretches along the southern coast of West Africa, with its lowlands running through the south-central area and a tropical forest that spreads along its western border (Country System Fact Sheet, 2006). It is bordered on the South by the Atlantic Ocean and Gulf of Guinea, Cote D'Ivoire to the West, Burkina Faso to the North and Togo to the East. It has an estimated population of about 31 million and over 100 ethnic groups with different dialects. The major ethnic groups are Akan, Ga, Ewe, and Moshi-Dagbani. As a country, Ghana is endowed with rich multicultural practices, traditions, and customs that make its people unique. Some of these traditions have a remarkably positive impact on the society. For example, marriage and childbearing are social traditions instituted by their ancestors that are acceptable for securing the continuity and survival (Gyekye, 2003). This cultural practice is considered worthy, well regarded, sanctified, approved and held close by the Ghanaian society.

Three types of marriages are accepted in Ghana: marriage under customary law, marriage by ordinance, and Muslim marriage (Kuenyehia & Aboagye, 2004). Marriage by ordinance

favours women, since men are only allowed to marry one woman, while the traditional system of polygamy under which men can marry more wives tends to favor men. The Ghanaian customary marriage known in Akan as “Aware” is the oldest practice of marriage in the society and an important occasion for most families in Ghana. “Aware” is regarded as the union of a man and woman into husband and wife, and also as the union of two families. Family is the basic foundation of the Ghanaian society and when more marriages are contracted between people, the society grows wider. The traditional marriage “Aware” begins with the knocking ceremony where the male suitor sends his family members to see the bride’s family and to make his intentions known as he seeks permission for her hand in marriage. On this occasion, the family of a male is expected to perform the traditional rites including the payment of a “dowry” (ceremonial presentation of money and drinks). It is a marriage requirement that is lawfully acknowledged by families and society.

Marriage in Ghana is an agreement between two families; for the majority of Ghanaian couples of marital age, the cultural standards of who one marry continue to involve family members (Addai, Opoku-Agyemang & Amanfu, 2015). Both extended families of the couple take keen interest and are deeply involved in the process of matrimony (Gyekye, 2003). In the case of a woman, the family members of the man look for certain attributes in the future wife, for example, a hardworking, supportive, obedient, respectful, and faithful woman (Bogya, 2014). Although beauty may play a role in marriage, it is not the most important influencing factor. Character is the decisive factor. Similarly, the family of the woman also looks for a future husband of good character and intelligence, who is hardworking and can support his wife and children.

Couples are informed during the ceremony that they are marrying into a family and not to an individual (Gyekye, 2003). This association strongly unites the families involved in a way that family elders are able to use their influence to encourage, support, and keep marriages healthy to avoid divorce. Divorce is not recommended in Ghana because of the belief that children born and raised in a marital relationship develop the right attitudes if both parents are involved (Gyekye, 2003). A marriage can only be annulled when there are repeated actions of abuse, violence, and infidelity. Even then, family elders try to resolve the problem before the final decision to seek a divorce is made. Marriage is a lifelong contract, considered a fundamental custom and a predominant tradition for nurturing children in most human societies (Jarnkvist, 2019). Marriage in Ghanaian culture is not only for couples to profess their love and form companionship, but most importantly, it is to bear children (Gyekye, 2003). The birth of the first child to married couples legitimizes their marriage (Holland, 2013).

Globally, the number of children women of reproductive age deliver has been decreasing (United Nations Department of Economic and Social Affairs, 2015). Likewise, in Ghana, the number of children per woman has decreased from “6.4 children per woman in 1988 to 3.9 in 2017” (Ghana Statistical Services, 2018, p.12). Childbearing expectations in most African cultures, including Ghanaian culture, however, remains high. Children are seen as the continuous existence of families and society; they significantly influence the population and economic growth and sustainability of a country (Dyer, 2007). The future of societies is partly determined by the presence of healthy children; without children in a society, there will be a cessation of life (Boakye-Boaten, 2010). In the Ghanaian cultural context, the continuation of the lineage is important to families and biological childbearing is the acceptable way to sustain this lineage. Children are a natural part of the reproductive life and a cultural expectation. The expectation to



have children emanates from young people as individuals, as couples, and the society to which they belong (Mabasa, 2000).

Children play a major role in the life of Ghanaians and their significance is communicated in some of the Ghanaian proverbs, such as “*There is no wealth where there is no child*” (Gyekye, 2003, p.84). This literally means that children are the reason parents seek wealth and that wealth is meaningless in a childless family. Another significant cultural belief in Ghana is the norm that children care for their parents in their old age until they die. In addition, they are responsible for organizing the funeral arrangements of departed parents. Within the Ghanaian society, the proverb “*Se wa wofo hwewo mawo se fifia, ewose wohwe won na won se tutu*”, which literally translates “*When parents look after their children to develop teeth, the children, in turn, are expected to look after them when they lose theirs*” supports this belief. It is the wish of every parent to die before their children so that their children can take care of funeral ceremonies for them. This involves extensive observations of funeral rites, decorations, and mourning by the children, family, and community members. The demise of a child before the parent brings profound pain to the parents. Given the high value placed on childbearing in Ghana, women who desire children feel fortunate and favoured by God when they experience pregnancy and motherhood. The problem arises when a marriage fails to lead to reproduction and a woman remains childless; she is overwhelmed by intense grief which needs to be managed very well (Leon, 2008).

Perinatal loss is a psychologically challenging event in Ghanaian traditional society. It is an experience that challenges and questions the ability of women to impart life to expand the next generation and the right to leave their genetic imprint (Obiyo, 2016). With all the glitches of pregnancy and the joy of bearing a healthy baby, perinatal loss affects a woman’s happiness with

a feeling of failure. It is an instant loss that denies women the needed opportunity to become mothers, robs them of the joy of experiencing motherhood, and throws them into eagle's claws to be devoured and perceived as unfortunate and unproductive women.

Although the value placed on children in Ghana is high, the death of a child, especially through perinatal loss, is not perceived or valued in the same way as that of an adult. It is considered a misfortune and therefore any physical or emotional grieving or performance of funeral rites is not encouraged. The Ghanaian society does not appreciate the pain associated with perinatal loss and its people are oblivious to the mother's intense grief, the loss of opportunity to hold and love her child, and the lost experience of becoming a mother in the community (Leon, 2008; Capitulo, 2005).

### **Problem Statement and Purpose**

Motherhood is an important cultural role for nearly all Ghanaian women. Women who are unable to have children are ridiculed, stigmatized, and judged by society for failing to achieve this milestone. Hence, pregnancy and thoughts of motherhood bring relief, confidence, and contentment. Women in most parts of Ghana desire motherhood as it is a fundamental traditional expectation of society (Hussein, 2005). The purpose of this manuscript is to explore and develop a deep understanding of the experiences of perinatal loss within the Ghanaian cultural context and more specifically the sociocultural factors (marriage, motherhood and childbearing) that influence the experiences of perinatal loss in this context. The research question I answered in this manuscript was “what is the opinion of Ghanaian women on marriage, motherhood, and childbearing within the framework of perinatal loss”

## Methodology

### Design

A focused ethnographic design was utilized to explore Ghanaian women experience of perinatal loss in the primary study. I selected this type of methodology because focused ethnography assesses the behaviour and social situations of specific cultural group and provides a thick description of the experiences of the participants (Dewan, 2018; Knoblauch, 2005). The cultural perspectives of this subgroup of women in their natural environment which include their beliefs, values, and experiences about marriage, motherhood, and perinatal loss emerged as one of the themes from the analysis of the primary study and will be the focus of this manuscript (Cruz & Higginbottom, 2013; Knoblauch, 2005). I used observation, interviews and filed notes to enable dependability.

The study setting has diverse cultural groups residing in the community. The cultural groups included in the sampled participants comprised of Gas, Ewes, Northerners, and Akans. These ethnic groups form part of the six main cultural groups found in Ghana. They are from the southern and northern parts of Ghana. Although these cultural groups have different languages and values, there is no major difference when it comes to customs and response to death (perinatal loss), however, their personal views may differ. Family and children obligations take precedence over everything else in all the cultures.

**Sample.** I used purposive sampling to select the study participants who have experienced perinatal loss in a tertiary institution in the Greater Accra Municipality. Thirty participants volunteered to take part in the study, however, it was narrowed to twenty as ten dropped out. Among those ten who dropped out, two dropped out without signing the consent form and four

refused to be interviewed as their spouses were not in favour of them participating in the research. Another four participants stopped halfway through the interview because of the sensitive nature of the topic and did not want their information to be shared, therefore that data were destroyed. The remaining twenty participants who ultimately agreed to participate did so with the intention of sharing their experiences to inspire and positively influence other women to find strength and purpose. I contacted the participants and arranged times and venues with them.

All the participants were Ghanaian women of reproductive age between 20-42 years. They comprised of sixteen married women and four women with partners. Some of the participants had experienced multiple losses. Their history of loss ranged between one to three.

### **Data collection**

Data collection occurred over a period of four months. I contacted the participants and arranged times and venues with them. The data collection for the 20 women took place in their individual homes, office and church premises. For most of the participants, the interview took place three weeks to six months after their loss. Guided by the principles of focussed ethnographic approach, I collected data using three methods: observation, interviews, and field notes (Roper & Shapira 2000). In conjunction with observation of participants, I also analyzed documents from the hospital; however, the main method used was a face-to-face interview using a semi-structured interview guide to encourage conversation and to obtain detailed information on the participants' narratives (Sullivan, 2012).

I conducted all the interviews as a graduate student, a researcher and a midwife who had been trained and taken courses in psychology and grief assessment. Each interview began with an open-ended question; “tell me about the loss of your pregnancy/child?” and one of the follow

up questions as “what will happen to you in the family or in the community if you decide not to have children?”. All interviews were conducted in Akan, the native language participants felt comfortable with. The interviews were all audio recorded with the permission of the participants and it lasted between 60 and 90 minutes each. Comprehensive field notes were taken to document participants’ mannerisms and other behaviours. The field notes provided me with vivid and introspective evidence of the cultural meaning and understanding of what the participants experienced. Data collection continued until an in-depth understanding of the phenomenon was obtained from participants and no new ideas emerged (Roper & Shapira, 2000).

Recorded conversations were transcribed verbatim. Data analysis started with listening to the audio recording three times to establish clarity of the answers and to confirm the accuracy of the transcripts. There was also an opportunity to go back to the participants after transcription for clarity and verification of unclear statements discussed during the interviews. Using Roper and Shapira’s (2000) strategies for ethnographic analysis, I analyzed the data in the following sequence: coding for descriptive labels, sorting for patterns, identification for outliers or negative cases, generating themes, memoing and reflecting on the emerging themes. In qualitative research, data analysis involves searching for patterns in the data to uncover an in-depth description of the cultural experiences of the research participants (Berg & Lune, 2012). Roper and Shapira’s (2000) thematic content analysis was employed to analyze the data. Each participant’s transcript, field note, and recording was read and listened to alongside each other for coding and constructing the themes. The contents of the transcripts were reviewed separately and coded line by line by the researcher to generate and identify common themes. The transcripts of the coded data were organized to identify and categorize key patterns and phrases within the

data. It was followed by the identification of potential subthemes. Emerging themes were compared across transcripts to ensure the selected quotes represented the themes. Memos were developed during the analysis and the emerged themes were compared to the memos to increase understanding of the context of the theme as well as reflection on the them.

I first analysed three transcripts with my supervisor and after that, I continued to analyze the rest of transcripts independently to identify all the codes and themes before meeting with the rest of my supervisory committee members to discuss, negotiate and resolve any discrepancies.

### **Rigor**

I adopted Meleis (1996) criteria for the development of cultural knowledge and achieving trustworthiness in qualitative research for this study because my topic is deeply rooted in the Ghanaian cultural context and it involves a vulnerable group of people. Meleis (1966) highlights the significance of developing culturally competent knowledge involving people who are vulnerable and marginalized and came up with eight criteria of assessing rigor and credibility. To develop this culturally competent knowledge, Meleis urged researchers to use eight criteria to confirm rigor and this include: contextuality, relevance, communication, awareness of identity and power differentials, disclosure, reciprocation, empowerment, and time. The criteria appropriately fit with this research because of the cultural background of the research, the vulnerability and marginalization of the participants involved. The detail description of Meleis eight criteria for rigor in qualitative research has been explained in previous chapter on methodology (chapter four).

In every qualitative study, trustworthiness is considered the suitable criterion to evaluate the study (Maher et al., 2018). Additional measures to ensure trustworthiness in the study are

multiple data collection methods, multiple reviewers, member checking, and reflexivity.

Creswell and Miller (2000) maintain that multiple peer reviews improve the trustworthiness of data and ensure a reduction in biases. Therefore, two researchers with experience in qualitative methods helped with the analysis; my supervisor and another member from the supervisory committee.

My supervisor and I initially opened the first transcribed document and manually coded that transcript together to guide me on coding of the transcript. Subsequent transcripts (two) were each coded separately, and my supervisor and I met again to discuss the emerging codes and patterns to arrive at a consensus on the patterns that were emerging. After that, I independently coded and analyzed the rest of the transcripts data. I then compared my findings to that of my research supervisor for consistency and accuracy. In addition, member checking was done by sending transcripts to participants who had better educational background and could read; I also played the audio recorded version to participants who could not read to authenticate their true stories. I also kept records in the form of field notes on all gestures, actions/behaviours, and mannerisms of participants. Additionally, all the interviews were in Akan and translated to English. This was checked by a native Akan (Twi) speaker and a translator from the University of Ghana for the quality of the translation.

### **Ethical Considerations**

Ethics approval was sought from the University of Alberta Human Research Ethics Review Board, Canada, and the Ghana Health Service Ethics Review Committee (Pro00073592 and GHSERC22 /06/17). Additional approval was sought from hospital administrators and chief nurse managers at the research site to permit the researcher access to midwives to support the recruitment of study participants. Recruitment was conducted by an intermediary, the midwives

working at the hospital's labour and delivery unit (McAreavey & Das, 2013). With the help of the hospital administrators, four volunteer midwives were identified to recruit participants from the outpatient departments, antenatal units, and obstetric units. Conditions of eligibility for participation included being a Ghanaian of reproductive age and having experienced a perinatal loss. Other conditions included those who showed interest, met the inclusion criteria, and consented for their information to be forwarded to the researcher.

Ethical procedures are fundamental to all parts of an ethnographic study (Lincoln & Guba, 1985). Considering the sensitivity of the research topic, perinatal loss, I was attentive to ethical considerations such as informed consent, voluntary participation, confidentiality, anonymity, and non-maleficent. Verbal, written, or fingerprint consent was received from participants. Participants were made aware of the voluntary nature of the study and their right to withdraw at any stage of the study. Throughout the data collection, I made the effort to be transparent and maintain privacy and confidentiality. Following each interview, the recorded conversations were played for participants to listen and agree to share. All references and locations linking to participants' information were removed and pseudonyms were used throughout the study to ensure anonymity. I informed the participants that information shared with me will be shared only with my supervisory team and their identity will not be revealed in the reporting of findings from the study. I made sure participants were not exposed to injury such as psychological harm from participating in the study. Thus, the interview was paused for participants who showed sign of discomfort during the interview and asked if they would like to be referred to a counselor or psychologist. Participants were reminded of the voluntary participation in the study that they can withdraw at any time.



## Findings

The findings revealed the following demographic and obstetric data of participants:

All 20 participants who took part in the study were Ghanaian women. Participants' ages ranged from 20 to 42 years, with the average age of 26 years. All participants except four were married. The four single mothers had partners. Seventeen of the participants were Christians; and three were Muslims.

Two of the participants held polytechnic degrees (10%), eight held high school qualifications (40%), four had junior high school qualifications (20%), three had primary school certificates (15%), and three (15%) had no education at all. Almost all the mothers were engaged in some sort of employment. Participants' employment histories ranged from secretary and office clerk to receptionist. Ten worked in government institutions and three in private institutions. However, five of them were into petty trading and two were unemployed housewives. They all worked and lived in the Greater Accra Region, except for the four participants who were referred to the hospital from other clinics in the suburbs of Accra.

Some of the participants did not attend antenatal clinic at the study site but all of them delivered at the study setting by either caesarean section or normal delivery. Their experiences of perinatal loss ranged from one to three deceased babies/pregnancies. Most of the losses were due to stillbirths, severe anemia, pregnancy complications like placenta abruption, oligohydramnios, complications of hypertension (e.g. eclampsia), atrial septal defect, and newborn deaths. Nearly half of the participants (nine participants) had experienced multiple losses; the rest (eleven) had only one loss. Length of pregnancy before experiences of loss ranged from six months of pregnancy to three weeks after delivery. Those participants who experienced multiple losses

were either due to two or three of the causes mentioned. Most of the participants with the exception of seven had children who are alive. The number of living children ranged from one to four. The participants had experienced their most recent loss between three week and six months before the interview.

The data presented in this manuscript was derived from the original purpose of the research, exploring the experiences of Ghanaian women who have experienced a perinatal loss. In this manuscript, I sought to explore Ghanaian women's perspectives of marriage, motherhood, and childbearing within the Ghanaian cultural context. This manuscript focusses on two main themes that emerged from the data; a) "beliefs and values surrounding marriage, motherhood and children"; and b) "views of childlessness and perinatal loss".

### **Beliefs and Values Surrounding Marriage, Motherhood and Children**

This is one of the two main themes that emerged from this manuscript. The theme generally expounds on Ghanaian women perception of marriage, motherhood and childbearing as a natural commitment expected from couple especially, women in Ghanaian society. Participants believed that entering into a marital relationship marks the beginning of a commitment of togetherness; and during the union, it is expected of the couple to start their own family. The following subthemes are part of the main theme that exemplified participants' views surrounding marriage and motherhood: i) marriage as an obligation for raising children ii) motherhood is equated with successful birth and identity and iii) children as gift from God and source of strength.

**Marriage as an obligation for raising children:** In this theme, majority of the participants made strong statements that demonstrated varying understanding of marriage. They,

however, agreed that though marriage is an essential requirement and a social fulfilment for Ghanaian women, it makes all parents more responsible. The following excerpts illustrated the beliefs of the women:

Afariwaa is an unmarried Akan woman from a large family with a rich ancestral heritage and tradition of marriages with large families. She lamented her decision of not considering advice from the elders in her family to formally marry before her first pregnancy. Afariwaa noted:

Married in a good and stable relationship is ethically the best option for raising children. Most fathers in this type of relationship get involved in raising the children to have a better future. Fathers' strong training offers male children good growth and direction, because most boys relate and learn more from their fathers. I want many sons in the future, and I feel my children will need their father.

Another participant described marriage as a different level of commitment and foundation for establishing a family. To her, marriage is a relationship bounded by sacrifice, responsibilities, and respect for each other which enhances the reputation of the couple in the society. Esinam continued to talk about marriage as an expression of Ghanaian culture based on consent between two adults. She decided to settle for marriage because she believed that marriage benefits both men and women especially their offspring:

Well, marriage is beneficial when one picks the right person. It is the confirmation of a private relationship in public and in the presence of witnesses. This comes with obligations; while women look up to their husbands for shelter and security for themselves and their children, men expect wives to be obedient, good homemakers, and care for their children.

Most of the participants alleged that marriage and children make most men more responsible. Their views were that, in marriage husbands are expected to be financially responsible to provide for the household especially the children.

Twenty-year-old Konadu is a single young woman and had a first-time experience in perinatal loss. She perceived marriage as an association between members of two families alongside the union of husband and wife. In this way, she feels there is a binding responsibility for parents to support each other to provide shelter and to financially support their offspring. She recommends women marry before childbearing. She shared her conviction:

I lost my child because I did not take my time to marry to have security and better finances for my child. If I had a man in my life who was legally married to me, I am sure I would have had a home of my own, good nutrition, and medication. All these services were difficult to access during my pregnancy because I did not have a man to legally take responsibility of the child.

**Motherhood is equated to successful birth and identity.** As part of the subthemes emerging from the theme “beliefs and values surrounding marriage, motherhood and childbearing”, motherhood is perceived as that which is equated to successful birth and an identity. It is a commitment all Ghanaian women must pursue to validate fertility and fulfill cultural responsibilities as women. Becoming a mother offers one an opportunity to contribute to the socioeconomic growth and development of one’s family. Most of the participants perceived motherhood as a position held by a woman grounded by her affiliation with a child. Some of the women disclosed their overwhelming fears of not becoming a mother. One of the participants, Cecilia, a 29-year-old woman who had experienced three losses when interviewed, perceived her losses as a loss of motherhood. She expounded:

Motherhood is central to women’s identity; it is one of the most beautiful life experiences. Becoming a mother meant everything to me and it was the reason for my early marriage. So, when I lost my children and my womb, I felt I had lost the right to be a mother forever.

Other participants described their experiences of motherhood as unconditional and genuine love. Adwoa perceived childbearing as a natural occurrence and an experience every woman in Ghana must embrace. Adwoa noted:

Motherhood is both amazing and fulfilling. To be a mother is like achieving a goal. You get to love, care, and teach that child your values. That child becomes your friend and you are able to share with the child everything you feel.

Motherhood was also interpreted as a new phase in a woman's life, an adventure of raising the newborn and instilling certain family qualities in them. Oboshie described her view of motherhood as a new strength and sacrifice:

This is my first child and the joy I experienced was overwhelming; my fears of never becoming a mother was gone for a while. There was a new colour to my life, it had become meaningful, I was not barren. My pregnancy and the thought of becoming a mother was the greatest thing that ever happened to me.

The first movements of a baby and the pleasant feelings of being called someone's mother and becoming responsible for someone's life were recounted by Hawa in her journey to attaining motherhood:

The day I felt the ripple effects of my child's movement was everything. It made me realize my closeness to attaining motherhood. Motherhood to me is about life with my kids, teaching and encouraging them to become better versions of myself. It is adding more value and dignity to my achievements and proving to society, my friends, and in-laws that I can also have a child. It is a sacrifice worth everything.

**Children as gift from God and source of strength.** Emerging as the third subtheme on beliefs and values, participants considered children as a blessing and a gift that brings stability in marriage and grants women the right or ticket to become mothers. Participants described that women in Ghana start planning for children soon after marriage. One participant depicted

children as a source of strength and contentment. She further stated that having children was an experience that added new colour and meaning to a woman's life. She commented:

Children are blessings from God and every woman should embrace them. They fulfill our lives as mothers. To me there is nothing more comforting than to have a child to go home to, to teach her/him my values, and see him/her grow to become a responsible adult.

