Exploring the lived experience of women, families and health care professionals of care and support following perinatal death in South-Western Nigeria: A Hermeneutic Phenomenological Study.

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health.

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Table of Contents

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List of Tables

List of Figures

List of Appendices

List of Acronyms

COVID-19 – Coronavirus

UK – United Kingdom

USA - United States of America

PSN Africa – Postpartum Support Network Africa

UN – United Nations

UNESCO – United Nations Educational, Scientific and Cultural

TFR - Total Fertility Rate

MMR – Maternal Mortality Rate

MDG – Millennium Development Goals

SDG – Sustainable Development Goals

PhD – Doctor of Philosophy

PTSD - Posttraumatic Stress Disorder

HND – Higher National Diploma

OND - Ordinary National Diploma

CS - Caesarean Section

NICE – National Institute for Health and Care Excellence

NEC - Necrotising Enterocolitis

UNICEF – United Nations Children's Fund

LMIC – Low- and Middle-income countries

CNO – Chief Nursing Officer

WHO – World Health Organisation

Abstract

Introduction

Perinatal death has a significant impact on the physical, emotional and mental health of women. This requires adequate bereavement care to limit the impact in the short and long term and on the quality of life. Women and families in sub-Saharan Africa and South Asian countries are most affected as they carry the highest burden of perinatal death. The experience of care and support in these countries has not been explored. Thus, there is a lack of understanding of the care and support received by women, and provided by healthcare professionals in South-Western Nigeria, one of the regions with the highest rate of perinatal death globally.

Aim

The aims of this thesis were (i) to identify, synthesise and critically reinterpret the findings of existing literature on the care and support following perinatal death in high burden settings, and to reveal gaps and new understanding, (ii) to explore the lived-experience of women and families of care and support following perinatal death in South-Western Nigeria and (iii) to explore the lived experience of health care professionals who provide care and support following perinatal death in South-Western Nigeria.

Methods

A metaethnographic metasynthesis was undertaken in synthesising and critically reinterpreting existing studies on women's care and support following perinatal death in high burden settings. Qualitative hermeneutic phenomenological studies using semi-structured interviews were conducted in exploring the lived experience of women, families and health care professionals of care and support following perinatal death.

Results

Perinatal death is not appropriately acknowledged, thus care and support in high burden settings is inadequate. Women are not adequately supported whilst in hospital and