Afi has three living children, and this is her first experience with perinatal loss. Afi reiterated what her grandmother told her about the significance of children: *my grandmother once told me that children are everything in a family, they hold the key to future prosperity in marriage and are an important part of every family in Ghana.* Even with present-day beliefs and enlightenment, childbearing is highly valued in the Ghanaian society and fundamental to every marriage. Families and in-laws demand and look forward to having grandchildren. For most of the participants, having a child is extremely important and failure to reproduce is a major setback in their lives. Adiza strongly believes children are the key to a successful marriage and long-term companionship.

Children are lifetime partners and will always remain with you no matter the circumstances, and being a mother is the best thing that can ever happen to any woman. Having children brings a lot of respect to both the couple and their families.

Another participant elaborated further and emphasized the value children add to a marriage. She expressed the satisfaction of increasing the size of a family through marriage. Adobebe stated:

In Ghana, marriage goes hand in hand with children. Marriage and children are highly acclaimed in our society; therefore, every woman who marries would want to deliver at some point in her life to increase her lineage. It will be a shame not to marry or deliver; people will talk.

All the participants in the study valued marriage as an important component of life and said that having children is a security or insurance for a longer relationship.

## **Views of Childlessness and Perinatal Loss**

This is the second main theme from this manuscript. The theme describes the perception of participants on childlessness in the context of perinatal loss in Ghana. The general opinion of participants on this theme was that being childless could arise from one of several causes including personal decisions such as being in a relationship where the partner does not want a child, perinatal loss, infertility, and diseases. In Western countries, being childless is often a viable choice for women; women can decide not to have children and yet enjoy fulfilling lives. On the other hand, Ghanaian women are culturally bound to bear and raise children. Although women in Ghana currently have the liberty to make decisions and choices on bearing children, the strong reaction from family, friends, and community members remains a challenge. The subthemes under the theme “views of childlessness and perinatal loss are”: i) childlessness as a failure for women, and ii) attachment, loss and isolation: a response to perinatal loss

**Childlessness as a failure for women.** Infertility and childlessness are culturally associated with sexual indiscretions by young unmarried women who often resort to induced abortion of unwanted pregnancies during their reproductive years. In the traditional Ghanaian setting, this lifestyle is frowned upon and when adult’s age women are not able to reproduce, they are stigmatized and verbally abused. Women in this study conveyed different understandings of childlessness in relation to their loss. The subsequent narratives from participants offer a valuable understanding of the effects of childlessness in Ghana.

Participants agreed and emphasized that childlessness is a failure for women and a threat to peace marriages in the Ghanaian society. Mariama believes women gain confidence and more respect through childbearing but her Muslim background puts fear of having a rival in her home if she continues to lose pregnancies:

Not only is it dignifying to give birth, childbearing and marriage brings respect and self-esteem. A woman who has a child is highly valued and feels more secure in her marriage. However, if I do not bear children as custom demands, there will be another woman to do it for me, and that is my fear.

Gifty also added that successful childbirth takes away humiliation and adds comfort in old age:

Children add to the social status and emotional fulfilment in the life of women. Success without children in Ghana limits women in accomplishing their dreams. In every woman's old age, children become the pillar of support. Without children, life becomes difficult.

Pokua is 27 years old with no children and she said that *the bonds that keep marriages together are children and that once a child arrives, relationships with spouses and family members improve greatly and spouses discover their responsibilities and shared interests, however if as women we fail to do so it becomes a stigma*". Participants like Pokua who experience multiple losses and are without children feel desperate and are overwhelmed with profound grief. She quietly continued to share her fears:

For three years, I have been going from one outdooing to the other with my husband and I wondered when people will attend my own. Just when I got the chance again, I lost it. When will this end? It is very clear from how my husband behaves that he is getting fed up with me, he avoids my conversations now.

Another participant (Brago) observed *"long term marriage without children create stress in relationships among Ghanaian couples"*. She further goes on to say that this type of stress naturally creates a rift between husbands and wives because of pressure from extended family members and friends; most husbands always look for a way to maintain their dignity amongst their peers. She described her experience:

It is hell being constantly reminded of my loss. Every time I see or meet with my in-laws, they show me in so many ways that I am a disappointment to them. Unlike other daughters-in-law, I haven't been able to provide them with a grandchild. The provocation



and pressure from them and my husband is driving me crazy. I feel like less of a woman because I think I have failed everyone.

Cecilia, who had difficulty getting pregnant after six years of marriage, narrated her encounter with her extended family:

Childbearing is a big deal in Ghana, and when you do not have a child, it gives people room to discuss you. Even family members can use the predicament to ridicule you. My mother-in-law and sisters-in-laws once told me to my face that if I know I am infertile, I should permit their son and brother to find himself another woman.

Felicia is a mother of two with one experience of perinatal loss. She shared how her community members and friends peddled false rumours that her inability to become pregnant was because she had been medically sterilized. Felicia related the rumour:

They started calling me all sorts of name like ‘Obonin’ (a woman who cannot give birth). Just because I was not getting pregnant after marriage and they thought I was infertile. This made my husband feel very tense. Though I was trying so hard to conceive, my husband was getting irritated with the poor outcome.

**Attachment, loss and isolation: A response to perinatal loss.** An important point of interest observed in this study was that regardless of the number of living children participants had they were still emotionally attached to their loss and wished they could have a replacement for their loss or still have those they lost back. Some of the participants’ grief response to their loss was isolation. Adwoa has three daughters and still desires a boy. She notes that having a male child in Ghana is important in most families. She related the birth of a male child to having a leader or heir to protect and support his female siblings in the future. Adwoa further stated that having a son in her culture is fulfilling and most spouses from her tribe are more appreciative when a pregnancy outcome produces a male child. But that is not to say baby girls are not appreciated, she added. To a mother, a girl child is as important as a boy child. Although

Adwoa's deceased child was not a boy, she was sad with the results. She desperately expressed her emotions and the wish of getting pregnant soon:

In the beginning, when I was told that it was a girl, I did not like the idea because I have girls already. But as time went by, I adjusted to having her and felt so attached to her. She was going to be my last child.

Other participants emotionally describe how they are becoming disconnected from society, friends, colleagues, and family members as well. They believe that withdrawing from society is affecting the support they receive from people. Guaaba admitted becoming bitter and resentful after her loss. Her resentment extended to almost all pregnant women she came across:

There are times I am filled with envy for women with newborn babies. I feel so sad and wish it was me. There were friends in my church who had their children and because of that I find it difficult to go to church. I have just decided to stay away for some time. I don't want any probing questions to remind me of my loss.

Like Guaaba, Oboshie perceived invitations to friends' christenings as a painful reminder of what she was not able to achieve. Therefore, she declined those invitations:

I feel I am losing support from friends and family, because whenever my husband asked me to go out with him, I made excuses. Discussions at meetings with his friends and family are always about their children, especially among the women. It puts me in a very uncomfortable position, so I try to avoid them. In so doing, they don't visit or call me. Sometimes I ask myself, "when will they learn not to talk about their children in my presence?"

## **Discussions**

The findings from this study highlighted the views of Ghanaian women on marriage, childbearing and motherhood in the framework of perinatal loss. These backgrounds provided an in-depth knowledge into the cultural norms on the importance of children in an institution of marriage and the need for Ghanaian women to attain the status of motherhood. The findings further describe how several sources of cultural beliefs shape the reactions and responses of

perinatal loss in the Ghanaian society. Two main themes: a) beliefs and values surrounding marriage, motherhood, and children; and b) “views of childlessness and perinatal loss” were discussed in this manuscript. In addition, recommendations for specific institutions and limitations of the study are described.

Ghanaian cultural norms like marriage, childbearing and motherhood plays a very significant roles in the lives of women in Ghana, however when the process of becoming a mother is averted by a sudden and preventable complications like perinatal loss, it affects the reactions and response of these women. Participants’ outlook on marriage was linked with family expectations and cultural and social status. Many of the participants in the current study perceived marriage as an important social medium for reproduction and enhancement of status; a requirement to be valued as women in Ghana and a legal security. This is consistent with previous studies claiming marriage as partnership with beliefs backed by religious, family and societal values which remain vital in Ghanaian social institution and a requirement in every adult’s life (Afful & Nantwi, 2018; Bogya, 2014; Oppong, 1974). Gyekye (2003) asserts that the African cultural system views marriage as “a basic social institution in human society that forms a link between families, establishing and maintaining lineage, but it is also for creating and sustaining ties of kinship” (p.76). Different opinions continue to be shared by other researchers on the institution of marriage. While some researchers have reported that children and pregnancy inspire thoughts of marriage (Lappegård & Noack, 2015; Le Goff & Ryser (2010), other scholars claim that many people marry due to cultural pressure although the expectation of having children when married is weakening (Billari, 2001; Wu & Musick, 2008). The participants in the current study corroborate that motherhood and marriage come with maturity and responsibility for raising children.

The findings from this study further bring forward the idea that marriage is a source of providing strong parental care and the legalization and legitimization of children. Married women with children in the study shared that marriage is an important attachment that offers a stable and economically sound environment for raising children. A good and supportive marriage with a robust relationship provides better economic relief for women and children; most women in the current study's idea of marrying because of the stability marriage offers them and their children which is supported in the literature (Kuo & Raley, 2016; Jarnkvist, 2019).

Another key finding from this study is that couples who were married and had children were more content with life in the Ghanaian culture. Lappegard and Noack (2015) reported similar findings from their study. This cultural perception of happiness based on marriage and having children contributes to the intense stress women who experience perinatal loss go through in Ghana. Ghanaian society needs education on how reproductive system works to bring about society shift in belief on marriage, motherhood and childbearing.

Participants perceived motherhood as that which is firmly linked with femininity and an important cultural value in Ghana. Many researchers through their findings have established that in the sub-Saharan African countries, motherhood is connected with the ability to bear and raise biological children (Kuti & Ilesanmi, 2011; Obi, Onah & Okafor, 2009; Obiyo, 2016). For instance, Obiyo (2016) study on childlessness in Nigeria identified the important sentiments Africans attach to motherhood. Obiyo (2016) emphasizes that traditions in the African society consider motherhood a significant transition to maturity and the most important attribute of a woman's life. Similar findings from a study on motherhood share that many cultures in Africa perceive motherhood as a symbol of respect, dignity, and identity and, like most women in this part of the world, motherhood is vital and relates to their status as women (Olayiwola &

Olowonmi, 2013). In the current study, participants' perception of motherhood is customarily determined by the ability to deliver a healthy baby and the number of children a woman can successfully deliver. Therefore, "when the road to motherhood is blocked—whether due to miscarriage, stillbirth, or other sources of perinatal loss—it is a traumatic loss often suffered in silence and isolation" (Jaffe & Diamond, 2011, p.166). Additionally, in the African cultural context when the positive expectation of pregnancy outcome becomes undesirable and the dream of motherhood is unclear, mothers suffer from lower levels of self-esteem (Wright, 2010).

Most participants in the study expressed opinions surrounding motherhood as central to their identity as women, and, hence, felt traumatized and devastated after experiencing a perinatal loss. Those who have experienced more than two losses expressed feelings of low self-esteem and emotional abandonment and those who lost the opportunity of becoming a mother felt that their identities as women were destroyed. The participants' narratives reveal that many Ghanaian women attempt to attain the position of motherhood, although not all are successful. Becoming a mother in Ghana means everything to the vast majority of women in that society. An article on motherhood in Africa by Akujobi (2011) similarly discusses the importance of motherhood as an experience which profoundly shape the social and cultural circumstances of women in Africa and ceases them from being an autonomous individual because their identity is attached to their children. Contrarily, Clark (2012) in her doctoral dissertation on meaning of motherhood for African Americans provided evidence that motherhood is a trade-off between work, success and economic cost. This outcome was not unexpected as children are seen as the pinnacle of marriage in Ghana and family members look forward to seeing children after the contract of a marriage.

The dynamics of motherhood were clearly demonstrated in the sentiments shared by participants in this study. Participants indicated that women's status and relationships with spouses are enhanced by the ability to give birth to their "own blood child": motherhood was crucial to strengthening the bond in marriage. Several studies on childbearing have confirmed that motherhood is about women bringing forth their own, that it strengthens mothers' sense of security in marriage. For instance, a study conducted on childlessness in marriage in the Lowe community in Nigeria found that motherhood and fertility as the strengthening factor in marital relationships that provides security to women (Obiyo, 2016). Similarly, other studies revealed that motherhood is among one of the celebrated and respected positions in Africa and Ghana. (Egede, 2015; Siwila, 2015). Motherhood through biological children is respected more in the African family structures than through adopting children, which is devalued and maligned (Egede, 2015). In Ghana, adoption defies the Ghanaian acceptable way of having children to increase the family size (Donkor & Sandall, 2009). The typical traditional families in Ghana hold the belief that children through adoption are not as natural as biological children and therefore perceive adoption as a failure to procreate (Donkor & Sandall, 2009).

Almost all the participants agreed that pregnancy and the birth of healthy children are considered a blessing and the most precious of possessions. They also deemed the presence of children in marriages as a critical factor in strengthening the bond between husband and wife and also that of in-laws and society. Thus, the inability to bear children as a result of perinatal losses construe a threat not only to the success of their marriage but to their prosperity in the marriage and in wider society. Childbearing usher women into the state of maturity and a deliberate attempt to refuse to have children is seen to be a disaster for any woman in Ghana (Bogya, 2014). Participants perceived children as the fruit of marriage and gift from God, they play a

pivotal role in the continuous commitment of marriages and establishing the family as a unit. Majority of the participants describe children as key to decisions of their parents' continuous relationship, whether to stay as a couple or divorce. This is consistent with the analysis put forward by Jarnkvist, (2019) claiming that children are important part meaning of marriage. The significance of children in Ghana commences from the marriage ceremony. Rituals commonly performed during marriages in Ghana include the pouring of libation<sup>1</sup> and prayers; and on this occasion, the newly married are bestowed with prayers of fertility and healthy children, as well as wealth (Gyekye, 2003). Subsequent to this, both families look forward to celebrating the birth of a baby within a year or two after marriage. The inability to have a child or repeated losses of pregnancy after the expected period, is a bad omen which is frowned upon with a saying that women who continuously experience perinatal loss are people “whose basket leaks” (using the uterus as a reflection of a basket) (Siwila, 2015, p. 61).

Most of the opinions shared by the participants in this study on the importance of children were similar to the nine components of how parents or couples of childbearing age value children (Hoffman, Thornton & Manis, 1973). The components included “achieving adult status and social identity; expansion of the self; primary group ties and affection; achievement, competence and creativity; social comparison; power and influence; economic utility; stimulation and fun; and, morality” (Hoffman, Thornton & Manis, 1978, p. 92). Children bring to parents the feelings of creativity and expansion of family and self, but their presence in a family demonstrates long-term commitment of the union of the parents (Hoffmann & Hoffmann, 1973;

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<sup>1</sup> Pouring of libation– The Ghanaian traditional way of performing rituals to their ancestors or the departed souls. It is done by pouring liquid on the ground to offer prayers in the memory of the dead

Trommsdorff & Nauck, 2006). The symbolic motive of Hoffmann's theory was emphasized in the participants' stories.

The common theme of the participants' narratives was that childbearing was an achievement that comes with power, success, and accomplishment. For most parents in Ghana, children do not only help to foster strong ties to nuclear and extended families, they are also considered an economic resource and a mark of social recognition and acceptance. Family members expect married couples and even single women of childbearing age in common-law relationships to have children soon after the union (Boakye-Boaten, 2010).

The findings of the current study highlights childlessness as a source of disappointment and abandonment for women in the society; they further describe it as a failure to renew the link between the ancestors and the living and therefore, creates rumours of witchcraft among neighbors. The women also express fear about the possibilities of their husbands having an extra marital affair. Childlessness through perinatal loss is a misfortune, and a woman's inability to bring her husband posterity is often attributed to her bad practices, like having illegal abortions during her youth (Gyekye, 2003; Wilkinson & Callister, 2010). The effects of this failure in societies like Ghana and other sub Saharan African countries are insults, scorned, mocked, humiliated, and denied leadership positions in their communities because of their reproductive failures (Tabong & Adongo, 2013). Obiyo (2016) points out that the pressure imposed on women by being childless and their failure to bear children through perinatal loss can offensively disrupt every aspect of women's personal and marital life. Further explanation has been given that women are domestically abused, and marriages are annulled when there is no child in a relationship however, previous studies have discovered that not all women encounter the such



humiliation (Nahar & Richters, 2011). Women from upper and middle social classes with higher levels of education and economic privilege experience less dishonour than women with lower educational backgrounds from poor families (Donkor & Sandall, 2009; Nahar & Richters, 2011). The present study did not assess the impact of either the participants' levels of education or their socioeconomic status on their experiences regarding perinatal loss. Although some participants in this study cited strained relationships with their husbands resulting from perinatal loss, none attested to domestic violence.

The findings in the present study indicated that childlessness in Ghana is seen as a failure in couples, but generally, women are the ones condemned and stigmatized even when they are not liable. Spouse, family members especially mother-in-law's put pressure on them to bring forth. Related to these findings were found in a study conducted by Tabong and Adongo (2013) on infertility and childlessness in Northern Ghana, where women were frequently chastised for their husband's incompetence to have children. The narratives of my participants increased the understanding of the issue and elaborated it more as they described the name given to them "obonin" (a woman's inability to bear children). However, findings from a study conducted by Obiyo (2016) reported that childlessness may not necessarily have a negative effect on women and their relationship.

Some of the participants offered valuable insights into the complexities of experiencing perinatal loss as Ghanaian women. Participants experienced reactions like depression, anger, loss of identity, and a sense of insecurity in their marriage. Participants were at a loss about the root causes of perinatal loss and whilst some blamed themselves for the loss, others blamed unseen "hands" like witchcraft or their enemies and rivals. Most of them had no idea that certain diseases arising out of pregnancy could lead to spontaneous abortion of the unborn

child. Participants talked about their withdrawal from society, friends, colleagues, and family members. They believe that withdrawing from society is affecting the support.

## **Recommendation**

Recommendations for specific government institutions in Ghana, the research setting and broad recommendation for the nursing profession are presented throughout the study. Based on the findings from the study, strategies that can help women meet their aspirations to become mothers and reduce the stigma of childlessness in Ghana and similar African countries with the same culture must be implemented. First, the Ministry of Gender, Children and Social Protection in various countries should consider educating the public about the causes of infertility and perinatal loss as well as the stigmatization of childless women in order to:

- a) increase public knowledge on perinatal loss
- b) strengthen the social support available to families especially women who have experienced perinatal loss.
- c) help reduce the fallacy about the negative views of childlessness and infertility and improve the reproductive rights of women.

More research is needed to further address the link between Ghanaian cultural values of marriage and motherhood. Further investigation into the involvement of Ghanaian men and how they perceive perinatal loss will be useful. Additionally, research into infertility in men will be an interesting evidence to demystify the myth that women are the only ones that are infertile. Last but not least, the government of Ghana through the National Health Insurance Plan may consider providing insurance for infertility treatment in order to make the service accessible to couples needing assistance with fertility issues.

## **Limitations of the Study**

The limitation of the study is that the research only captured the perspectives of the women's experiences of perinatal loss and did not cover the opinions of Ghanaian men. An additional limitation was that the participants were located in only one institution in Ghana, which may not represent the views of all the women in the country. It would be beneficial to include women from different educational and social classes.

## **Conclusion**

This article sought to explore the perception of Ghanaian women on marriage and motherhood in relation to perinatal loss. Findings from the study highlighted the importance of children in traditional Ghanaian society. As stated earlier, children perpetuate the existence of family and cultural legacies. In the Ghanaian traditional context, a child is the hope of the future in the sense that they are trained to continue the family lineage and cultural legacies. Children are also seen as the economic future, as they are expected to support and provide for their aging parents and other relatives. The paper contributes to knowledge on gendered concepts of motherhood by exploring the cultural perspective of motherhood among Ghanaian mothers who have suffered perinatal loss. Women all over the world contribute to lineage and population creation and the advancement of strong economies. This study also focuses on a grey area where there is very little focus; the hope is that it could lead to improvements in maternal and child health care delivery in Ghana and worldwide.

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## **Chapter Six**

### **Understanding the Grief Experiences of Perinatal Loss within a Cultural Context:**

#### **Ghanaian Women's Call**

##### **Abstract**

Ghanaian women of reproductive age who experience perinatal loss become vulnerable to social stresses. The occurrences of this loss remain a significant challenge as the cultural expectations of women are to reproduce. Building on the previous work on experiences of perinatal loss in Ghana, the writer sought to understand and explain the grief and lived experiences of perinatal loss among Ghanaian women. A focused ethnography methodology was used to explore the cultural understanding of women's experiences of perinatal loss in Ghana. Twenty Ghanaian mothers who experienced a perinatal loss were recruited between July and November 2017. Semi-structured interviews were conducted to collect in-depth data to understand how these women feel about their loss. Data were analyzed using Roper and Shapira's (2000) outline of analysis.

Findings from the analysis highlighted two main themes: understanding the association between pregnancy and loss in the context of Ghana; and impacts of loss on women. Few research studies have been conducted on understanding perinatal loss in Ghana. Creating awareness of the lived pain and emotional effects of perinatal loss through research could help contribute to understanding and acceptance by society and improve services and support rendered by the health care professionals to women who experience perinatal loss. This study discovered a pressing need for the women to reduce their pain and restore their lives back to normalcy.

**Key words:** perinatal loss, grief experiences, disenfranchised loss

## Understanding the Grief Experiences of Perinatal Loss Within a Cultural Context: Ghanaian Women's Call

*“Before attempting to understand how parents create sense or meaning out of their loss, it is critical to understand the nature of those losses. What is so powerful about losing a child? What is particular to perinatal loss that makes grief so poignant and recovery difficult?” (Claudia Malacrida 1999, p.1)*

For an enhanced understanding of the women's experiences, I briefly present for reflection the story of Cecilia (pseudonym), a participant whose story stood out among the rest. Cecilia is a 29-year-old woman and—like any married Ghanaian—she is expected by her in-laws, family members, and society to start a family soon after marriage. Cecilia was amongst the first participants who agreed to be part of the study. She believed that sharing her story is a good coping strategy for herself and other women. Cecilia always began her story of loss with this assertion *“my losses; my silence”!* In Cecilia's words,

*I have always wanted children since my childhood, unfortunately, I haven't been blessed with any, neither am I ever going to have one. I am a mother without a child; experienced pain without reward. I am still processing my losses. I am too young for what has happened to me. Every piece of me weeps every day.*

Cecilia was on a family planning method (Depo-Provera). When as a couple they decided to have children, she stopped the method and prepared for pregnancy. She shared her story:

*Unfortunately, I have had to say goodbye to three beautiful children through perinatal losses: two girls and a boy. The length of pregnancy before death were between six to eight months and two weeks. Throughout my pregnancies, I had attended antenatal regularly and made sure I never missed any of my appointments. I followed all the advice the midwives gave to me and ate all the right types of food, at least, those recommended by my midwife. I never missed taking my daily vitamins and I always made sure to rest and sleep under a mosquito net.*

Experiencing perinatal loss forever changed Cecilia's path. She spoke about her grief:

*I found it difficult to believe what I was told, especially the news of the removal of my uterus. I wished these words were never spoken to me: “there is no fetal heartbeat.” I wished for the midwife to be wrong. Life has been unfair to me. I don't ever think I will be able to come to terms with what has happened to me... never!!! The question I keep asking is, “why me? Why do I have to give up such an important piece of me?” A body part and all that it represents to be a woman. My ability to give my husband children has been taken away from me. What will be my connection with other women? Why do I have to face it at all? It makes me feel unfeminine and defective in so many ways.*

*I struggle to make meaning of my losses. I cannot sleep, my days are blurred with pain and heartache. I spend my days crying in bed and feeling sorry for myself.*

## **Introduction**

Perinatal loss is defined as the nonvoluntary end of pregnancy or the death of a fetus occurring between 22 weeks of gestation and seven days after birth (WHO, 2006). It occurs unexpectedly and brings along with it, a profound emotional changes and challenges to all affected: mothers, close family members, and friends. The pain experienced is difficult to explain and can span across time (Scott, 2011). This psychologically stressful event is commonly experienced but often not shared in Ghana. Culturally, continuous perinatal losses are seen as the inability of women to prove their womanhood and this can interfere in the marriages and social lives of women in Ghana (Haws et al., 2010).

Understanding Ghanaian women's experiences of perinatal loss is a way of assessing the women's individual perceptions of an issue to determine why and how they respond to those experiences. In contrast to high-income countries, Ghanaian women's experiences of perinatal loss are not reflected in research literature. The emotional challenges women face in Ghana are overwhelming but often lived silently. Presenting their voices through research is, therefore, a way of acknowledging women's pain and providing avenues for change in policies as well as existing cultural beliefs that affect women. To understand the experiences and the impact of perinatal loss in Ghana, this study explored and shared 20 Ghanaian women's grief experiences of perinatal loss in their cultural context.

## **Background**

The normal physiological occurrence of pregnancy and delivery of a healthy child is an occasion of happiness in nearly every home. It is an achievement of a purpose and a period of change and families look forward to welcoming a new member into their lives. Many expectant

mothers frequently perceive pregnancy and delivery as normal but fail to acknowledge that not all pregnancies are without complications (Bangal, Sachadev & Suryawanshi, 2013).

Perinatal loss results from complications of pregnancy. It occurs with pregnancy beyond 22 weeks of gestation to 7 days after delivery (WHO, 2006). Diagnosis of pregnancy complications and the sudden death of the newborn are mostly unexpected and met with unpreparedness. The related frustrations, loneliness, and pain experienced after a perinatal loss is frequently not understood by society (Due, Chiarolli & Riggs, 2017). Researchers believe perinatal attachments begin in early pregnancy and continues after birth; making it difficult for mothers to overcome their grief, especially after bonding with the child (Maddahi, 2016; Muller, 1993). The emotional responses of a mother to a perinatal death is often determined by the extent to which she bonded with the child or how much the baby meant to her. Grieving of perinatal loss is complex and individual factors like past history, duration of pregnancy, how long the woman has been attempting to have a child, and pressure from family members influence the extent of their grieving (Armstrong, 2002). The importance of understanding the impact of perinatal loss on parents has been recognized by scholars, who believe that the understanding, support, and care shown during this difficult journey help reduce the grieving process (Kersting & Wagner, 2012; Klaassen, Young & James, 2015; Neimeyer, Klass & Dennis, 2014).

### **Perinatal Loss in Ghana**

Perinatal loss numbers are high in the African continent especially sub-Saharan Africa. A report from UNICEF (2014) claims that 80% of these deaths occur as a result of causes that could have been prevented by fundamental needs like clean water, better nutrition for mother and child and skilled professional healthcare workers. Similar to most African countries, perinatal loss is common in Ghana. Statistics from United Nations report (2015) and Ghana Statistical

Service (2015), show Ghana's total neonatal mortality rate is at 28 deaths per 1,000 live births. The report further claims that within the urban areas of Ghana, rates are higher at 33 per 1,000 live births and the rural areas are 29 deaths per 1,000 live births. However, perinatal losses are underreported in rural parts of the country and 70% of the deaths that occur in individual homes may not be registered at the appropriate facility (Carlo et al., 2010; Cousens et al, 2011). These statistics additionally suggest that low reporting of perinatal deaths in the rural areas is related to inadequate report of perinatal loss in the health facilities where women deliver. Children born to low-educated or illiterate mothers are about 1.3 times more likely to die during the first month of life than those born to mothers who are highly educated (Ghana Statistical Service, 2015; United Nations, 2015).

The WHO maternal and child epidemiology report in 2015 cited the main causes of newborn deaths in Ghana to be prematurity, birth asphyxia and sepsis, congenital anomalies, acute respiratory infections, injuries, and tetanus. Like maternal death, perinatal loss continuously occurs in low-income countries such as Ghana as a result of multiple factors including a lack of adequate facilities and resources, inability to access health facilities with skilled professional health workers, and early discharge with no follow up by health professionals (Ghana National Newborn Health Strategy and Action Plan 2014-2018). Contributing to this is the poor care-seeking attitude of the Ghanaian public especially those in the rural areas. Most babies who are born at home without experts sometimes develop complications and die and their deaths are normally not reported or documented (Engman et al., 2012).

Perinatal loss affects many women and their families and must, therefore, be a concern for health authorities and policymakers. Without understanding the complexities of these



women's experiences, addressing their real needs will be difficult. Evidence-based research findings have been identified as contributing immensely towards intervention, adaptation, and setting the priorities for problem solving in most countries. Yet, limited research has been published on understanding perinatal loss experiences of women in Ghana.

### **Perinatal Loss Grief and Attachment Theory**

Bowlby (1973) theory of attachment is considered to provide a meaningful understanding of the grief that follows perinatal loss. Bowlby viewed attachment as both a long-term shared relationship occurring between people that creates a lasting bond and also how those individuals respond to separation from that bond. The theory further reveals that attachment behaviours are involuntary and could be triggered by anything that threatens the security of the individual—for example, separation, loss, and fear (Bowlby, 1973). Bowlby believes grieving starts from four overlapping, sequential, and flexible phases: shock and numbness, yearning and protest, despair and disorganization, and reorganization and recovery.

Bowlby asserts that shock and numbness is the beginning of grief or the immediate reaction when victims are first told of the separation. At this stage the bereaved person gets traumatized and distressed and everything becomes unreasonable and difficult to accept. The individual develops awareness of the vacuum left in her life from the separation or loss and her anticipated future is no longer plausible (Bowlby, 1973). The next phase is the yearning and searching, where the griever develops anxiety and tries to fill the emptiness by constantly looking for reminders or objects to make meaning of the dead. As these objects gradually become meaningless and the loss of the dead becomes a reality, hopelessness and despair sets in (Wheatherby, 2017). There is anger, questioning, and withdrawal from society, and life may feel as though it will never be the same. Individual creations of new goals and day-to-day life

patterns help people who grieve to realize that life could be positive again—though the grief may not disappear, victims may recover from the initial shock and cope better (Lichtenthal et al., 2016).

Using the relationship between children and parents, Bowlby's theory highlights the significance of bonding and early attachments, which form between mother and child during the early stages of pregnancy (Bowlby, 1973; Buglass, 2010). Bowlby's theory additionally suggests that the sudden or uncontrolled parting of loved ones causes emotional suffering to those left behind because the attachment formed during the person's existence remains active throughout life. In perinatal loss, the grief experienced by a mother is a normal adaptive response to the broken affectional bond created during pregnancy. When a fetus or infant dies, the perceived connection by the parent(s), which is broken, can be a driving force in the bereavement outcomes. This theory "provides an explanation for the common human need to form strong affectional bonds with other people and the emotional distress or reactions caused by the involuntary severing of these bonds and loss of attachments" (Buglass, 2010, p.45).

### **Problem Statement**

In life, the normal expectation is for parents to die before their children, however, like the death of an older child, perinatal loss is a death that does not follow this expectation; children are born dead before they take their first breath or thereafter and before becoming part of society. The unexpected loss of a baby is psychologically stressful, and it is silenced in families and societies. Death by perinatal loss is not a conversational topic to discuss in the family; it is publicly not observed or mourned (Gallagher, 2013). Understanding the grief process associated with perinatal loss is fundamental to assist with the formulation of appropriate policies and services to support and manage the women who are faced with such grief and associated

challenges. This manuscript is a subsection of a larger study being undertaken to explore and understand the experiences and impacts of perinatal loss from the perspective of women within the Ghanaian cultural context. The study seeks to explore and describe an in-depth understanding of the experiences of perinatal loss within the Ghanaian cultural context.

## **Methodology**

### **Design**

A focused ethnographic design was used to explore and obtain an in-depth knowledge of participants' cultural beliefs and experiences of perinatal loss. This methodology was chosen because it allows me to study the life of particular group of people and also focuses on a more "narrowly defined culture" (Cruz & Higginbottom, 2013. p.38). I believe it best fits my research topic because in focused ethnography, there is the belief that cultural knowledge is implicit, however, researchers using this methodology are encouraged to use both emic and etic approaches in order to acquire a detailed cultural knowledge (Fetterman, 1998; Aldiabat & Le Navenec, 2011).

As a Ghanaian and a student who has been outside my country for a long period of time, I used both my emic and etic views to understand and interpret the lifestyles of the participants. My insider's approach helped me to understand more of the cultural structures of Ghana. Often however, the participants provide less information as they expect the insider researchers to have existing knowledge about what they are studying (Merriam et al., 2000).

Understanding and interpreting of cultural knowledge are made feasible through the collection of data. In focused ethnography, there are three primary processes of data collection vital to the work of the researcher in order to achieve a deep understanding of the culture being

investigated. These are participant observation, interviews, and review of relevant documents (Cruz & Higginbottom, 2013). Researchers using focused ethnography aim to physically participate and conduct an in-depth interview to clarify the ethnographers' observations and obtain an emic view of the culture (Roper & Shapira, 2000).

I entered the field and formed relationships with the participants (Aldiabat & Le Navenec, 2011). During my interviews, I did observation in the field, I paid attention to the environment of the participants, the participants' interactions with family members as well as artefacts using symbolic interaction to generate meaning of the culture I observe. Additionally, I also attempted to understand the experiences of these individuals and tried to capture their behaviours within the respective cultural contexts (Wall, 2015). In the field, I took on the role of a learner, especially when I didn't have enough idea about that particular culture (Aldiabat & Le Navenec, 2011).

### **Sampling and Sampling Size**

I used purposive sampling to identify and select 20 women who have rich information for proper utilization on the topic on experiences of perinatal loss (Benoot, Hannes & Bilsen, 2016). The women who were recruited to participate in the study were Ghanaians who have had a specific experience in a particular setting. They also served as sensitive informants who enriched the data collection of the phenomenon and added to the general understanding of experiences of perinatal loss (Benoot, Hannes & Bilsen, 2016). Criteria for participation in the study included Ghanaian women with experience of perinatal loss, ranging from 22 weeks of pregnancy to 28 days after delivery; women who delivered at the study site and lost their babies; and women who were willing to talk about their experiences and signed the consent to contact form.

## **Recruitment and Data Collection**

Study recruitment occurred between July to November 2017 in one of the major health institutions in the capital city of Ghana, the Greater Accra Region. The hospital is strategically located and has a resourceful obstetrics department to serve multiple municipalities around the area. Access to the participants was negotiated with the help of four experienced practicing midwives who supported the recruitment process. The participants were initially contacted by the midwives and were provided with an information sheet. Thirty prospective participants who were willing to participate met the selection criteria. However, ten dropped out due to family reasons and sensitive recall memory. Finally, twenty women agreed to participate. Informed consent was obtained before the interview started. Participant's appointments were scheduled at their convenience and conducted in places of their choice. Seven of the participants were interviewed more than once. Multiple visits were made to follow up to continue with unfinished conversations and to clarify statements that were not clearly articulated. Pseudonyms were used to protect participants' privacy and identity.

I will like to note that most of the interviews were conducted in participants home and seven of them were done in an office and church premises on request by the participants. The interviews were conducted between three weeks to six months after the loss. As a midwife, I have attended workshops on providing emotional support to grieving patients and their families. My journey as a graduate student has offered me so many opportunities to be trained to interview different kinds of participants from many research studies. In addition to having a degree in nursing with psychology, one of the courses I recently took in my PhD course work was on grieving and hope which further prepared me to conduct the research on this sensitive topic.

A semi-structured interview schedule was used to guide the conversations with the participants, and it focused on understanding participants' grief experiences. Samples of the questions used for the interview included "Do you mind explaining to me the circumstances regarding the loss of your baby?" Probes such as "could you provide specific example of the experience" was used to enable participants elaborate on their experience. Another question on disenfranchisement was "Were you able to openly mourn your child?" The interviews varied from 60 to 90 minutes. Utilization of this type of interview helped the conversations to flow naturally as well as to question ideas that needed more clarification. The interviews started with an explanation of the purpose of the study and a description of the anticipated use of data. Participants shared their experiences of perinatal loss and their views on how they were cared for during their loss by health professionals, family members, and the community. Recognizing the sensitivity of the topic, participants were given the option to avoid questions they did not want to discuss. I regarded participants' contributions as meaningful and showed respect towards them. I also informed them of an arrangement I had made with a psychologist at the hospital which was free. Some interviews had to be rescheduled due to intense emotions or recall of painful memories. With the permission of the participants, all interviews were audio recorded. Pseudonyms were used to protect the participants' identities and privacy.

While there is no set time for conducting interviews, researchers propose a range between three months to two years after the perinatal loss for effective recall (Byass et al., 2009; Garenne & Fontaine, 1990; Lulu & Berhane, 2005). Soleman et al. (2006) asserts that the effects of recall might differ depending on the background and circumstances of the death, however, Engman et al. (2012) theorize that people that are interviewed at a time close after the death of their loved

one may be unwilling to discuss their experience. Participants were observed throughout the interview and participants mannerism and facial expressions were recorded into the field notes.

### **Data Analysis**

Data was analyzed based Roper and Shapira (2000) approach for analysing focused ethnographic data. This approach was employed because of its clarity and applicability to focused ethnography. I transcribed all the interviews and read all the field notes several times to get an overall understanding of what the participants are saying. Data were analysed and coded by grouping sentences and text of the same kind into meaningful descriptive labels. The descriptive labels were re-examined and were summarized and reduced to a manageable size. I regularly reflected on the interviews and continuously asked questions (Roper & Shapira, 2000 p. 69) to help me gain a full understanding of the experience of perinatal loss from the participants cultural perspective. I identified patterns by organizing the descriptive labels into similarities and differences across the participants transcripts. Similar descriptive labels were identified and arranged into smaller patterns and categories and then developed into themes. Furthermore, I identified statements that deviated from the rest of the information (outliers)

Additional subthemes were also developed from each theme. The themes and subthemes were compared with the memo I created during the data analysis and to the evidence in the literature. I reflected on the themes and subthemes as well as met frequently with my supervisory committee to discuss and negotiate for consensus on the evolving themes. At the end of the data analysis, six broad themes emerged from the Ghanaian women experiences of perinatal loss. From this, two themes emerged for this manuscript and they are a) understanding of pregnancy and loss in the context of Ghana, b) subsequent impacts of perinatal loss on women.

## **Rigor**

I used Meleis (1996) guidelines of maintaining rigor and that of focused ethnography design. Meleis proposed eight essential categories for researchers whose topics are embedded in culture, marginalization and vulnerability to evaluate rigor. This involves contextuality, relevance, communication, awareness of identity and power differentials, disclosure, reciprocity, empowerment, and time. The quality of this research is influenced by the researcher's perception, integrity, adaptability, and skills (Nyumba, Wilson, Derrick & Mukherjee, 2018). As a person who had personally experienced perinatal loss, it was challenging to be absolutely objective on the field. According to Knoblauch (2005), in focused ethnography the researcher uses her experience or knowledge of the study to bring forward the perceptions of the culture (Knoblauch, 2005). My experience of losing a child and my knowledge of the culture of Ghana were beneficial in recognizing moments and accessing in-depth information on perinatal loss. I documented my impressions of reflexivity and drew on my reflections to engage the participants in a deeper conversation on perinatal loss.

## **Ethical Consideration**

The University of Alberta Human Research Ethics Review Board, Canada, and the Ghana Health Service Ethics Review Committee granted ethical approval to conduct this study. The approval numbers are Pro00073592 and GHSERC22 /06/17. Additionally, the administrators of the hospital granted permission to access their facility and staff (midwives) to provide support in recruiting study participants.

Recruitment was conducted by an intermediary, the midwives working at the hospital's labour and delivery unit (McAreavey & Das, 2013). Further approval was sought from hospital administrators and chief nurse managers at the research site to permit me access to the midwives



to support the recruitment of study participants. With the help of the hospital administrators, four volunteer midwives were identified to recruit participants from the outpatient departments, antenatal units, and obstetric units.

Ethical procedures are fundamental to all parts of an ethnographic study (Lincoln & Guba, 1985). Considering the sensitivity of the research topic, perinatal loss, I was attentive to ethical considerations such as informed consent, voluntary participation, confidentiality, anonymity, and non-maleficent. Participants provided verbal, written, or fingerprint consent. Participants were made aware of the sensitive nature of the study and their right to withdraw at any stage of the study. All the 20 women wanted their stories to be heard by other women and therefore promised to go through with their stories. I made the effort to maintain privacy and confidentiality throughout the data collection. Following each interview, the recorded conversations were played for participants to listen and agree to share. All references and locations linking to participants' information were removed and pseudonyms were used throughout the study to ensure anonymity. I also discussed confidentiality that information shared with me will be shared only with my supervisory committee and their identity will not appear in the reporting of findings from the study.

## **Findings**

Two main themes compatible with understanding the participant's grief experiences of loss are discussed in this manuscript. However, these themes do not stand alone; they occurred with six subthemes that have been merged to describe each participant's story. The two themes are a) understanding of pregnancy and loss in the context of Ghana and b) subsequent impacts of perinatal loss on women. Under the theme understanding of pregnancy and loss in the context of Ghana, the subthemes are i) mothers' attachment to pregnancy and preparation ii) grief reactions,

iii) reflection and a new understanding of loss; and, i) relationship before and after perinatal loss, ii) fear of the unknown and iii) disenfranchised grief are subthemes under the theme subsequent impacts of loss on women.

Participants recounted their responses and reactions when the professionals at the hospital communicated the news of their loss. Although participants varied slightly in their experiences, there was a common thread in all the discussions. Participants' demographic information is presented in Table 1. This table includes participants' ages, educational levels, employment, and lengths of pregnancy and pregnancy complications.

**Table One: Demographic Data**

<b>Participant</b>	<b>Age</b>	<b>Education level</b>	<b>Employment</b>	<b>Complications of Pregnancy</b>	<b>Length of Last Pregnancy</b>
Rosemary	40years	Primary school	Businesswoman	High blood pressure	Eight months
Esinam	35years	Senior High School	Receptionist	Oligohydramnios	Seven months
Cecilia	29years	Polytechnic	Secretary	High blood pressure complications	8 months two weeks
Konadu	20years	Junior High	Petty Trader	Not known	Full-term
Adwoa	38years	No Education	Hairdresser	Diabetes/Malaria	8 months three weeks
Adobea	32years	Senior High	Secretary	Not known	9 months one week
Oboshie	34years	Senior High	Clerk	Anaemia/ Typhoid fever	6 months
Saadia	30years	Junior High	Petty Trader	Stillbirth	8 months 3 weeks
Abena	33years	Primary School	Petty trader	Foetal Macrosomia/Birth	Full-term Baby died

				Complications from birth	one week after birth
Mariama	25years	Senior High	Photographer Assistant	Complications from high blood pressure	8 months three weeks
Adiza	26years	Senior High	No Job	Not known	9 months
Afi	35years	Senior High	Businesswoman	Placenta abruption	Full term–Baby died few hours after birth
Lucy	35years	Primary School	Petty Trader	Anaemia	7 months 2 weeks
Hawa	30years	No Education	No Job	Not known	Full term–baby died two days after birth
Felicia	42years	Junior High	Businesswoman	Eclampsia	8 months
Gifty	41years	No Education	Trader	Complications from high blood pressure	7 months
Afariwa	28years	Senior High	Clerk	Atrial septal defect	Three weeks after birth
Guaaba	33years	Polytechnic	Secretary	Malaria/ Anaemia	6 months 3 weeks
Brago	24years	Junior High	Salesgirl	Placenta praevia	9 months
Pokuaa	27 years	Senior High	Businesswoman	High blood pressure	7 months

### **Understanding of Pregnancy and Loss in the Context of Ghana**

The death of a baby through perinatal loss can create many negative emotional griefs. In this theme, I discuss the grief experiences and challenges Ghanaian women face when they lose a child in a society where children are the bond of relationship, the pride of parents, and where childlessness is distasteful and seen as a taboo.

**Mothers attachment to pregnancy and preparation.** The preconception preparation women make helped to increase their chances of delivering a healthy baby. These are important steps and advice from health personnel that prepare women physically, psychologically, and physiologically for pregnancy and delivery. It involves changing lifestyles and behaviours to achieve a better pregnancy outcome. Discontinuing birth control methods, being financially stable, eating healthier to prevent infections, managing to reduce stress, and becoming emotionally prepared for the arrival of the newborn are examples of these steps. Most participants claimed strict adherence to the advice and guidance. Expectant mothers adhere to these guidelines in the hope of delivering healthy babies and thereby having the opportunity to proudly present their new babies to their families at a traditional naming ceremony, popularly referred to as “outdooring ceremony”. Outdooring or “abadin to” is a naming ceremony of a newborn child in Ghana. It is a ritual or practice by Ghanaian parents of naming and showing the infant to the rest of the society. Customarily, this takes place on the eight day after the infant is born; and is habitually performed at the father's house. The first name received is called the “kra din or soul name”. This is determined by the day of the week that the child is born. The traditional reason for waiting for that number of days is to ensure that the baby has come to stay.<sup>2</sup>

None of the participants anticipated their pregnancy to end in a perinatal loss. All of them including those with children, were expecting a positive outcome. Guaaba spoke about her

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<sup>2</sup> {<sup>2</sup>Outdooring or “abadin to” is a naming ceremony of a newborn child in Ghana. It is a custom or practice by Ghanaian parents of naming and showing the new-born to the rest of the family and society. Customarily, this takes place on the eight day after the infant is born; and is habitually performed at the child's father's house. The first name received is called the “kra din or soul name”. This is determined by the day of the week that the child is born. The traditional reason for waiting for that number of days is to ensure that the baby has come to stay}.

journey with her third child, who was also her second perinatal loss. She described how she tried to achieve her goal:

I wanted this child so badly; I had planned ahead of time about what to do. The type of cloth to wear during the naming ceremony. Hence, I took extra care with the type of food I was eating and attending antenatal as required. In fact, I never missed an appointment. I feared for my child's life and therefore did not want to do anything to jeopardise it. But I had a complicated malaria.

Afi learnt from her past mistake and wanted to make sure her present pregnancy was without complication. She noted:

From my previous experience of loss, I was made to believe that the first three months of pregnancy was dangerous; that there could be complications if a pregnant woman does not prepare or look after herself well. With this at the back of my mind, I was extra careful and followed all the instructions.

Participants admitted planning and buying clothing and the necessary items in preparation for delivery. For Lucy, and many other participants in the study, naming their children was an important part of the preparation for welcoming the new child. Lucy shared:

We planned to have our first child a year into our marriage and God granted us our wish. I bought all his things when I got to know through [a] scan that it was a boy. My husband and I wanted the name Emmanuel for him but his siblings wanted him named as "Nyame Ye" (God is good). We grew so attached to him therefore we did not think and wasted much money buying his things and he did not survive.

Felicia was on a family planning method for many years after the birth of her first son. Preceding her decision to conceive, she discontinued her family planning method and was later diagnosed with multiple uterine fibroids. Determined to have children, she went through two surgical procedures to remove the fibroids in preparation to become pregnant. She shared her frustration:

I have gone through two myomectomy surgeries to prepare my uterus. I got pregnant four months after the second surgery, and unfortunately, I have lost the baby. This child was my heart he meant everything to me and my new partner. So, I did everything, including paying regular visits to the antenatal clinic, to keep myself and my baby healthy.

Brago is a first-time mother. Unlike most participants, she was psychologically unsure of how she felt about becoming a mother until her loss. She described her preparation as:

I got pregnant before marriage so I will say that I wasn't actually prepared for the baby. Moreover, I did not have much knowledge about pregnancy, and I was not yet prepared to become a mother. Although I started antenatal as soon as my pregnancy was confirmed, I was still in limbo and unsure of myself. It was when I lost her that I quickly came to my senses that I had lost part of me, but it was too late.

**Grief reactions.** The experience of perinatal loss is a significant moment in every mother's life, but the grief experiences differ from one woman to the other. This theme reflects the emotional reactions and the behavior of participants following notification of the loss. The findings in this study indicated profound emotional grief for all the women. Participants' emotional experiences of grief were expressed as confusion, guilt, self-reproach or self-blame, self-pity, and shock. Some went from feelings of guilt and loss to deep emotional pain.

Afariwa's baby had an atrial septal defect and was scheduled for an operation. Approximately two and a half weeks after birth, he developed complications during feeding and was rushed to the hospital. Unfortunately, her child died before they got to the emergency unit. Her reaction was one of shock and disbelief. She describes how she felt when informed about the death of her child:

It was like I did not exist at all and the world had come to a standstill. I felt dazed and numb, and I could not feel myself. I could hear people talking but I could not react to what they were saying. It was too difficult to believe it. My very first instinct was to take my child and run out of the place because I was just holding and feeding my child and why should they be telling me that he was dead. The death of my son affected me both spiritually and emotionally. It left me with a pain that was so frightening and overwhelming. As if I was having a dream and waking up from it.

Similar to Afariwa's reaction, most participants repeatedly alluded to feelings of shock and disbelief. Gifty went from shock to reacting with extreme pain when she received the news of the death of her unborn baby in the ultrasound room.

Immediately, I heard the news, I didn't know how I managed to jump from the room to the door and landed on the floor crying bitterly (silence... tearing). Part of me died instantly because I felt numb on the floor. I felt dizzy, choked with tears; my head was spinning and felt like throwing up at the same time. I was very angry with myself and with what I had just been told. All I wanted was for the doctor to reverse his statement.

At 20 weeks of pregnancy, a woman is aware of the heartbeat and kicking of the baby and can feel the movements of the unborn child. In many cases, mothers manage with labour discomforts and expect the child to live. Mothers who encounter perinatal loss feel disheartened when they experience what Afariwaa has just narrated.

Mariama is 25 years old, unmarried, and wanted to pursue her career as a flight attendant. At the beginning of her pregnancy, she was determined to abort the fetus to concentrate on her career. However, Mariama's attitude towards her daughter changed the first time she felt her child move in utero and she decided to keep the pregnancy. Instantly, she began communicating with her. She struggled both financially and emotionally to keep her pregnancy because her boyfriend abandoned her, and she had no choice but to turn to her mother who is a petty trader. This was her reaction to her loss:

My daughter became my friend and someone I used to talk to every day. So, when the news was communicated to me, I felt lost. I sat alone on my bed, I looked around and saw other mothers holding and feeding their babies. Then, some of the babies began to cry: seeing the way their mothers were cuddling them made me feel very, very sad. That was when I felt it. I could not control my tears and wept. I refused to look at the mothers with their babies. I felt God punished me for my thoughts and selfishness of wanting to abort her from the beginning. I feel very guilty and I blame myself for everything.

While Mariama blamed herself for what had happened, Rosemary was relieved she lost her child, because she had four children already and was finding it difficult to support them financially.

This was her second perinatal loss and at 41 years of age she felt people would make fun of her and, therefore, when she got pregnant, she was not regularly attending the antenatal clinic. Her reaction was of both remorse and relief.

Oh, I was hurt; I know it may sound unusual to you because I have told you that I did not want the pregnancy. But sincerely speaking, even if I had delivered my child alive, I would have given her up to a wealthy couple for adoption because I don't think I would have been able to provide for her in addition to the ones I have now. Even with my four children, it hasn't been easy for me.

Participants admitted having feelings of grief and longing even after the loss. Pokuaa wondered why she was still grieving and having feelings of depression six months after her loss. Pokuaa powerfully shared her thoughts:

I feel grieving a deceased infant is not something that goes away easily because of the deep bond one shares with her unborn child. That brief attachment, the bond between a mother and child, and the resultant love make it difficult to forget. The memories of the child, the name given, and her place in the line of children in the family are all reminders of a great loss.

This assertion speaks to the complexity of a mother's attachment, perinatal loss, and grief.

**Reflection and a new understanding of loss.** Mothers make plans when they are ready to conceive, and during pregnancy they make plans of seeing their future in the context of the arrival of a newborn into their families. During this time, bonds and attachments are formed between mother and child and this gradually grows throughout the pregnancy. The natural growing affection and bond do not simply stop when a mother loses her child, rather, mothers are left with feelings of shock, disbelief, guilt, anger, and ultimately sadness and depression. These



women not only grieve for the death of their child, they also grieve for the lost opportunity of motherhood.

Gradually, feelings of loss decrease and the mother's condition stabilizes, which is followed by introspective questions of the loss (why me?), then understanding (no baby in my arms or no baby to show), and, finally, coming to terms with what has happened (no control over what happened). Participants in the study shared their thoughts and reflections about their losses. They described their ongoing feelings and thoughts of how they were trying to process and make sense of their experiences. Their reflections included self-blame, not knowing the cause of death, and the guilt of having to tell people of one's failure.

Leaving the hospital without her child was the most difficult thing Pokua had to do. She contemplated how to speak about her loss to other people. Thoughts of how to tell her story to family members, friends, and colleagues of her failure to reproduce a live baby after pregnancy was of much concern.

She shared:

Words fail me anytime I have to talk about my child. My time with her was short and it breaks my heart to let her memory leave my thoughts. In the immediate aftermath of my loss, I sat into the night, spent hours thinking about the later part of my pregnancy, the process of labour, the communication of my loss and how I was going to convey my loss to people who knew of my pregnancy. At that point, I wanted to remain where I was; I did not want to go home.

Such are the conflicted emotions of most of the bereaved mothers in the study. Their bewilderment was how to begin their narrative of telling friends and relatives about their losses. The next challenge after their loss was how these grieving mothers could smoothly move on with their lives. Another challenge was how to end the story to be accepted and move on with their

lives. Cecilia's reflective thoughts were focussed on her reproductive system and how it has failed her as a woman, depriving her of her baby and the joy of motherhood.

My body has failed me, it could not contain all the malaras, anaemias, and other complications of pregnancy that I experienced. I could not control what was happening to me and my children. I wonder if I could have done things differently to save my children. But I need to heal, to survive and avoid insanity; therefore, my reason for seeing the psychologist.

Finding ways to reminisce and understand helped mothers experiencing perinatal loss to gradually come to terms with their loss. Saadia explained:

Within a few days, my life changed. I held my child in my arms; I was a mother to him days back, but I am not anymore. It breaks my heart to remember that my son died in my arms and I could not do anything about it. But my experience has taught me to acknowledge and accept my loss and see every day as a blessing. I am finding ways to accept it and stay focused for the rest of my kids; they need me more.

### **Subsequent Impacts of Perinatal Loss on Women**

Here I describe participants' responses after the loss of their children in terms of relationship with spouse, family members and society and their fears of the future. This theme came up with the following subthemes: relationships: before and after perinatal loss; fear of the unknown; disenfranchised grief.

**Relationships before and after perinatal loss.** There was a change in marital or familial relationships involving spouse/partner, in-laws, and family members as well as attachment with children after the loss. The loss of a child is extremely distressful for both parents. It is an additional source of stress that can positively and negatively affect marital relationships. Married couples who have other existing children sometimes are able to adjust to their losses faster, and this can create intimacy among them and other family members. However, women with partners

and nothing to hold on to (no children) become vulnerable to the loss and this could lead to either a break or tension in their relationship.

Among the 20 women who participated in the study, 16 were married. Two of the married women feared divorce or the possibility of their spouse marrying a second wife. Esinam is fortunate to have two children. She lost her third child. She felt the interference from her mother-in-law after her perinatal loss was driving her marital relationship apart. Esinam's relationship with her mother-in-law has been a difficult one, and it got worse after her loss. She simply stated her relationship with her in-law after her loss was "very bad."

All the single women in the study found it difficult to maintain their relationships with their partners after the loss. For instance, Adiza who is an unmarried woman openly voiced her emotions on the changes in her relationship with her boyfriend before and after her loss. She shared:

I thought I had a good relationship with my boyfriend, but he disappointed me. He refused to accept responsibility and humiliated me in the presence of my mother and his family members. He has refused to get in touch and has never called or come to see me after my loss.

While Konadu expressed the pain, she experienced after her loss and her uncertainties about her relationship with her partner, she appreciated the length of time she spent with her child, the memories of the child's movements, and their chats together. She interpreted her experience as a chapter in her life from which she was learning. Konadu recounted her relationship:

The rejection from my partner in the later part of my pregnancy made me grow closer to my child. I valued the little time I had with my child in my womb. We bonded very well at that time. He inspired and gave me hope when I had lost every hope with my partner. Our relationship continues to live on. I feel his spirit is with me everywhere I go.

Participants spoke about the relationship they encountered with some of the health professionals who nursed them during their admission at the ward. Participants shared both helpful and unhelpful services they received from friends, in-laws, and health professionals in the crucial moments after their loss. Rosemary felt grateful and happy with her friends from church who attended to her during pregnancy and after the birth and death of her child. She talked about the kind gestures of two friends who were always compassionate. She shared:

God bless my friends. I feel so blessed to have those women in my life. They have been there throughout my pregnancy and even when I struggled with sadness and depression of my loss. Without them, I am sure I wouldn't have made it this far. Their friendship and support gives me strength.

Competent and compassionate midwives are generally respected and valued by patients who are fortunate to be managed by them, and often very fond memories of them are kept by such patients. However, not all participants in this study were fortunate to come across such efficient midwives during their admissions at the hospital. Mariama was not impressed with her interactions with some of the midwives she had previously encountered at the labour ward when she went into labour. In her case, she had met some of them during an earlier encounter and had been nursed by them. She expected the midwives who had nursed her before to recognize and treat her well, but they ignored her and she felt abandoned. She shared:

I formed a good relationship with some midwives at the labour ward and antenatal unit during my attendance, so I was expecting them to manage me better since we had met earlier, and they knew my history. Rather, they neglected me and left me to my fate. Even after losing my baby, they failed to show sympathy. On the many occasions they met with me at the hospital corridors, they passed by as if there was never an encounter between us. It contributed to making me feel deserted and unhappy.

The problems of perinatal losses are often considered a disruption of the natural order of life and death where a child born to a parent is expected to outlive the parent. The situation where a

pregnant woman loses a child definitely goes against this natural order and this leaves mothers distressed and experiencing profound bouts of grief.

**Fear of the Unknown.** When confronted with the experiences of loss, most participants became vulnerable. Fear and intense despair were a common reaction amongst the women who experienced perinatal loss. Some of the participants felt insecure and were not certain of what might happen with their relationships with spouses and parents-in-law after the loss. In addition, participants were emotionally distressed, anxious, and fearful of the next pregnancy. Esinam recalled her mother-in-law's reaction to her loss:

My mother-in-law's reaction to my loss almost had my husband breaking up with me. My husband at times became irritable and continuously told me to shut up about my loss. My reaction was that I have lost my child and I do not want to lose him too. This fear suppressed my grief; I became apprehensive and was afraid to lose my husband.

A lot more of the women in the study acknowledged being fearful of their next pregnancy and what could happen.

Gifty explained:

These words put a lot of fears in me: "God who gives and He takes, therefore, if you keep crying you may be punished and will not be able to get pregnant again." I straight away feared for my next pregnancy and the thought of mourning this one was a nightmare for me. My fears were that if I think about it, I may not be able to get pregnant again.

For Hawa, the possibility that a pregnancy could lead to an outcome of the death of an unborn child instead of the delivery of a healthy child was a shock to her. She described her experience as:

I never considered death as outcome of my pregnancy, but with three perinatal losses, my fears are for my next pregnancy. I keep asking myself if what happened with my previous pregnancies will happen again. I started having these panics and anxieties the first time I lost my child through stillbirth. Now I am so nervous as to what will happen next.

Sometimes, the death of a precious child can trigger anxiety, as shared by Brago:

I am not the same person again; the death of my child changed my perspectives of life. It made me realize that anybody can die in my family at any time. Now, I am afraid to have another baby knowing that what has happened could occur again. My mind is filled with so many doubts; it's like even if I deliver again, the child may not live long.

**Disenfranchised grief.** The study further established a significant form of disenfranchisement coming from health professionals, family members, and society. In this case, the victims (bereaved mothers) were being held to certain standards and behaviours as to when and how to grieve after experiencing perinatal loss in accordance with cultural norms. Thus, the bereaved mothers were not given privacy nor encouraged to mourn their losses and come to terms with their situation. Traditionally, such grieving is not encouraged, but suppressed, in the hopes that the victim will quickly recover and attempt another pregnancy. However, participants in many ways felt disenfranchised (lack of acknowledgment) because there was no empathy from the health professionals, members of the community, or even friends and family members for the pain associated with their loss. To the bereaved mothers, an endorsement of their grief would rather speed the healing process, while a rejection was a slap in the face that created more pain.

Perinatal loss is as painful as any other type of death, and participants stories attested that most Ghanaians are indifferent toward these experiences of loss and the effect it has on parents. Generally, participants described how their emotions were suppressed by family members, friends, and health professionals. They further expressed their dismay regarding the dismissive way some family and friends swerved or ignored their conversations on the topic and the insensitive way health professionals communicated the news to them. Participants verbalized how Ghanaian society has varied sentiments and instructions on how bereaved parents are

supposed to grieve. *“The gestures and demeanors of members of the community clearly showed lack of interest and lack of respect for my grief,”* Lucy confirmed. Participants further alleged that the failure of the populace to acknowledge their dilemma impeded their recovery and led them to isolate themselves or hide from others in order to grieve.

Perinatal loss is a perfect instance of how society restricts parents from grieving what they see as a legitimate loss. Adobea was told to feel grateful that she did not have complications and the child died when she was young. Often dismissed and feeling insignificant, Adodea shared her thoughts:

Can you imagine your child died and you are told to not to mourn and not to think about it? These words were told to me in several ways. My friends and family over the past two months have continuously told me to stop talking about the dead and move on, that I am lucky I already have a child. It looks like my loss is irrelevant to them. I don't know how to behave when they are around and I feel trapped within.

Death, like marriage, marks an important role in Ghanaian society. The deceased are normally interned and celebrated with observations involving family members and the community where the person lived. Perinatal deaths do not get such responses and festivities; they are viewed as discreditable deaths that do not need much attention from society. Lack of acknowledgement of any loss by community members becomes difficult for bereaved mothers to accept and this contributes to disenfranchisement. Adwoa shared her opinion on this:

Adults and other deaths are commonly the concern of the community. Funerals are held and rituals performed. But the death of a baby through perinatal loss is not highlighted and it is less discussed. It is seen as a bad death, so, no funeral or even ritual is performed, and only mothers suffer in silence.

It is natural for mothers to feel traumatized and depressed when they experience perinatal loss because of the attachment and bond created during conception. Traditionally in Ghana, when a woman experiences perinatal loss, messages are commonly conveyed to them to reassure them,

but some of the harmless messages which are unknowingly shared for comfort subjugate people to feel marginalized. Many of the participants described how they were repeatedly told by friends and family members not to weep over a child who did not reach term to be delivered or live longer. They also shared their thoughts on other things. One participant, Pokua, was stunned and upset when a neighbour painfully told her not to mourn her deceased. She described:

My pain of losing my child at the age of 24 and alone was utterly unvalued by the people I am surrounded with. One woman in my community horrifically told me point blank that it is good I lost my boy because she feels he would have become a burden on me looking at my present circumstances and that I may have eventually sent him to the children's home. I felt very hurt and disappointed by her words.

Grieving expectations may differ among family members and grief response to loss can be dismissed or disregarded. When close family or those with power negatively silence or ask the bereaved to cope or move on with the loss, it causes disenfranchisement. Saadia's husband felt it was inappropriate for her to continue grieving. Therefore, he ordered her not to continue.

Even my husband kept telling me that he does not want to see me crying anymore, because my crying will not make any difference in my predicament. It will not restore my child's life back. That I have mourned enough for one child. With this said, how do I share my problems? It is like they know the answer to your suffering: "stop grieving and you will be fine."

In their narrations, participants spoke about the health professionals' pronouncements during admission and the language used in communicating the loss. The majority of the participants (16) were significantly offended by the midwives' behaviour. "The midwives clearly demonstrated their lack of sensitivity and their intimidation. While they did not offer counselling services to me, they suppressed my grief by ordering me not to cry at the ward," Oboshie asserts.



## Discussions

The purpose of the study was to explore and assess the experiences of pregnant women who lose their children during childbirth or are unable to carry their pregnancy to term in an environment where childlessness is frowned on and a source of insecurity for women. The findings highlight the emotional suffering and grief experienced by Ghanaian women as a result of existing cultural biases that frown on grieving the loss of a baby who did not make any impact on the society. The findings from the study showed that participants wanted some space to mourn their loss, like any other individual who is going through separation by death.

All the participants had challenges accepting the news of the loss due to the already established emotional and physical connections with their children. They were very clear about the natural feelings of love and how preparation for the arrival of the baby impacted their everyday lives. These findings suggest that the mother and child bond start at conception and continues throughout life. This sudden separation can generate fear and distress in daily functioning. Research shows that during pregnancy an unseen bond and love develop between a mother and her unborn child, the significance of the bond and attachments of pregnancy and sudden separation from the bond is noted to affect the physical and psychological well-being of mothers and is a reason mothers experience an intense grief reaction (Buglass, 2010; Bowlby, 1973). Similarly, evidence shows that the separation is the compelling drive that contributes to the profound emotional responses and the high levels of anxiety in mothers and difficulty in investing emotionally in the next pregnancy (Wheatherby, 2017; Buglass, 2010; Bowlby, 1973).

There is a need to educate expectant couples about the probability of the complication of perinatal loss during antenatal clinics in order to reduce fear and the impacts of shock and pain associated with the sudden news of death (Baffour-Awuah & Richter, 2020). It must be noted

that the topic of death is not always well received by the public; in Ghana it evokes bad omens and society refrains from talking about death out of fear of incurring it or evoking its presence on innocent souls like unborn children.

The immediate responses of participants to grief were uniquely different among themselves but very similar to the theories set out by Kubler-Ross and Bowlby. While Bowlby believes grieving consists of four overlapping, sequential, and flexible phases of shock, yearning and protest, despair, and recovery, Kubler-Ross set five stages of grief as denial, anger, bargaining, depression, and acceptance (Bowlby, 1973; Kubler-Ross, 1969). Participants in my study indicated experiencing feelings of shock, numbness, depression, and a wish to wake up to discover what had been told to them was not the truth. Reactions of speechlessness, disbelief, and craving were additional responses from participants. However, grieving was also seen as a process of healing, and, according to participants, their acceptance and recovery from the loss depended on the values attached to the loss involved—the kind of relationship with the deceased, length of pregnancy, and cultural beliefs. These results are consistent with the theory of attachment and they offer further evidence of a connection between the influence of mothers' attachment on grief.

Quality of relationships during vulnerable periods is critically important to uplifting affected women, especially grieving parents (Gravensteen, 2017). A good relationship during perinatal loss prevents psychological distress and improves healing (Gravensteen, 2017; Gun-Mette et al., 2014). Relatedly, it has also been established that the psychological impact of perinatal loss is a factor for breaking relations in marriages, family, and friends (Vance, Boyle, Najman & Thearle, 2002). Women who experience stillbirth have an increased risk of divorce after their loss and those who continuously experience perinatal loss/stillbirth are four times

more likely to experience divorce (Human et al., 2014). The current study patterns revealed different positive and negative relationships. While five of the married participants recounted difficulty in communicating their grief experiences to their spouses due to differences in opinion of the appropriate way to grieve, eight had stronger connections with their in-laws and spouses, encouraging a better acceptance and healing.

Some of the effects of the loss discussed were separation of relationship. Almost all the single mothers in the study described the loss of their children as the worst separation of a good relationship they have ever formed. Losing their children brought them to an impasse, which adversely affected their relationships with partners and in-laws; however, they reiterated that they had an inner peace with a personal relationship with the church and God. Evidence from literature suggest that a positive relationship and the company of spouses, living children, and family contributes to healing and acceptance of loss (Bhat & Byatt, 2016). Bhat and Byatt's (2016) study on infertility and perinatal loss further disclosed that a strong relationship allows bereaved mothers the opportunity to openly discuss their thoughts and fears. The process of recovering from perinatal loss takes time, but a compassionate understanding with committed relationships (couples, in-laws) is vital for relinquishing the attachments and reconciling with the future. A perfect relationship is fundamental to survival and progress in difficult situations; however, it must be noted that other people survive these situations on their own.

Knowing the ramifications of continual perinatal losses in the Ghanaian traditional setting, there was no doubt that fear was an expected aspect of participants' experiences. The theme of fear in the study implied a significant connection between participants' grief following perinatal loss and their fear of the future. The expression of fear ranged from fear of the

unknown to coping with the loss, as well as family members' reactions to the loss and failure. Participants' fears were embodied in many things: fear of losing the next pregnancy, becoming childless, becoming divorced, losing status in society, and fear of what may lay ahead in the future.

Previous research has demonstrated that women who have experienced losses during pregnancy experience fears of insecurity and doubts about their capacity to have normal pregnancies and deliveries (Bailey et al., 2019). Bailey and colleagues found that women who have previously experienced perinatal loss have unresolved grief issues and a higher fear of losing the next pregnancy. It is unclear whether this experience is universal to all women, however, three of the participants in the current study reported behaviours similar to Bailey et al. (2019) findings. Participants were stuck with the probability of losing another pregnancy, and, therefore, had difficulties readjusting and moving on.

Moreover, participants articulated that their fears were particularly heightened by comments from friends and family members such as "God gives and He takes away, be grateful that He spared your life" or "If you cry too much you may not be able to deliver again." Almost all the participants who traditionally are suppressed from expressing any emotions with respect to their losses frequently expressed these comments as fears. Concurring to this finding, Smith et al. (2020) and Lee and Steel (2020) reported the loss of a child through perinatal loss presents a major crisis which impacts untold stress in most mothers' lives; it is a devastating loss that tarnishes hope and dreams of becoming a mother. The findings offer additional evidence of the need for establishing psychological counselling for the women. Further research regarding the psychological and spiritual dynamics of perinatal loss on women in Africa must be performed to confirm this finding.

Motherhood in Ghana links women to their husbands and in-laws. Women in Africa and Ghana need to demonstrate the capability of motherhood, otherwise, the African norm of men remarrying when their spouses fail to give birth will prevail (Obiyo, 2016). There was a strong fear and awareness among participants of the significant role played by in-laws in many marriages in Ghana. It was evident from the interviews that the majority of the participants also feared the possibilities of divorce and abandonment. Even though the present study did not reveal all the experiences of perinatal loss, it did at least unravel that perinatal loss can generate self-doubt and anxiety. Participants, therefore, feared the possibility of divorce if they were not able to satisfy their in-laws and spouses with children.

Data from the current study identified experiences of non-acknowledgement of loss by participants' immediate family members, health professionals, and their neighbours. A large proportion of participants in the study provided evidence of intimidation and disenfranchisement by people who they thought would understand and support them during their loss. The literature continues to show the intense emotional challenges and difficulties associated with perinatal loss and it has also been revealed that recovery from such situations depends largely on the support from relations, friends, and health professionals during the loss and grieving stages. Understanding and acknowledging the loss by close relations and society hasten recovery (Fernandez, Harris & Leschied, 2011). However, according to Lang et al. (2011) disenfranchisement causes people to feel dismissed, intimidated, and undermined. The study further shares that failure to appreciate and acknowledge perinatal loss as a significantly hurtful event leaves grieving parents feeling traumatized and disenfranchised (Lang et. al., 2011). Participants claimed their conversations on the loss were ignored, silenced, or dismissed with insensitive comments from close family members. Participants also felt judged, blamed, and

marginalized by friends and health professionals who used unkind words with them. This concurs with Attig's (2004) assertion that the primary results of disenfranchised grief is the failure of people to respect and acknowledge others' misery.

### **Limitations**

This study as any other study was not without limitations. The first limitation is the high attrition rate; about 30% of the recruited participants dropped out along the way because of a recall of suppressed emotions. The data was only collected in one region of Ghana and therefore cannot be generalized to all mothers who have experienced perinatal loss in Ghana. Another limitation is that the study only focused on understanding the experiences of mothers, excluding the feelings of their spouses and other family members. Further research into fathers' experiences will provide an in-depth understanding related to perinatal losses.

### **Recommendation**

A recommendation to help support these women will be for Ministry of Gender, Children, and Social Protection act and address the norm of preventing women from mourning after a perinatal loss. Health and public education, allowing bereaved mother talk about their loss are essential to accurately relieve this women's pain, fear, and disenfranchisement. Family members such as spouses, mother-in-law's, and health professionals including midwives need to know and understand the intensity of grief associated with this loss and be more supportive. Future researchers should compare and contrast the effects of perinatal loss on Ghanaian men and women. This will significantly contribute to literature on the understanding and counselling of perinatal loss. Likewise, it would be of great educational value to the general public and hospital administrators for knowledge and guidance to improve on some of the difficulties

associated with understanding and caring for the pregnant women they come across at work. The nursing profession and healthcare professionals could implement this study's findings in clinical practice by educating both health professionals and professional counsellors that the outcome of pregnancy following a loss is mostly shaped by the preceding loss as a result every pregnancy and delivery should be recognized as important and a risk for complication (Fernandez, Harris & Leschied, 2011).

### **Conclusion**

Human experience is inherently emotional, and human beings experience the world and others in it emotionally. Adjusting to a live and healthy baby is gratifying but adjusting to the death of a baby through perinatal loss tests mothers' endurance and their ability to withstand difficult and distressing moments. The resultant pain, frustration, and, in some extreme cases, depression are hurdles for many women who go through this loss. The experiences shared by mothers in this manuscript revealed that women who experienced perinatal loss in Ghana go through different types of experiences. These women experienced emotional pain, anxiety of losing spouse and future pregnancy as well as feelings of failure.

Health professionals rely on evidence-based information to work effectively. Having extensive knowledge and understanding about how people deal with bereavement will improve the confidence and expertise of these professionals to offer better services for bereaved mothers. Findings from this research will help these professionals to diagnose and care for patients. It will contribute to the increase of knowledge in the unique understanding of how perinatal loss is emotionally and psychologically experienced by Ghanaian mothers.

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## **Chapter Seven**

### **Culturally Sensitive and Inclusive Care for Women who Have Experienced Perinatal Loss in Ghana**

#### **Abstract**

Inadequate care and support rendered to parents after perinatal loss is a major contributor to psychological trauma and prolonged grief recovery that requires attention in Ghana. In view of this, beneficial and culturally sensitive strategies and procedures for rendering services to mothers must be put in place early for successful recovery. As part of a larger study seeking to understand and attain further insight into Ghanaian women's experiences of perinatal loss, this study further explored the types of support systems and care rendered by health professionals, family members, and friends after the loss. A focused ethnographic method was used to explore the type of inclusive care provided for women who have experienced perinatal loss in a tertiary institution in the Greater Accra Region in Ghana.

Twenty female participants were purposively selected and interviewed. Data was transcribed, coded, and manually analyzed thematically. The findings revealed several themes and subthemes. Ghanaian women grieving from perinatal loss clearly verbalised their need for culturally sensitive care based on their unique desires. There were gaps in care and support rendered to the women. The article summarizes and discusses the various support systems available to women in Ghana. The need exists for health professionals to have adequate resources and relevant training to enable them to provide quality health care. Bereaved women should be handled with compassion and empathy and have sufficient time dedicated to



understanding their predicament by both health personnel and family members as a major step to promoting healing and recovery.

Key words: Perinatal loss, grieve, support, culturally sensitive care

## Introduction

From ancient days to contemporary Ghana, childlessness (“obonin”) and perinatal loss (“awomawuo”) remain taboos and considered sensitive topics that are frowned upon in the Ghanaian society. Perinatal loss, for example, produces a strong emotional outcome for couples, especially the woman; it creates long-lasting sadness and causes adverse effects on the physical and mental health of parents (Alam et al., 2012). Perinatal loss is a very common occurrence in Ghana, yet, research on perinatal loss in Ghana has focused more on reporting on statistics and causes than on the profound emotional effects such occurrences have on women including the coping strategies following the event.

In comparison to other human deaths, perinatal loss is marginalized and lacks much attention as a social problem. Consequently, mothers who experience this loss tend to go through emotional isolation, psychological distress (post-traumatic stress disorder), and anxiety that lead to prolonged depression (Frøen et al., 2011). Current studies that have explored perinatal loss concluded that a strong support system is the foundation to recovery during these experiences (Boyden et al., 2014).

This study describes the culturally sensitive care Ghanaian women who have experienced perinatal loss receive. I used interviews and stories shared by participants to better understand both the difficulties associated with perinatal loss and the type of support and care Ghanaian women receive during such experiences, as well as make recommendations for more effective hospital services and family support. The study further concludes with the importance of support and care in reducing grieving after the loss of an infant.

## Background

Pregnancy and delivery are perceived as a major transition in a woman's reproductive life. It is an evolution into the next step of the future, a goal to accomplish, and a challenging period that exposes mothers and their unborn children to many complications (Bangal, Sachadev & Suryawanshi, 2013; Dako-Gyeke et al., 2013). Highly feared among these complications are maternal and fetal mortality, where fetal mortality (perinatal loss) is perceived as unfortunate and insignificant among the two incidences (Kersting & Wagner, 2012). Perinatal loss or the death of an infant is an undesirable outcome of pregnancy, mostly occurring as a result of preventable complications like infections (WHO, 2019). The rate of occurrence in low-income countries is about four times higher than that of the high-income countries (Cousens et al., 2011). Currently, in Ghana, evidence shows that newborn deaths and stillbirths represent about 40% of children who die before the age of five years (Ghana Health Service Annual Report, 2016).

Although the rate of loss is high in Ghana (25 per 1,000 live births), it becomes a visibly common event to mothers only when it occurs to them or a close relation or friend (Ghana Statistical Service [GSS], 2018). Women do not envisage or prepare for a perinatal loss; "even if they know of it, they consider it as an unlikely event that would never affect them" (Malacrida, 1998, p.14). The unanticipated death of a child through perinatal loss changes the objective and direction of most mothers' plans and thoughts from the route of expectation of joy to that of grief (Boyden et al., 2014). They encounter silence in their families and discover that it is a forbidden topic at home, among friends, and at antenatal and postnatal clinics (Baffour-Awuah, Mwini-Nyaledzigbor, & Richter, 2015). The profound psychological and emotional distress of the event, the lack of knowledge and sensitivity from the public and health professionals as well as some family members contribute to why perinatal loss is relatively kept quiet in the Ghanaian

society. In the aftermath of loss, affected parents must be acknowledged, supported and motivated to overcome their pain in a culturally sensitive way. The following topics will be discussed as part of the background: - Culture and grief of perinatal loss in Ghana and support.

### **Culture and Grief of Perinatal Loss in Ghana**

Culture is perceived as the totality of traits, values, taboos, and customs shared by a group of people in a specific area, which uniquely characterizes them from other societies (Idang, 2015). These cultural values, beliefs, and norms prescribe or set standards for how people live, behave, and perceive daily life occurrences such as death (Napier et al., 2014). Thus, culture influences and shapes the way individuals' approach, perceive, and form strategies to respond to death (Kaphle, Hancock, & Newman, 2013).

Many researchers hold the opinion that the process of grieving involves diverse reactions and emotions that are dynamic and different for all individuals (Cacciatore, 2010; Paudel et al., 2018). However, the griever's reactions, approach, and disposition to grieving are shaped by the culture and society in which they reside. Depending on the relationship with the deceased person (child) or the value placed on it and the length of attachment, people may or may not be deeply affected or devastated as generally or culturally expected; it could also be a relief rather than grief (Malacrida, 1999).

In Ghana, certain cultural values heighten the emotional distress of perinatal loss. For instance, grieving is intensified for Ghanaian women who experience perinatal loss because of the strong cultural belief and expectations to procreate after marriage or at an adult age. Another cultural trait that intensifies grieving in Ghana is the non-encouragement, non-acknowledgment, and disenfranchisement of perinatal loss by family, friends, and society which unhelpfully creates silence and profound emotion (Capitulo, 2005).

There is the belief that a child who dies at birth or is miscarried during pregnancy is an unwilling spirit who does not want to stay with the family into which it has been born. As such, tradition demands that such deaths should not be mourned but rather an effort should be made to sever any emotional ties to prevent repeated losses (Shear, 2012). These taboos create untold suffering for bereaved parents and their families. Ignoring or failing to acknowledge the profound emotions attached to the loss of a loved child under this traditional belief and cultural norm significantly create pressure and distress. The outlook of Ghanaian society ultimately forces grieving mothers into conforming to social norms in contradiction to their pain and desire (to mourn openly), leading to isolation and emotional instability. Most bereaved mothers become emotionally unstable and battle with themselves to be able to adjust effectively into a new life as expected.

The culture also discourages the prolonged expression of grieving among couples, especially for men. The traditional society has no place for men who exhibit any public emotion and even more so for publicly mourning the loss of their children. Being able to endure trauma and stress is culturally and informally reinforced for men (Malacrida, 1999). Men are not expected to have depressive symptoms; they are expected to be tougher with their emotions to support the vulnerable in the family during the event of a loss (Murphy & Cacciatore, 2017). For instance, Ghanaian cultural practices and beliefs leave men responsible for burial arrangements of the dead, contributing to the disenfranchisement of the men's right to grieve and the women's right to also be part of the burial process. Lastly, the cultural belief that the spirits of the departed ancestors influence the lives of the living strictly impacts grieving.

## Support

Recent studies have demonstrated that prolonged grief from perinatal loss affects women, their families, and their relationships, but with strong support systems, mothers are likely to recover from the grief faster and avoid poor relationships and health outcomes (Kuti & Ilesanmi, 2011; Modiba & Nolte, 2007; Obi, Onah, & Okafuor, 2009). The greater possibilities of helping mothers in Ghana to embrace and accept this loss is through support from close relations (family and friends), religious communities, and health professionals. Support during bereavement comes in many different forms, including through counselling, emotional and physical support, information, and guidance.

**Family, friends, and social support.** Experiencing perinatal loss during pregnancy or after delivery is overwhelming and adds to the stress of women and families. One in five couples experience prolonged and severe grief after encountering perinatal loss (Koopmans et al., 2013). The unexpected change in condition and the need to adjust to the new situation makes it critical for women to receive the necessary support to cope with their loss (Kavanaugh, Trier & Korzec, 2004). Genuine and all-inclusive support from close and extended family members offers mothers the opportunity to share their fears and thoughts and a shoulder to cry on whilst minimizing their pain and stress. The quality of physical and emotional support rendered by family members is important to prevent psychological trauma and motivate successful recovery (Hutti et al., 2016).

Most African families are seen as safety nets where members are shielded from all sorts of crises during difficult moments (Oppong, Antwi & Waerness, 2009). The traditional cultural practice is for family members to rally around and provide emotional, physical, and socioeconomic support when a member has a problem (Oppong, Antwi, & Waerness, 2009). In

Ghana the traditional social morals of the society guide its members to look out for the good of their neighbours and to build strong relationships (Gyekye, 2003). The highest good an individual can offer in his/her society is to look out for the welfare of members of the community (Gyekye, 2003).

Social support from friends, religious communities, and health professionals are relative, “based on how the griever and the deceased are valued by members of the society” (Rando, 1984, p. 54). The lack of support to parents occur because of the lack of significance other people attach to the loss (Malacrida, 1999). The society also lacks knowledge and there is a social norm that mothers are better off without encountering reminders and discussing the loss of their children with family members, friends, and the society.

**Religion as a source of support.** Religious teachings and practices influence everyday life and decisions made by individuals on health and bereavement (Koeing, 2012). Like culture, religion shapes and influences individuals’ perceptions and lifestyles. A study conducted on the psychological impact of perinatal loss on Malaysian Muslim women revealed that religious people take challenging situations as signs from God to test their faith (Sultan & Miskam, 2012). Personal attachments, beliefs, and faith in God are key components for coping with stress. Most parents who experience perinatal loss and other deaths sought for and benefited from spiritual and religious counselling as they struggled to cope with the loss (Sutan & Miskam, 2012). These religious groups provide rich and emotional support to people who have lost an infant through perinatal loss.

Ghanaians believe that their faith provides healing and influences the decision making on health, emotional, and physical issues. As well, religion plays an important role in acceptance and recovery from stressful situations. Thus, religious people in the society resort to faith in

times of life crisis, to achieve calmness and to be able to cope with stressful situations. In other words, strong religious beliefs and support from members of the congregation lower grief and hastens recovery (Kersting et al., 2007).

**Culturally sensitive and inclusive care.** Culturally sensitive and inclusive care is identified as an important component of patient-centered care. It embraces “the provision of care that is respectful of, and responsive to, individual patient preferences and cultural values and needs, and ensures that the patient values guide the clinical decisions” (Tucker et al., 2011). Culturally sensitive and inclusive care is a patient-provider partnership approach of care to provide services rendered to patients based on their individual cultural outlook which empowers them to contribute to providing safe, effective care to meet their specific needs (Tucker et al., 2011). It is believed that contentment and distress of the bereaved are usually linked with the services and support provided by people in close contact. Patient satisfaction with healthcare outcome is associated with providers offering services that are culturally focused, supportive and respectful (Tucker et al., 2011). Health professionals who are efficient in providing culturally sensitive care and support do so by taking a holistic approach to physically and emotionally provide quality services to patients (Kingdon et al., 2015; Murphy & Cacciatore, 2017). However, a study on perinatal deaths disclosed that health professionals also find caring for mothers who have experienced perinatal loss emotionally demanding (Montero et al., 2011).

The unexpected deaths of an infant place parents in a vulnerable position. The complex and emotional situation makes it difficult to make meaning and find hope. This requires considerate emotional support based on the views of the bereaved. A health professional’s role is to observe, listen, and understand the challenges facing such bereaved women with the aim of assessing and providing services that are sensitive and compassionate to those mothers and their



family members. Perinatal loss is one of the challenging situations that affect the care nurses give to patients. Identifying parents' beliefs and culturally influenced practices can help communicate sensitive information and provide the best support and care. Health professionals need to culturally engage these women and their families in a dialogue about their experiences.

Ghanaian cultural practices of laying the deceased to rest and performance of rituals provide valuable and therapeutic ways for bereaved mothers to deliberately come to terms with grief following their loss. The rituals' performance renews ties and brings the community and friends together to support the bereaved person. There is also a cultural belief that the spirits of departed ancestors influence the lives of the living and therefore the departed soul must be grieved properly.

### **Purpose**

In this study I will describe the culturally sensitive care Ghanaian women who have experienced perinatal loss receive. The objective was to explore what relevant and culturally sensitive care means within the Ghanaian cultural context and to describe the components of culturally sensitive and inclusive care for women who have experienced perinatal loss.

The main questions guiding this research study were:

1. What are the types of culturally sensitive care available to grieving women to enable them to cope with perinatal loss?
2. What do women think about the care they do or do not receive when they experience perinatal loss?

## Methodology

### Design

A focused ethnographic design was utilized to explore Ghanaian women experience of perinatal loss in the primary study. I selected this type of methodology because focused ethnography assesses the behaviour and social situations of specific cultural group and provides a thick description of the experiences of the participants (Dewan, 2018; Knoblauch, 2005). The cultural perspectives of this subgroup of women in their natural environment which include their beliefs, values, and experiences about marriage, motherhood, and perinatal loss emerged as one of the themes from the analysis of the primary study and will be the focus of this manuscript (Cruz & Higginbottom, 2013; Knoblauch, 2005). I used observation, interviews and filed notes to enable dependability.

The study setting has diverse cultural groups residing in the community. The cultural groups included in the sampled participants comprised Gas, Ewes, Northerners, and Akans. These ethnic groups form part of the six main cultural groups found in Ghana. They are from the southern and northern parts of Ghana. Although these cultural groups have different languages and values, there is no major difference when it comes to customs and response to death (perinatal loss), however, their personal views may differ. Family and children obligations take precedence over everything else in all the cultures.

**Sample.** I used purposive sampling to select the study participants who have experienced perinatal loss in a tertiary institution in the Greater Accra Municipality. Thirty participants volunteered to take part in the study, however, it was narrowed to twenty as ten dropped out. Among those ten who dropped out, two dropped out without signing the consent form and four

refused to be interviewed as their spouses were not in favour of them participating in the research. Another four participants stopped halfway through the interview because of the sensitive nature of the topic and did not want their information to be shared, therefore that data were destroyed. The remaining twenty participants who ultimately agreed to participate did so with the intention of sharing their experiences to inspire and positively influence other women to find strength and purpose. I contacted the participants and arranged times and venues with them.

All the participants were Ghanaian women of reproductive age between 20-42 years. They comprised of sixteen married women and four women with partners. Some of the participants had experienced multiple losses. Their history of loss ranged between one to three.

### **Data collection and analysis**

Data collection occurred over a period of four months. I contacted the participants and arranged times and venues with them. The data collection for the 20 women took place in their individual homes, office and church premises. For most of the participants, the interview took place three weeks to six months after their loss. Guided by the principles of focussed ethnographic approach, I collected data using three methods: observation, interviews, and field notes (Roper & Shapira 2000). In conjunction with observation of participants, I also analyzed documents from the hospital; however, the main method used was a face-to-face interview using a semi-structured interview guide to encourage conversation and to obtain detailed information on the participants' narratives (Sullivan, 2012). As a midwife, I have attended workshops on providing emotional support to grieving patients and their families. My journey as a graduate student has offered me multiple opportunities to be trained to interview different kinds of participants from many research studies. In addition to having a degree in nursing with psychology, one of the courses I recently completed in my PhD course work was on grieving and

hope which further prepared me to conduct the research on this sensitive topic. I conducted all the interviews as a graduate student, a researcher and a midwife who had been trained and taken courses in psychology and grief assessment. Each interview for the main conversation began with an open-ended question; Tell me about your delivery experience at the hospital? Can you recall some of the things that were most helpful during your stay at the hospital? Which of them were not helpful? and Were you given the opportunity by health professionals to be with the deceased baby?". All interviews were conducted in Akan, the native language participants felt comfortable with. The interviews were all audio recorded with the permission of the participants and it lasted between 60 and 90 minutes each. Comprehensive field notes were taken to document participants' mannerisms and other behaviours. The field notes provided me with vivid and introspective evidence of the cultural meaning and understanding of what the participants experienced. Data collection continued until an in-depth understanding of the phenomenon was obtained from participants and no new ideas emerged (Roper & Shapira, 2000).

Recorded conversations were transcribed verbatim. Data analysis started with listening to the audio recording several times to establish clarity of the answers and to confirm the accuracy of the transcripts. There was also an opportunity to go back to the participants after transcription for clarity and verification of unclear statements discussed during the interviews. Using Roper and Shapira's (2000) strategies for ethnographic analysis, I analyzed the data in the following sequence: coding for descriptive labels, sorting for patterns, identification for outliers or negative cases, generating themes, memoing and reflecting on the emerging themes. In qualitative research, data analysis involves searching for patterns in the data to uncover an in-depth description of the cultural experiences of the research participants (Berg & Lune, 2012). Roper

and Shapira's (2000) thematic content analysis were employed to analyze the data. Each participant's transcript, field note, and recording were read and listened to alongside each other for coding and constructing the themes. The contents of the transcripts were reviewed separately and coded line by line by the researcher to generate and identify common themes. The excerpts of the coded data were organized to identify and categorize key patterns and phrases within the data. It was followed by the identification of potential subthemes. There were several constant comparisons of the themes to ensure the selected quotes represented the themes. Memos were developed during the analysis and the emerged themes were compared to the memos to increase understanding of the context of the theme as well as reflection on the them.

After that I continued to analyse the rest of transcripts independently to identify all the codes and themes before meeting with the rest of my supervisory committee members to discuss, negotiate and resolve any discrepancies.

### **Rigor**

I adopted Meleis (1996) criteria for the development of cultural knowledge and achieving trustworthiness in qualitative research for this study because my topic is deeply rooted in the Ghanaian cultural context and it involves a vulnerable group of people. Meleis (1996) highlights the significance of developing culturally competent knowledge involving people who are vulnerable and marginalized and came up with eight criteria of assessing rigor and credibility. To develop this culturally competent knowledge, Meleis urged researchers to use eight criteria to confirm rigor and this include: contextuality, relevance, communication, awareness of identity and power differentials, disclosure, reciprocation, empowerment, and time. The criteria appropriately fit this research because of the cultural background component of the research, the

vulnerability and marginalization of the participants involved. The detail has been explained in previous chapter on methodology (chapter four).

In every qualitative study, trustworthiness is considered the suitable criterion to evaluate the study (Maher et al., 2018). Additionally, trustworthiness was enhanced using different data collection methods, multiple reviewers, member checking, and reflexivity. Creswell and Miller (2000) maintain that multiple peer reviews improve the trustworthiness of data and ensure a reduction in biases. Therefore, two researchers with experience in qualitative methods helped with the analysis; my supervisor and one member from the supervisory committee.

My supervisor and I initially opened the first transcribed document and manually coded that transcript together to guide me on coding of the transcript. Subsequent transcripts (two) were each coded separately, and my supervisor and I met again to discuss the emerging codes and patterns and arrived at a consensus on the patterns that were emerging. After that, I independently coded and analyzed the rest of the transcripts data. then compared my findings to that of my research supervisor for consistency and accuracy. In addition, member checking was done by sending transcripts to participants who had better educational background and could read; and I also played the audio recorded version to participants who could not read to authenticate their true stories. I also kept records in the field notes of all gestures, actions/behaviours, and mannerisms of participants. Additionally, all the interviews were in Akan and translated to English. This was checked by a native Akan (Twi) speaker and a translator from the university of Ghana for the quality of the translation.

## **Ethical Considerations**

Prior to conducting the investigation, ethical authorization was granted to the researcher in both Canada and Ghana by the University of Alberta Human Research Ethics Review Board, Canada, and the Ghana Health Service Ethics Review Committee. The reference numbers are Pro00073592 and GHSERC22 /06/17 respectively. Verbal and written agreement was obtained from individual participants. Additional approval was sought from hospital administrators and chief nurse manager at the research site to permit me have access to midwives for the recruitment of study participants. With the help of the hospital administrators, four volunteer midwives were identified to recruit participants from the outpatient departments, antenatal units, and obstetric units. Conditions of eligibility for participation included being a Ghanaian of reproductive age and having experienced a perinatal loss. Other conditions included those who showed interest, met the inclusion criteria, and consented for their information to be forwarded to the researcher.

Ethical procedures are fundamental to all parts of an ethnographic study (Lincoln & Guba, 1985). Considering the sensitivity of the research topic, perinatal loss, I was attentive to ethical considerations such as informed consent, voluntary participation, confidentiality, anonymity, and non-maleficent. Written consent was received from participants. Participants were made aware of the voluntary nature of the study and their right to withdraw at any stage of the study. Throughout the data collection, I made the effort to be transparent and maintain privacy and confidentiality. Following each interview, the recorded conversations were played for participants to listen and agree to share. All references and locations linking to participants' information were removed and pseudonyms were used throughout the study to ensure anonymity. I also informed participants of the presence of a psychologist should they want to see one.

## Findings

All participants were Ghanaian females between the ages of 20 to 42 years who lived within the setting but were from different ethnic groups. Participants' experiences of loss ranged from one to three times and varied from between 20 weeks of pregnancy and three weeks after full-term normal delivery. Two-thirds had living children at the time of their loss. Eighty percent of the participants were married, and the rest were single but in a relationship. All the participants except two had full-time employment.

Findings indicated that most of the women felt deserted by health professionals, friends, and some family members. The main themes that emerged from the study are A) support and B) culturally sensitive care. The emerging subthemes under theme (A) are i) immediate communication and interactions, ii) support from significant others, iii) seeing and holding, iv) being with, v) mothers' perceptions of relevant and meaningful care vi) psychological counselling. Theme (B) has the following subthemes: i) burial and funeral arrangements, ii) creating meaningful memory, iii) follow up/postpartum care. The subsequent narratives embody the conversations of participants and their perceptions of the services received and what they actually wanted.

### Support

This is the first important care participants wished they received from people around them immediately after the loss of the baby. It is a fundamental care provided to mothers at the time of their vulnerability to enable them pick up and find meaning to their experience. This is a crucial time for understanding, encouragement and support to overcome distress, confusion, and unhealthy emotional thoughts. The subthemes under the theme "support" are: i) immediate communication and interactions, ii) support from significant others, iii) seeing and holding, iv)



being with, v) mothers' perceptions of relevant and meaningful care vi) psychological counselling.

**Immediate communication and interaction.** Typically, and in the hospitals, the norm is for health professionals—especially nurses and doctors—to communicate, confirm the news of death to relatives, and provide support during the event of perinatal loss. Communicating the sensitive news must be done compassionately with respect and genuine sympathy. Conversations with many of the participants revealed almost all of them received the news from the health professionals. However, participants reported feelings of disappointment resulting from a lack of empathy from the health professionals during communication of the news. Most of them felt disrespected and unsupported and, according to some of them, it had a negative influence on their grieving process.

Mariama's experiences with some health care professionals on admission made her request to be discharged prematurely. She shared:

They should have considered my loss; they should have been thoughtful enough to have given me more room to understand what they were telling me. I still feel I deserved a better communication than what was provided and more support and attention than what I got from the professionals. I realized I did not belong there anymore and needed to go home.

Mothers who experience perinatal loss go through severe grief, especially when they had to go through treatment of infertility before conceiving. The unexpected death causes mothers to become confused, unprepared, and depressed. Brago was informed of her child's death one hour after her delivery and found it difficult to promptly consume all the information being provided by the professionals. Anger and frustration were how Brago described her feelings when she was first told of her child's death:

There was no compassion, no reassurance, and no time to waste. The midwife just broke the news to me and left me sitting on the bed. She was too busy to hang around to notice

my eyes distended and swollen and my head bursting with pain. She has done her share; the rest is mine to deal with. Her unkindness made me more depressed.

Breaking unpleasant news is difficult and can be very distressful, but mothers after delivery anxiously wait to know the condition of their children and that must be satisfied. Being experts, health professionals are the reliable source to relay such news.

Konadu had not been shown her child two hours after her normal delivery: her aunty, who was visiting, informed her of the child's death. In her words:

I was not prepared for that bad news, at least not from my aunty. The professionals were supposed to tell me, not my aunty. I was wondering why I was not told earlier about my child's death. Were the professionals hiding something from me? I desperately needed to know the truth about what caused my child's death.

Most participants agreed and concluded that the health care professionals showed less concern and more indifference, but a select few were fortunate to have come across midwives who supported and understood them. Amongst them was Felicia, who elaborated on how refreshing and meaningful it was when one of the midwives came up to her after the news and enquired if she needed to speak to a family member or her priest. Felicia recalled her experience with gratitude:

The pain may have been visible in my face. The midwife walked up to me and put her arms around me and said, "it seems very difficult now, but you will pull through." The sincerity, sympathy, and warmth in her voice was all I needed at that time and which I will never forget. What surprised me most was when she took her personal phone to make that call for me.

**Support from significant others.** Health professionals and family members are often the first to be present at the hospital in times of bereavement. Given the unexpected nature of this death, immediate support from people who are present can reduce the physical and psychological trauma and help to overcome the emotional challenges that follow. Gestures like sitting and talking to them normally about their experience will help to reduce high levels of anxiety and

distress. All the participants acknowledged and appreciated the support offered to them, especially that from family members: husband, children, parents, and siblings. They described it as valuable, genuine, and spontaneously given. Others were particularly grateful for the way their family members availed themselves to listen and answer their despairing questions. A participant disclosed how the immediate intervention and support from family members became important in the loss of her pregnancy at seven months from a complication of placental abruption. Pokuaa narrated her story:

My loss felt like being shot in the chest. I fought for days to keep my sanity. My survival depended on my husband and sisters. They were there when the news was communicated to me and has been instrumental in my gaining strength and recovery.

Regardless of the level of support participants enjoyed, some of them felt alienated by the way some members of the family expected them to quickly move on with their lives. As a bereaved mother who just lost her child, Adiza felt grieving takes time and as such people need to understand and give them time to work through the process. Comments from some family members made her feel unsupported. Adiza recounted:

While other family desperately do all to help lessen their pain, my family only visit to surprise me with comments that makes it impossible for me to forget. Comments like “this is nothing, he is dead and gone, burry your pain and move on, you will have another child soon.” But the one I lost is never going to come back.

Grieving the sudden loss of a loved one is painful and exhausting. There are different kinds of sudden emotions and difficulties and this is the time for emotional support from close relations for the bereaved to logically process their grief. Abena said her husband failed to appreciate the depth of her pain when she was informed about their child. Abena narrated:

Immediately, I was informed about the death, I looked deeply into my husband’s eyes for support and comfort, but he only stood there watching me quietly without any emotion on his face as I cried. My husband abandoned me in my time of trouble and his reaction really hurt me.

Participants' expectations of better emotional support were not what they received from health care professionals. Their evaluation of the services they received from these professionals was the least mentioned as supportive. In their conversations, participants recounted the insensitive and undesirable remarks from the midwives. For instance, Gifty touched on some of the discouraging comments directed towards her by a midwife: "*I am not here for you alone, okay?*" and "*It is your fault you are in this position; you did not report early.*" Such were some of the unkind remarks' participants received.

**Seeing and holding.** Most mothers, after hearing the bad news, desire to see their children. Seeing and holding are thought to help create bonding and memory between the deceased and their parents immediately after the loss. Encouraging parents to bond with deceased children is a recommended action perceived to comfort parents and reduce prolonged grieving. It is common in hospitals in other parts of the world, but less common in Ghana. In this study, with the exception of six women, the participants were given the opportunity to see and take pictures of their children immediately after delivery. However, they were not encouraged to hold and be with them.

Felicia was among the fortunate mothers who had the opportunity to see and take photos of her child. To her, the photographs and the piece of cloth her baby was wrapped in represent the physical evidence of her daughter's presence. Felicia explained:

The midwife showed my daughter to me right after delivery. There was no sign of death; it was like she was asleep. Unfortunately, I could not bring myself to hold her. I was so shaken to see her beautiful face and yet dead. My husband took pictures of her.

People make different choices and in the case of Esinam she declined to see or hold her baby. This was her first experience of losing a child and the shock and distress made her

frightened and uncomfortable to touch her deceased child's body. She also considered it unusual and a taboo to cuddle a deceased baby and therefore refused to do so. She shared:

Fear and nervousness prevented me from taking the opportunity to hold my child. I just could not bring myself to hold her cold body and be with her. It is not part of our culture and she looked still and unresponsive.

Hawa asserted:

I did not see my son because I had a caesarean section done and was on the anaesthetic drugs for quite a while. But they showed him to my husband, who took pictures.

Other participants stated that they neither saw, held, nor took pictures of their children. They believed that seeing and holding their children could have given them a sense of finality to reduce the process of grieving.

**Being with.** Being with was perceived in two ways: being with deceased children, and the physical presence of family members and health professionals at the time of loss. A few of the participants who expressed their willingness to be with their children never had the opportunity to do so. They were neither encouraged nor asked to be with their children, and even when they had the opportunity many of them lacked the confidence to be with their deceased children. Gifty refused to see or be with her macerated baby a few minutes after birth. Gifty explained:

My confidence to be with my child was shattered because of the information I gathered from the midwives' conversation about my child. They said my baby's body was deformed and does not look good. I did not want to keep that memory of that child, I wanted to keep the image and features of the baby I imagined I was going to have; like my other children.

In contrast, Cecilia physically held her deceased child. This was the third time Cecilia had experienced perinatal loss and therefore did not want to bury this one without having time alone and a conversation with him. She was given the opportunity at the time she

had her family members around, and she expressed her gratitude at being allowed to be with her child:

I requested for them to bring him to me and the midwives obliged. Perhaps it was because they knew of my situation and wanted to give me that space to be with him or they did not want to do anything to offend me. I had my quiet time, prayed, and sent a message through him to my other children.

Afi, amongst other mothers, was not given the chance to be with her child. In her conversations, she discussed how it would have benefited and reduced her present pain. She felt being with her child would have significantly improved her memory of the child. Afi unhappily answered:

I had no chance of seeing or being with my son. No photo to remind me of my son. It was an emergency, so they rushed me through everything. They did not discuss anything with me and from their behaviour at the ward I did not dare to ask them anything. I did not want to be yelled at.

Other participants had a different interpretation of being with. Instead of their children, they sought the presence of family members and midwives for emotional support. Konadu's experience of loss overwhelmed her with emotion and she needed more support. She stated:

Immediately, I heard the news, I panicked and was gripped with fear. My immediate thoughts were to have a lot of people around me. People whose presence and support will calm my nerves. The nurses did not have time to be with me and I needed my husband and parents around.

**Mothers' perceptions of relevant and meaningful care.** Support becomes relevant when the outcome of the support positively impacts the lives of the recipients and their well-being. Discussions with participants generated the theme of meaningful support—the type of support participants found helpful. Participants placed great value on care that promoted interaction with health professionals during their distress; care that is culturally appropriate and meaningful.

Many participants perceived support to be relevant and meaningful when family, friends, community members, and health professionals accepted, respected, and shared their grief. There were shared experiences of positive and negative stories of how participants were treated by family and health professionals. They described the significance and influence of support from family members. Some of the responses included Afariwaa's story of her family sympathizing with her:

All my family members and friends came to my house to keep me company. We sat and talked for some time about my predicament and they prayed for my daughter's departed soul. This was memorable, it is something I will never forget.

Saadia was looking forward to having a healthy baby like her previous children. She felt very guilty when she lost her child while living anemia and continuously blamed herself for her loss. The encouragement and actions of her nuclear and extended family immensely contributed to the early recovery of her loss. Saadia explained:

My parent in-laws, ... my husband and two living children, were influential in my early recovery. Their understanding, acknowledgement, support, and the time they spent listening to my long stories without condemning or blaming me made a difference.

Others had friends, church and community members coming around to keep them company and help with the house chores. Rosemary's neighbours offered to care for her other two children when they heard of her loss. Rosemary recounted:

The presence of my neighbours in my house at that time gave me time to reflect and make decisions on other issues. Some amongst them had experience the same loss as me and therefore truly understood my pain. They made it easy to converse with them.

Another thing the research participants thought would have been significant and more meaningful was changing the arrangements of the ward so as to separate bereaved mothers from mothers who had live babies. Esinam shared:

I was put in between two women. I did not know which part of the bed I should sleep. Anywhere I turned, I face a mother who had a live baby by the side either crying, sleeping, or being breastfed and that was enough pain for my stay at the ward. It would be better if the authorities separate us.

There are certain practices and beliefs among Ghanaian traditional society around death and they can affect the family's preference of care and the process of mourning; one example is the pouring of libations while in the hospital vicinity. None of the participants were given the chance to perform this.

**Psychological counselling.** In addition to providing support for mothers to bond with their children, it is imperative to consider the psychological effects of the event on the bereaved mothers and therefore necessary to refer them to a psychologist. The offer of seeing a specialist came up several times in conversations with participants. While some of them completely refused to see a psychologist because of a fear of being perceived as having a mental illness, others had already been referred and were being seen. My observation of most participants demeanor and facial expression revealed that they were uncomfortable meeting with the psychologist because of the stigma attached in society.

Due to her circumstances of three losses and the loss of her uterus, Celia had already been assigned to a psychologist which she said had calmed her down on her previous suicidal thoughts. Afi initially agreed and later changed her mind. She asserted that:

I am not comfortable going to the psychologist; people will think that losing my child is making me go crazy, that stigma alone will make things worse for me. I believe with time I will gradually get healed.



Mariama was willing to go but her spouse and family members were against the idea. They wanted her to leave everything to God. She commented:

I am hurting so much and needs someone to talk to; but at the same time, I don't want to go against my husband and family's advice and see the psychologist. My family have the idea that if someone in the community gets to know about me seeing the psychologist, they will tag the whole family with mental illness.

### **Culturally Sensitive Care**

This is the second theme of the manuscript. Here I discussed the concerns the participants had. Their beliefs and values. The subthemes under culturally sensitive care are: i) burial and funeral arrangements, ii) creating meaningful memory, iii) follow up/postpartum care.

**Burial, funeral arrangements.** Interment is the final separation of children from their parents. Ideally, every parent facing such circumstances would want to be part of the decision making, finding out the cause of death, arranging for burial of the deceased child, registering the death, and creating memories. However, the cultural norm in Ghana is that men and elders of the family are responsible for handling such arrangements and therefore the question of mothers getting involved and making decisions on where and how the children are buried does not arise.

Most of the participants were comfortable with burial planning being handled by family members. They perceived it as a traditional call of the males and therefore could not be part of the arrangements. A few participants, however, disagreed with the cultural tradition and wanted to be part of burial arrangements. Some were concerned about the cause of death and wanted a post-mortem to have a medical explanation to identify the source. Hawa did not feel confident with the decisions made for her regarding burying her child without finding out the cause of death. She commented:

Burial decisions were taken by my husband and his uncle. The hospital released my son's body to him in a small box immediately after birth. He did not request for post-mortem, he felt it was not necessary and expensive to do so, but I wanted it done. I wanted to know what caused my child's death.

Another participant, Abena, shared her displeasure about her spouse's decisions:

Well, I don't even think her death was even registered. My husband took all the decisions alone. He even asked the hospital to cremate her. I wanted her to be buried at a place I could go and visit. But my husband refused to listen to me. Now I don't have any memories of her and no specific place to go to pay homage. I could not properly part with her.

Others also wondered in what way and where their children were laid to rest. Among them is Adwoa. Unaware of whether her child was given a befitting burial, Adwoa's reasons for wanting a proper burial of her child was to prevent her spirit from wandering around and for her as a mother to have a sound mind. This is a brief statement of how she recalled her story:

I relive my pain every time I remember I did not take part of my child's burial. My mind keeps wondering of what happened to her. I feel my daughter was not properly laid to rest: the proper rites of ushering her into the next world was not done. I am afraid to find out what happened to her, whether she was actually buried or thrown somewhere. I am not getting the answers I want. I feel her spirit will never rest.

**Creating meaningful memory.** An additional important dimension in helping a mother adjust to life after the sudden loss of her child is creating memories. Many actions can be taken to help form identity or validate the baby's presence in the mother's life. Personal items like clothing and blankets, baby's nails, hair, footprints and fingerprints, and photographs are some of the important items, parents use as memory preservation.

Nearly half of the participants mentioned that they kept all the clothing they bought for the babies and copies of scan images. Others also felt fortunate to have personally taken pictures as physical evidence in case their memory of the child begins to fade. Some used anniversary dates, for example, the date(s) of birth and death as a reminder. Four of the participants neither kept their children's clothing nor took pictures for fear of those items inciting more grief.

Narrating her story to others was an important grieving process for Brago and a way of keeping the memory of her child alive. Brago shared what she believed was her unique way of remembering her child:

Even though I did not see her, when I am speaking about her, I speak about all the beautiful things I imagined of her. These things I say about her keeps her memory fresh in my mind.

**Follow up/postpartum care.** Returning home from the hospital without a baby to show as anticipated by all family members is the most difficult and emotionally challenging situation many mothers experience. Mothers who experience perinatal loss usually go home in a state of shock and therefore cannot even remember some of the advice given to them at the hospital about their physical and emotional upkeep. Follow-up visits by health professionals is a crucial task that provides the opportunity for mothers to be re-evaluated and supported. It is a long-term support and a step to address and access the progress of bereaved mothers after discharge. It is to educate mothers on their individual questions and concerns and especially on suppression of milk since there is no baby to suckle.

Follow-up or home visits have lately been discontinued in Ghana due to lack of staff and resources. Although participants remembered wanting a follow-up visit in their homes by the midwives, none of them received that after leaving the hospital. Participants perceived these visits to be an important step after discharge to help them reconcile their grief. The loss of a child does not affect the normal physiological changes of the body. There is shedding of lochia and production and suppression of breast milk. This is a mentally and emotionally involved phase, especially for new mothers who at this time will need education and guidance as to how to

suppress lactation since there is no baby to feed. Emotional support at this time is very crucial.

Two of the participants shared their views on why they needed a home visit.

Guaaba asserts:

I had so many unanswered questions. My mother-in-law did not understand why I had to lose my child when there was nothing wrong with me or the baby. A visit or a phone call from the midwives would have been refreshing and put all these questions to rest.

Afariwaa continued by saying:

I had to nurse my son who was delivered with the complication of atrial septal defect at home pending surgery. I believe home visits could have extended his life a little bit. They could have detected some symptoms and referred us back to the specialist.

Many participants including Mariama wondered why their midwives have not called as they used to do when they were attending antenatal. Although Mariama claimed she did not have any health issues, she still needed a visit to confirm that:

I wonder why nurses do not visit after discharge these days? Their visits at home would have made a lot of difference in my house. Maybe their job ended the day they discharged me to the house.

### **Discussion**

The study explored and reported on the type of meaningful care and support rendered to women who have experienced perinatal loss in Ghana. The present study reveals that the participants have not been given the type of culturally sensitive support they expected from health professionals, family members and friends. The main emerging themes a) support and b) culturally sensitive care. The responses of the participants clearly showed a lack of support from professional workers and occasionally from other family members.

Findings from this current study revealed that the women who experienced perinatal loss had many unanswered questions. The reason for the participants wanting answers to their loss

was because many of them felt they were well prepared and followed all instructions during pregnancy aiming to have a successful pregnancy and a live baby. They also needed more information on the possible outcome of subsequent pregnancies. Kersting and Wagner (2012) reported similar findings where participants in their study on complicated grief after perinatal loss were seeking for answers on their loss.

Another unique finding from the current study is the ineffective communication between midwives and mothers who experience perinatal loss. Evidence from literature shows that, how messages are conveyed to the bereaved mothers, may positively or negatively impact on the length of their grieving process (Gold et al., 2017). Other scholars believe that such news must be sensitively broken with compassion and in clear language when both parents are present to support each other (Erlandsson et al., 2014; Peters et al., 2015). In the process of communicating information to mothers, Peters et al. (2015) caution health professionals providing such information to consider the receiver's emotional state regarding their capacity to contain and process what is being provided. It is imperative for the communicator to carefully choose his/her words, use clear and simple language, and gently break the news to parents (Silman, 2014). Contrary to the findings in the literature on providing information of perinatal loss to mothers, findings from the current study revealed that communication was rushed, and the health professionals were indifferent, unsupportive, and disrespectful to the participants' grief.

Immediate communication of the news of the death and interactions was important to participants; many of them reported that they received the news many hours to a day after the death and when they requested an additional explanation on the issue, they were ignored by the health professionals. The reason the health professionals delayed giving information to the women about their loss could be the inadequate preparation on providing sad information/news

on death to mothers. This discomfort of health professionals on breaking unfavourable news to patients is documented in the literature (Smith et al., 2020). Smith et al. (2020) suggest that health care professionals should be trained on how to effectively communicate and offer better support to bereaved mothers which is in line with the study participants' suggestions. Other related findings from Silman (2014) urge health professionals to provide information precisely when it is needed and to be thorough with what is presented to the bereaved parents. Researchers believe that failure of health professionals to provide immediate and effective support during the critical period of loss is a powerful determinant of the psychological complication (Killeen, 2015; Kingdon et al., 2015).

Participants' accounts revealed the significance of family support and its positive influence on successful recovery from perinatal loss. The majority of the participants identified nuclear family members as the best source of support and strength because of their ability to listen, recognize their emotional distress, and reassure them. Many researchers believe that health professionals and family support systems are necessary for a bereaved woman's recovery; since they are people that bereaved mothers naturally turn to during an event like this (Boyle et al., 2015; Jarvis et al., 2017). Evidence shows that the actions and support health professionals and family members render, assist women to recover fast and reintegrate back into their normal lives (Smith et al., 2020)

Participants' compared the support they had from health professionals to that from their family; they concluded that family support is unwavering and the best support system. Most of them agreed that the support they received from family was more than they expected. These findings are not surprising as traditional Ghanaian families are naturally seen to be the bedrock and support system for its members (Gyekye, 2003). The findings from the present study are

similar to Jarvis et al. (2017) study on experiences of family caregivers on post obstetric fistula repair. Jarvis and colleagues reported that it is the custom in Ghana for family members to offer support to their members to recover from grief and difficulties; however, the authors agreed and cautioned that there are some family members who become frustrated and resentful when they have to take on responsibilities of offering such support. Boyle et al. (2015) also offer insight into the uncaring attitudes of members of the family, which is highlighted as having an impact on bereaved parents' grief and is a factor that slows the grieving process.

Although family members in the Ghanaian culture can be supportive in time of loss, the participants in this study shared that some family members dismissed their feelings of grief and therefore these family members were seen as insensitive. Related findings reported in other studies establish that family members' indifferent and unsympathetic attitudes towards a parent's loss forced bereaved mothers to isolate themselves from family meetings (Kavanaugh et al., 2004). Despite the differences in family support, not much attention has been paid to this area in terms of research in Ghana.

In this study, there was an opinion difference on how health care professionals and participants perceived perinatal loss. Whilst the professionals typically viewed it from the medical and physiological perspectives, the mothers perceived it as a representative piece of themselves and therefore felt unhappy when their views were not acknowledged (Simwaka, de Kok, & Chilemba, 2014). Their expectation of health care professionals to be considerate, sensitive, and supportive in acknowledging the human dignity of their loss as an average person's death was absent. Furthermore, participants who experienced the loss at an early gestational age were concerned with how the professionals ignored, rejected, and treated their loss as a mere medical condition. Researchers have emphasized that empathy, sensitivity, and

sympathy are essential aspects of the work of health professionals (Boyle et al., 2015; Kersting & Wagner, 2012; Silman, 2014).

The participants also pointed out that separate from the medical care, the physical and psychosomatic care they received was substandard and that it intensified their grief. Some participants expressed absolute dissatisfaction with the care and support they received. Evidence shows that bereaved mothers are likely to develop psychological problems if health professionals do not provide the necessary care and support (Montacute & Bunn, 2016). Caring for patients is an important and principal work of nurses and the motivation is to assist patients to come out successfully with their problems (Chokwe & Wright, 2012). Swanson believed that providing nursing care is a process that is shaped through interactions and relationships with patients and their family members and it should be nonjudgmental (Hutti et al., 2016; Jansson & Adolfsson, 2011). None of the twenty participants perceived the health professionals as a source of emotional support.

The practice of mothers bonding with their deceased children (seeing and holding and being with) started in the 1980s in high-income countries. Conversations with participants in this study revealed that the choice of bonding with a deceased child is based on the assessment and decision of the midwife present at the time of delivery. Of the participants who had the courage and opportunity to see and hold their children, some of them found it unusual and culturally and morally inappropriate to cuddle a deceased baby and therefore refused to do so. One participant refused to see her deceased baby because she did not want to blemish the imagined beautiful image she had created of her child. Overall findings indicated that most of the participants were neither encouraged nor informed about the options available to them to bond with their babies (Üstündağ–Budak et al., 2015). Erlandsson et al. (2014) caution that mothers who are not offered



the opportunity to hold or be with and those who declined to see or hold their babies have a higher risk of developing severe long-term psychiatric trauma. Researchers also emphasize that though health professionals could suggest and advise about the advantages and disadvantages of seeing and holding a deceased child, the final decision is a choice bereaved parents have to make on their own (Silman, 2014).

While some of the participants yearned to be with their deceased children others wanted to be with their family members. The first part of the findings corresponds with Kuti et al. (2011) study on perinatal loss on Nigerian women which revealed the importance Africans to be with their dead before the final burial; the researchers believed that seeing the dead body of a loved one helps in bringing closure to the family members. They also cautioned that when the body is not found, it may be harder to believe or come to terms with the fact that the loved one has died. Other participants decision to be with their families shares certain similarities with the second component of Swanson's middle-range theory of caring, dubbed "being with". Swanson (1991) interpreted being with to simply mean being there emotionally and physically as well as availing oneself when it is needed to bring comfort to the grieving individual and family. It is clear that during the period of bereavement women experience varieties of emotional difficulties and, therefore, certain actions are necessary to help women cope with their pain (Modiba & Nolte, 2007; Sutan et al., 2010). Some of the actions that can be employed to provide support and comfort to these women are sitting, chatting, and sharing different types of feelings (crying) with the women (Swanson, 1999).

Isolating a deceased child from the mother may be a gesture of goodwill by well-meaning health professionals to reduce a parent's agony, but there are recommendations that parents must

be the exclusive decision makers on this issue (Kingdon et al., 2015; Koopmans et. al., 2013). Research literature proposes that parents must be encouraged and supported to make these decisions (Kingdon et al., 2015, Koopmans et. al., 2013). However, there are uncertainties regarding the risk and benefits of parents seeing and holding their deceased child. For example, a study by Hughes et al. (2002) on psychological care of mothers after a stillbirth revealed that women who see and hold their deceased babies have the worst psychological outcomes and are likely to experience anxiety during subsequent pregnancy, most probably in the third trimester. Other researchers who sought to investigate the evidence behind seeing and holding reported that bonding with the deceased child can produce a positive and beneficial long-term impact when mothers are guided by sensitive, skilled, and compassionate professionals (Kingdon et. al., 2015; Murphy & Cacciatore, 2017).

Cultural practices such as laying the deceased to rest and funeral rites provide valuable and therapeutic ways for parents to deliberate and come to terms with grief following their loss (Rosenblatt, Walsh & Jackson, 1976). Similarly, rituals and funerals renew ties and bring the community and friends together to support the bereaved person and reduce anxiety. There is also a cultural belief that the spirits of departed ancestors influence the lives of the living and therefore the departed soul must be grieved properly. A concern shared by some of the participants was the refusal of spouses to request a post-mortem. Studies have shown that explanations from autopsy findings can reduce anxiety, guilt, and grief and, in addition, help mothers to understand possibilities of risk for future pregnancy (Einaudi et al., 2010; Peters et. al., 2015). As culture demands in Ghana, the elders and men of the family are responsible for funeral arrangements; therefore, participants in this study had no opportunity to make decisions or arrange for burial. Research discloses that bereaved mothers from high-income countries are

given the choice of private arrangements for burial or cremation of the children in funeral homes of their choice (Gold, Sen, & Xu, 2013). There are additional services of social workers, spiritual care, or bereavement coordinators in the hospital for these arrangements (Bereavement Care Standards Development Group, 2016). The women also have the option of choosing the hospital burial program, which is of no cost to families. None of this exists in Ghana.

Creating memories is part of meaning making and is a comforting way bereaved parents deal with feelings of grief. An important aspect of parents' grieving, memory creation is an opportunity to have symbolic items to remember the deceased child. Items like photographs, footprints and handprints, and memory boxes are mementos that help create memories for many grieving mothers (Capitulo, 2005). In Mexican American families, mothers who experience perinatal loss cherished objects that were used during and after the birth of the deceased baby, for example, the baby's dresses, blankets, and toys (Doran & Downing-Hansen, 2006). These are considered as positive and symbolic memory making and a way to constantly remember that child (Doran & Downing-Hansen, 2006). Although all the participants collectively wanted to keep the memory of their children alive, there were some individual differences in how they wanted to do it. Some of them kept the sheets, photographs, and clothing of their babies, but for others they were a painful reminder that contributed to the grieving process and they, therefore, gifted the items to other expectant mothers. Contrarily to this findings, Nigerian women from Kuti et. al., study on perinatal loss, found the idea of having pictures of the infant strange and unnecessary. In other parts of the western world, having these items provide comfort and help parents to come to terms with their grief (Killeen, 2015).

On many occasions during the interviews participants consistently described positive and relevant support as having people who understand and share their predicament, a listening ear, and acknowledgment of their loss and grief. Participants also characterized sincere emotional and psychological support as that which is essential to help them cope and successfully overcome their loss.

Frequently identified among participants was the suggestion of a change in the design of the ward arrangements. In their investigation into providing meaningful care for families experiencing stillbirth, Peters et. al. (2015) reported on parents' experience of the maternity ward environment, their experience of distress by the inappropriate ward layout, and the suggestion to be relocated. The findings of the present study support the need to effect rearrangement of the ward to help create privacy and minimize intense grieving. This finding correlates with other studies found to have cited participants as having difficulty with constantly being among women who had normal deliveries and the cries of their children (Mulvihill & Walsh, 2014; Sutan & Miskan, 2012).

Participants showed interest in having a follow-up visitation by health professionals. Participants felt it would be beneficial and relieve their stress if the health professionals, especially midwives, continued to support them by following up in the house or calling to ask of their condition. In Kuti and llesanmi's (2011) study on the experience of perinatal loss among Nigerian women, it was revealed that the participants recommended the midwives pay them a visit at home. Findings from other studies revealed participants' interest in health professionals communicating with them through phone calls after discharge from the ward. Follow-up visits were also seen as an opportunity to provide adequate education for subsequent pregnancies.

## **Implications**

Women who experience perinatal loss may be emotionally compromised and will require culturally appropriate and meaningful support. This research can be used to effectively plan the type of support bereaved mothers may need at the time of experience. The findings can assist in providing information to health professionals and family members on understanding how to support and identify ways to provide quality care.

## **Recommendations**

In view of the apparent ineffective ways participants depicted how they were handled by health professionals; the researcher recommends that the Ghana Health Services provide relevant training to health professionals (midwives) who deal with women who have experienced a perinatal loss. Providing training for Ghanaian health professionals on communication and interaction about grief and loss would be beneficial to improve their skills of care. Health professionals need more information to adapt to the unique needs of mothers who have experience perinatal loss and to be able to help create awareness to change the cultural norms of grieving and performing rituals for this type of deaths in Ghana.

Moreover, it is critical that hospital administrators develop evidence-based standard guidelines or protocols to guide care provided to families who have experienced a perinatal loss. The need for change in public perception of perinatal loss as a taboo must be taken up by health professionals and ministry for gender, children, and social protection to educate family members and the general public. Public awareness and understanding of the causes and emotional experiences of perinatal loss are necessary to improve how support is provided to affected parents. This awareness can be created through education on social media and support groups.

## **Conclusion**

Perinatal loss is common in Ghana and the traumatic experience from the loss leaves mothers deserted and overwhelmed with grief. The support provided to these mothers during and after experiencing the death have a significant impact on their grieving process. Accepting and caring for these bereaved mothers are important basic needs and aspects of nursing that facilitates a sense of belonging. The findings from this study revealed that there were challenges with the support and services provided to the women, especially by health professionals.

Many of the participants desired culturally sensitive care and were therefore distressed with the care they received; there was no communication or relationship to create a sense of attachment or belonging. The current study suggests Ghanaian health professionals need some training in the management of perinatal loss to help them develop the essential skills to provide quality care. Hospitals in Ghana must have perinatal loss counselling units where the women can go and share their thoughts.

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## Chapter Eight

This chapter presents a summary of the research findings, recommendations, and limitations of the study. The study explored Ghanaian women's experiences with perinatal loss, their coping mechanisms, and the type of support available to them. The findings from the research revealed that most Ghanaian women who experience perinatal loss do not get much public sympathy and support due to misconceptions related to traditional and cultural beliefs. Due to this lack of support, women experiencing these losses have little coping mechanisms and they tend to grieve in private and internalize their grief in ways that may contribute to prolonged depression.

The research also revealed that health professionals provide little support to women who experience these losses and the medical care that is given is often short of women's expectations. The findings from this study show that health professionals in Ghana do not have effective training to help bereaved mothers cope with the tragedy of perinatal loss and, hence, the mothers struggle both physically and mentally.

Similar recommendations suggest midwifery curricula must include effective aspects of providing care for parents who have experienced perinatal loss (Kersting & Wagner, 2012). A related study by Roehrs et al. (2008) on care nurses provide to families coping with perinatal loss suggests continued research on educating health professionals about bereavement and the process of communicating the news of the death.

Chokwe and Wright (2012) stated that Swanson's theory is applicable in education; it offers suggestions on how midwifery students are supported to bridge the theory-practice gap and create a caring, trustful, and sensitive environment that enhances students' learning.



## **Implications and Recommendations for Practice, Education, Policy, and Further Research**

### **Implications for Nursing Practice**

The findings revealed that many of the women in the study were emotionally challenged and disenfranchised and did not receive the anticipated support they expected from the health care professionals. Even though grieving is individual, and the research findings may not be applicable to every mother who experiences perinatal loss, the findings can inform and guide clinical practice regarding the support women who experience perinatal loss in Ghana expects. This finding is fundamental in informing existing deficits in skills and knowledge of health professionals and advises effective training to equip health professionals with the needed skills to support women who have experienced perinatal loss. The findings will inform and guide best practices in nursing and maternal and child health care delivery in Ghana. During the subsequent pregnancies, health professionals attending to women of past history of perinatal loss should make it a point of taking detailed information to guide them in their care.

### **Implications for Education**

Participants reported feeling responsible for the death of their children and some of them felt psychologically threatened of their subsequent pregnancy. It is essentials for nurses to educate mothers on pregnancy signs and symptoms and of some sudden complications such as perinatal loss to help decrease the amount of guilt mothers may feel towards the death of the child. It will also be necessary for the health professionals to encourage mothers to voice their concerns and discuss with them their emotions and feelings of their loss.

Participants also reported of poor management, of being marginalised and isolated. It is imperative for the health administrators to organize and provide in-service training, workshops

and conferences focusing on bereavement of care for nurses/midwives and all other health professionals on handling unexpected complications like perinatal loss. I believe incorporating interprofessional education will enhance learning opportunities and improve understanding of how nurses and other professionals can work together for a successful recovery of their patients during perinatal loss. It is also an effective tool to help build confidence of relevant health professionals to develop effective care programs for handling the bereaved mothers.

Health professionals can also help create awareness to change the public perception of perinatal loss by inviting parents and the public to watch their role plays and having some of the affected mothers talk about their experience to educate the public about the intense grief associated with this loss. The health professionals can also create awareness through education on the social media for example giving health talks on radio and television to demystify the myth surrounding perinatal loss and childlessness.

## **Implications for Policy Development**

### **Ministry for Gender, Children, and Social Protection**

Despite the efforts of African and Ghanaian governments towards eliminating gender-based discrimination, women's and men's experiences related to human rights are different. Women still remain victims of gender inequality and are vulnerable in Ghanaian society (Ministry of Gender, Children and Social Protection, 2015). Men hold the majority of the decision-making power. The right of women to make reproductive health choices is limited and is mainly controlled by men as leaders of the households. While the traditional perceptions and roles of women are changing and advancing in high-income countries, gender inequality remains obscure for most women in Ghana. They continue to take care of the household tasks and care

for the children. Inequality is deeply rooted in African/Ghanaian society and women are more vulnerable where reproduction is concerned. According to Bayeh (2016) it is impossible to achieve growth among the pillars of sustainable development attaining gender equality and empowering women. The researcher encourages governments to work harder to change the existing position of women and achieve gender equality and improve on the country's growth. My recommendation to the ministry of gender, children, and social protection is to make policies for women to prevent women who are childless from being slandered.

Based on the information acquired, I believe it will be beneficial to women if the Ministry for Gender, Children, and Social Protection collaborate with Ministry of health and other health agencies to educate the Ghanaian public on the psychological trauma associated with perinatal loss. This in a way will help change people's perception about perinatal loss and allow people to empathize with families who experience it. The study supports the notion that policies that support women's empowerment reduce unfair gender roles (Bayeh, 2016). Furthermore, vulnerability is not only associated with comparing men and women, it is also about who is the weakest in the society (patients versus health professionals).

### **Ministry of Health**

The Ministry of Health, hospital administrators, and heads of health institutions should develop clear policies on management of perinatal loss to improve services and protect and enforce patients' rights, including the right to have a significant say in their own care. Projects like community follow-up of patients with reproductive challenges—particularly infertility and perinatal loss—should be reintroduced into the system as part of the Community Health program by the Ministry of Health, Ghana. The home visit services are necessary for continuous support

to vulnerable patients as well as bereaved parents to help maintain adequate care and counselling services.

Home visits help to assess parents' coping strategies and provide an opportunity to answer any remaining concerns the mothers may have (Jarvis et. al., 2017). Evidence shows that follow-up visits are important, especially immediately after discharge when the possibility of depression is high; they give room to continuous care, show sympathy, and provide emotional support to the bereaved.

Furthermore, the Government of Ghana through the Ministry of Health should ensure that the facilities and resources for maternal and child services are available in all communities and are equipped with skilled professionals and necessary tools to provide high quality and universally acceptable care. A better equipped facility with strong systems of referral and interventions can overcome barriers of giving quality obstetric care and improve birth outcomes.

### **Ministry of Information**

*Create policies and a platform for health professionals and mothers who have experienced this loss to educate the public about reproductive health with its sudden complications such as perinatal loss and the psychological trauma associated with this loss.*

*Raising awareness of perinatal loss* Moreover, it is becoming increasingly clear that taboos in Ghana are creating untold suffering for bereaved women and their families and these sensitive cultural beliefs ought to be revisited and meaningful solutions offered. The Ghanaian public need to understand and appreciate the occurrence of this death during pregnancy, labour and delivery. It is important to provide accurate information from the community level to correct the myths around perinatal loss and childlessness. This can only be achieved through education

by media and posters related to the causes of perinatal loss and the profound outcome of perinatal loss on women.

### **Implications for Nursing Research**

Future research on psychosocial intervention for women with perinatal loss would be useful to address the cultural needs and reduce anxiety in affected women. Health professionals need more than just guidelines and protocols to deal with the culturally sensitive nature on perinatal loss.

### **Recommendations for Nursing Practice**

Health care professionals globally and in Ghana may utilize these study findings to support families and help them to provide care that is culturally sensitive and effective for parents who have experienced a perinatal loss. Researchers have suggested that culturally sensitive practice is fundamental to providing better health care service that is shaping and transforming patients' health, health care institutions, and policies (Browne et al., 2016).

Providing culturally sensitive care is rendering quality of care—it enables the health professionals and patients to reflect more on the care needed and it impacts on health care outcomes for patients (Cameron et al., 2014; Greenwood, McGregor & MacDonald, 2017).

Health care professionals are often the first to communicate the news of the death to the mothers and it is clear from the findings of this study that the bereaved women were mostly unhappy with the manner the news were broken to them. The findings from this study provides a basis from which health care professionals in Ghana can review their services and develop a more sensitive approach to handling women and the grief they often experience.

The study also revealed that many of the women who suffered a perinatal loss have little to no idea of the factors that led to their loss. Knowledge from this study can be used by health care professionals especially nurses/midwives to provide holistic education to women explaining some of the factors that lead to perinatal loss and how to prevent it. It is imperative for health professionals to ensure that expectant mothers and their families receive sufficient information on the probable causes of perinatal loss during antenatal education. Regular antenatal visits should be promoted, and early danger signs assessed. Furthermore, health professionals can develop strategies to ensure mothers are provided with information in relation to fetal development and the small possibility of perinatal death as an outcome.

In the process of grieving, health professionals must encourage mothers to seek early and timely support. The professionals are required to constantly encourage and create opportunities for bereaved mothers to be with or spend time with the deceased baby.

An important recommendation of interest is listening to the voices of grieving mothers. To support them in grieving the loss of their children, participants needed and requested for certain services at the hospital to be implemented and improved. First to be mentioned is a counselling unit for perinatal loss to be instituted at the site. Studies have shown that mothers who experienced perinatal loss encounter different forms of psychological problems; an invitation for counselling after the loss is a meaningful opportunity to reduce stress (Einaudi et al., 2010).

The culture of showing respect and being respected by health professionals was very important to the study participants. Most of the participants expressed fear and disappointment in the way the professionals yelled at them and other mothers at the ward. A noteworthy argument

raised by participants was dissatisfaction with the ward arrangements. Findings from the current study showed that participants were not satisfied with some of the care they received, however, the most frequently mentioned issue was the arrangement of the ward. According to participants, these arrangements adversely affected and intensified their grieving process, particularly being paired with mothers who were privileged to have delivered live and healthy children. The participants recommended the ward to be laid out either in cubicles or to pair patients with the same experiences to protect their privacy and enhance their comfort.

### **Recommendations for Nursing Education**

The present research findings demonstrated that many of the participants encountered profound grief when they experienced a perinatal loss which they received limited support from their nurses. Participants suggested that nurses must be equipped with the knowledge and skill to provide nursing care to bereaved parents. Thus, I recommend that nursing training programs globally and in Ghana educate their students on the effects of perinatal loss on patients, its management, and support. Nurses in Ghana need additional training to have insight into the unique grieving process after perinatal loss to effectively improve the quality of care offered to bereaved parents in distress. Perinatal loss is associated with severe psychological and social distress which may cause anxiety and depression. Hall and colleagues (2015) suggested that health professionals receive training in the management on psychosocial needs of individuals with perinatal loss and ways to support them- Researchers should make available findings of their research on experiences and how to communicate with parents. The findings of the current study can inform curricula updates in midwifery and nursing programs.

Furthermore, it is important to incorporate the effects of perinatal loss and its management in the curriculum of Baccalaureate nursing programs and the hospital protocol

manuals. Nursing institutions, the Ministry of health, and Ghana Health Services should conduct workshops and conferences for health professionals focusing on the management of bereavement as an effective tool to build confidence in caring for bereaved mothers. Though being empathetic towards other people does not come naturally, I recommend health professionals especially nurses/midwives are taught such skills during their bachelorette training.

### **Recommendation for Future Research**

In Ghana, most research and investigations have focused on the causes and statistics of perinatal loss; very little attention has focused on the grieving process and the management and support provided to bereaved parents. Gaps in the literature show that there is little understanding of the severity and effects of perinatal loss and how it changes women's lives and that of their families. Based on these findings, the following are suggestions for further research investigations:

- a) Investigate Ghanaian health professionals' attitudes and knowledge about the effects of perinatal loss and the grieving process of parents who have lost an infant.
- b) Explore strategies to provide all-inclusive and meaningful support for mothers who have experienced perinatal loss to cope and to reduce the grieving process.

Perinatal loss is linked with profound psychological distress that takes months to years for parents to recover from. Parents who have experienced this loss have high levels of anxiety. Therefore, an area of critical interest would be to investigate the effects of past experiences of perinatal loss on stages of new pregnancy until one year after birth.

Factors like culture, religion, decision making in the family, age, and socioeconomic status affect the way Ghanaian women approach and perceive perinatal loss. Other studies have shown that



culture and religion play a major role in how women perceive perinatal loss and its effects of intensifying or reducing mental stress (French, 2011; Shurack, 2015). Due to time constraints, the current study was not able to explore these factors in detail.

- a) It will be interesting if further research is done to see how these factors help parents to cope with handling the loss and grieving process.
- b) Some of the mothers in this study felt abandoned by some family members; future investigations can also focus on ways family and friends provide support and share grieving within themselves after a perinatal loss.

Another research area of importance is the disenfranchisement of parents experiencing perinatal loss. Disenfranchisement cut across for both men and women. While cultural norms enforce men to stand strong as heads of families during bereavement, women are silenced by the same norms. A suggested question for future research is: Do Ghanaian men desire to openly express their emotions during bereavement or is the cultural system biased or restricting them? Other areas to explore in future research include:

- a) the extent to which bereaved mothers are disenfranchised in hospitals, homes, and society.
- b) the grieving experiences of men compared with the grieving experiences of women to further advance knowledge on the effects of the experiences of perinatal loss in Ghana
- c) cultural expectations of how Ghanaian men should conduct themselves in the period of perinatal loss.

Other areas of interest in research are the management of bereaved parents and the emotional effects of the loss on health care professionals (midwives and doctors) during perinatal

loss. Are Ghanaian health professionals equipped with enough knowledge on perinatal loss to deal with their own emotions and further provide services to these women and their families? Further research must aim at evaluating the management of perinatal loss in hospitals in Ghana. There is also the need to increase awareness of the grief experiences of perinatal loss and the importance of support through research.

### **Sociocultural Relevance**

The social and living environment of women who experience perinatal loss and their daily interactions with community members influence grieving and recovery. Members of families respond better if they are informed and have knowledge about the cause of the perinatal loss (Pesantes et al., 2018). An important recommendation is creating an awareness among the Ghanaian public of the causes and griefs associated with perinatal loss in order to prevent disenfranchisement and improve the support women receive from society and community members. Participants reported that the cultural and traditional norms of Ghanaians have an influence on pregnancy outcome and affect how the loss of a child is grieved.

Another area for future research is the sociocultural and religious influence on grieving of perinatal loss. This should aim at informing people about factors which lead to maternal and child mortality and best practices for pregnant and expectant mothers to avoid complications. These public campaigns could help dispel the notion that perinatal losses are cursed from the gods and assist in creating public understanding leading to more positive outcomes for women and families who suffer such losses.

## **Limitations of the Study**

Notwithstanding the valued information the study has produced, there are clear limitations. One major limitation was that a small sample of participants from only one institution in Ghana was recruited to represent the voices of Ghanaian women who have experienced perinatal loss. Participants were recruited on the basis of their capacity to inform the study and on their status as women who have experienced perinatal loss in the setting. However, women with the same status from different ethnic backgrounds were not given the opportunity to be part of the study due to language barrier and, therefore, there is a limitation in the extent to which the findings can be used for other bereaved mothers who are not similar to the study participants with respect to experiences of perinatal loss, grieving, language, and culture. Cruz and Higginbottom (2013) indicate that knowledge produced from research using a focused ethnographic method cannot be generalized but can be transferable. I recommend that future researchers should conduct similar studies in other hospitals in Ghana using a larger sample.

Another limitation is that the researcher only recruited women and, therefore, lacked information or contributions from Ghanaian men and their experiences of perinatal loss. This limits the understanding of both parents' grieving dynamics of the deceased child (Silman, 2014). A suggestion for future study is to conduct research related to the coping strategies of men who experience perinatal loss in Ghana.

## **The Way Forward**

The significance of this study is that it has multiple implications to change practice. I have presented at two international conferences and one internal conference at the Faculty of Nursing, University of Alberta. One of my abstracts is published in the International Journal of

Qualitative Health Methods. Chapter two of the dissertation is accepted to be published in the African Journal of Nursing and Midwifery.

The findings of this research and my encounters with the management of perinatal loss in Canada have helped to identify the challenges women from Ghana go through when they experience perinatal loss. In my role as a midwife who has been in contact with many parents who have experienced perinatal loss, coupled with my loss and that of my study participants' unique experiences, I have come to appreciate the complexities involved in coping with perinatal loss in sub-Saharan Africa and Ghana. I have already started talking to some institutions and authorities in Ghana about my plans to set up perinatal loss social groups in Ghana. My objective is to help reduce the intensity of grief women from Ghana experience during the experience of perinatal loss.

### **Creating Perinatal Loss Association in Ghana:**

In Canada and other high-income countries, apart from familial support, several perinatal support groups offer their services to bereaved mothers either online or through local meetings. Literature has proven that women who experience “perinatal loss need a group that they can closely relate with, a safe haven where they can feel comfortable sharing real feelings in pursuance for hope and healing” (Carlson, Lammert & O’Leary, 2012. p.279).

Grieving provokes different emotions and mothers who experience perinatal loss must be acknowledged and supported (Gold, Sen & Xu, 2013). Most mothers who experience perinatal loss become vulnerable and need emotional support to heal. For many mothers, the loss strikes unexpectedly, and it is stressful and psychologically harmful. Support groups provide an

opportunity for bereaved parents to connect with other couples who are experiencing a need to grieve. Participants shared that they needed people who share the same emotional experience and understand their grief; people that they can talk with. However, while they have no knowledge of the existence of perinatal loss groups in Ghana, they agreed to be part of a support group that would positively reduce their depression. Attaining development among all the pillars of sustainable development is unthinkable without empowering women and obtaining gender equality, thereby using the entire potential of the country.

### **Conclusion**

This study explored the experiences of perinatal loss among women in Ghana. The stories shared by participants in the study provide insight into the complex nature of perinatal loss and the grief associated with it. The findings revealed an urgent need to acknowledge and support the grief experience of parents who experience perinatal loss in Ghana. Cultural norms are part of the people's sense of identity in Ghana, and therefore changing a norm will be difficult; however, I hope the findings from my study helps to shape the cultural norm on how parent's grief is disenfranchisement during perinatal loss and also increase the rate of support in the society.

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## APPENDICES

### Appendix A: Information Letter for Participants

#### Experiences of Perinatal Loss: A Focused Ethnographic Study of Ghanaian Women in the Greater Accra Region

##### Researcher information:

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##### Introduction

I am a doctoral student at the Faculty of Nursing, University of Alberta, Canada. I have worked as a midwife and lecturer who teaches maternal and child health at the University of Health and Allied Sciences, Ho, since 2012. I am doing a study on Ghanaian women experiences of perinatal loss. This letter outlines important information to help you decide whether or not you would like to take part in this study.

##### Purpose

I am asking you to participate in a research study. The purpose of the study is to understand Ghanaian women experiences of perinatal loss.

##### Study procedure

If you decide to participate in the study, you will take part in a face-to-face recorded conversation that will last approximately 1 hour. It might be necessary to have a second conversation with you. It will occur at a place of your choice and at a convenient time agreed upon by you. I will ask you to sign a consent form. The conversation will be about the loss of your child and/or pregnancy. The audio recording of the conversation will be private, and your name will not be used in this study. I will write out the recorded conversations. A summary of the findings will be shared with you to ensure that your experiences have been accurately represented. Participation is voluntary. You are free to withdraw at any time without any complications.

##### Benefits:

You may not benefit directly from the study. However, findings from this study will contribute to nurses knowledge about the best care for women who experience perinatal loss.

**Risks:**

It is not expected that taking part in this study would cause any harm to you. If you experience any emotional discomfort, I will refer you for counselling if needed. The only requirement from you is your time and willingness to engage in the conversation. You have the right to refuse to answer any questions.

**Confidentiality:**

The data will be kept private. All identifying information will be removed from the data and kept in a password protected and encrypted file on a computer in the researcher's office. Nothing you have shared with me will be connected to your name. You will be given a pseudonym of your choice, during the study and you will not be identified in any publication or presentation. Only the research team (researcher and supervisors) will have access to what you have shared. The research team members will be asked to sign a confidentiality agreement. The data will be stored for an undetermined period of time. When we decide to destroy the information, it will be in a way that ensures privacy and confidentiality.

**Use of Data**

The data collected from this study will be summarized into a study paper that will form a partial fulfillment for my doctoral degree. The data will also be used to write academic papers and policy information sheets. The study paper will be made available to the University community and the public through the University of Alberta library. In addition, the results from the study will be presented at conferences and published as papers. Your name will not be connected to these sharing events. The data collected from this study could be used in future research, if we do this it will have to be approved by a Research Ethics Board.

**Freedom to Withdraw:**

You are under no obligation to participate in this study. If you agree to be in the study, you can change your mind and withdraw at any time. If you decide to stop participating, you can ask for all information you have shared to be removed and destroyed. You can ask that any information you have shared be removed up to the end of the study (December 2017).

**Additional contacts.**

You are welcome to ask any questions, at any time, regarding any aspect of this study. If you would like to participate or receive additional information on the study please call or email me, I will respond to your questions or concerns immediately. The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta and Ghana Health Service Review Board. The contacts are:

- Alberta Baffour-Awuah, Principal Investigator: Tel- +233208311111, email address- [baffoura@ualberta.ca](mailto:baffoura@ualberta.ca).
- Hannah Frimpong, Administrator, Ghana Health Service Ethics Review Committee Research and Development Division: Tel- 0507041223

If you want to have a copy of the final write up, please mark the appropriate box

I want a copy of the final report:

Yes	
No	

If 'yes' add you email address or home address:

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**Appendix B: Consent Form for Participants**

**Title: Experiences of Perinatal Loss: A Focused Ethnographic Study of Ghanaian Women in the Greater Accra Region**

Researcher: Alberta Baffour-Awuah

Phone Number: 0208311111

Supervisor: Prof. Solina Richter

Phone Number(s): +1780-492-7953

I have received a copy of the attached Information Sheet, read and understood the contents, benefits and risk involved in taking part in the above-mentioned study. OR This research has been explained in detail to me to understand the contents, benefits and risk involved in taking part. YES  NO

I have had the opportunity to ask questions and discussed this study and have understood that I am free to withdraw from the study at any time without having to give a reason and without penalty. YES  NO

Issues of confidentiality and anonymity has been explained to me and I have also been made to understand that the conversations will be recorded. YES  NO

I also understand and agree that portions of the final research may be published in professional journals or presented at conferences. YES  NO

This study was explained to me by: \_\_\_\_\_

I have read and understood the above information, and agreed to participate in this study:

Signature/Thump print of Research Participant

\_\_\_\_\_

(Printed Name) \_\_\_\_\_

Date: \_\_\_\_\_

Signature of Witness

\_\_\_\_\_

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee \_\_\_\_\_ Date \_\_\_\_\_



## Appendix C: Interview Guide

### **Title: Experiences of Perinatal Loss: A Focused Ethnographic Study of Ghanaian Women in the Greater Accra Region**

The questions are about the loss of your baby, and it will be used to guide the conversation. Feel free to ask for an explanation if the question is unclear. Additional conversations will be conducted to obtain more information on areas that are not clear to the researcher.

Please let me know anytime you wish to skip a question. Please provide me with your honest response and always remember that the information you share with me will be confidential and it will not be identified with you

### **Background**

Tell me a little bit about yourself

- How old are you?
- Do you have any children/dependants?
- What is your level of education?
- Are you employed?
- Who has the ability to make decisions in your family or in the society, concerning your delivery, at what time to go for care and when to plan a pregnancy?
- What will it be like for you in the family or in the community if you decide not to have children?

Tell me about the loss of your pregnancy/child?

- When did you experience perinatal loss? Is this the first time?
- Do you mind explaining to me about the circumstances of your loss? How many months were you? What was the cause of the death?
- Tell me about your delivery experience at the hospital?
- How did the midwives care for you during your loss?
- Can you recall some of the things that were most helpful during your stay at the hospital? Which of them were not helpful?
- Let's talk about your first reaction to the experience of losing your baby. Would you be able describe to me how you felt when you were told about your loss? Is that all? Tell me more.
- Were you able to openly mourn your child?
- Were you given the opportunity by health professionals to be with the deceased baby?
- Were you also given the opportunity to have some memoirs (hair, nails, footprint) of the baby?

Please describe for me exactly how you recuperated emotionally from the loss?

Describe in detail to me the type of support you got from the following people:

- Support from family
- From friends
- Community
- Health professionals

How do you feel now? What makes you feel that you are recovering?

In what ways do you think the health professionals (midwives) can improve on the care of women experiencing perinatal loss? (i.e., in terms of delivery of message, being sensitive, giving women access to bond with their deceased children)

Are there any additional things that you would want to talk about that we have not discussed?

### **Ending**

Thank you for sharing and contributing your experience to the study, I am very grateful. If you realise later that our discussion has aroused any emotional sentiments that needed a specialist, please let me know. If you wish to have the final copy of the study, It would be a pleasure to send you one. Again, my sincere thanks.

**Appendix D: Consent to Contact Form**

**Title: Experiences of Perinatal Loss: A Focused Ethnographic Study of Ghanaian Women in the Greater Accra Region**

Principal Investigator: Alberta Baffour-Awuah

I .....  
[Name of potential participant] hereby on behalf of

.....  
[Name of person at organization and name of organization]  
gives permission that my name is forwarded to the researcher conducting a study on Ghanaian women’s experiences of perinatal loss.

The University of Alberta and the Ghana Health Service Ethics boards has given permission for this study to be conducted. Therefore, I will like to invite you to be part of this study for a conversation of approximately one hour. The conversation will focus on experiences related to perinatal loss in Ghana. Please feel free to choose the time and place that will be the most convenient for you. If you are interested in participating in this study, kindly sign this form and give your contact information to be forwarded to the researcher. She will contact you to set up an appropriate time to talk to you.

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I hereby give my consent to be contacted by the research team of the study: Ghanaian women’s experiences of perinatal loss: a focused ethnographic study. I would like to know more about this study. However, this is not my consent to participate in the study.

Name \_\_\_\_\_ Signature/Thump print \_\_\_\_\_

Phone number \_\_\_\_\_ Email \_\_\_\_\_

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**Appendix E: Confidentiality Agreement.**

**Research Title – Experiences of Perinatal Loss: A Focused Ethnographic Study of**

**Ghanaian Women in the Greater Accra Region**

This form is intended to further ensure confidentiality of data obtained during the research study on Ghanaian women’s experiences on perinatal loss.

**Consent:** This is to certify that:

- I, \_\_\_\_\_, agree to maintain the confidentiality of the research information/data to which I have access through interviews in the above study confidential.
- I will make sure research participants understand the language of the research and that they are also given the opportunity to ask questions during the conversation.
- I will not discuss or share the research information (e.g. tapes, transcripts) with anyone other than the research team.
- I will not reveal the name of any participants, neither will I play the tapes of the data in the hearing of others apart from the research team I am working with.
- I will make sure that all the data in my possession are safe and secured and return in whole all the information in my possession to the research team when my part of the work is completed.
- I will not retain in my possession copies of the data or other information about study participants and destroy all the data in any form relating to this research project.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Witness: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix F: Ethics Approval (University of Alberta)**  
**Notification of Approval**

Date: June 7, 2017

Study ID: Pro00073592

Principal Investigator: [Alberta Baffour-Awuah](#)

Study Supervisor: [Magdalena Richter](#)

Study Title: Ghanaian Women’s Experiences of Perinatal Loss:  
A Focused Ethnographic Study

Approval Expiry Date: Wednesday, June 6, 2018

Approved Consent Form:	Approval Date	Approved Document
	6/7/2017	<a href="#">Consent form</a>
	6/7/2017	<a href="#">Information letter</a>

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Trish Reay, PhD  
Associate Chair, Research Ethics Board 1

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

**GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE**

*In case of reply the  
number and date of this  
Letter should be quoted.*

Research & Development Division  
Ghana Health Service  
P. O. Box MB 190  
Accra.

*MyRef. GHS/RDD/ERC/Admin/App  
Your Ref. No.*

*Tel: +233-0302-960628  
Fax + 233-0302-685424  
Mob + 233-050-3539896  
Email: ethics.research@ghsmail.org*

Alberta Baffour-Awuah  
P. O. Box 5875  
Cantonment, Accra

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	GHS-ERC 22/06/17
Project Title	Ghanaian Women Experiences
Approval Date	20 <sup>th</sup> July, 2017
Expiry Date	19 <sup>th</sup> July, 2018
GHS-ERC Decision	<b>Approved</b>

**This approval requires the following from the Principal Investigator**

- Submission of six (6) monthly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report **after completion** of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....

Professor Moses Aikins  
(GHS-ERC Vice-Chairperson)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

## Appendix G

### Themes and Sub-themes`

<b>THEMES</b>	<b>SUBTHEMES</b>
Beliefs and values surrounding marriage, motherhood and children	<ol style="list-style-type: none"><li>1. Marriage as an obligation for raising children</li><li>2. Motherhood is equated with successful birth and identity</li><li>3. Children as gift from God and source of strength</li></ol>
Views of childlessness and perinatal loss	<ol style="list-style-type: none"><li>1. Attachment, loss and isolation: A response to perinatal loss</li><li>2. Childlessness as a failure for women</li></ol>
Understanding of pregnancy and Loss in the context of Ghana	<ol style="list-style-type: none"><li>1. Mothers attachment to pregnancy and preparation</li><li>2. Grief reactions</li><li>3. Reflection and a new understanding of loss</li></ol>
Subsequent Impacts of perinatal loss on women	<ol style="list-style-type: none"><li>1. Relationship before and after perinatal loss</li><li>2. Fear of the unknown (Divorce)</li><li>3. Disenfranchised grief</li></ol>
Support	<ol style="list-style-type: none"><li>1. Immediate communication and interactions</li><li>2. Support from significant others</li><li>3. Seeing and holding.</li><li>4. Being with</li><li>5. Mothers' perceptions of relevant and meaningful care</li><li>6. Psychological counselling</li></ol>
Culturally sensitive care	<ol style="list-style-type: none"><li>7. Burial and funeral arrangements</li><li>8. Creating meaningful memory</li><li>9. Follow up/postpartum care</li></ol>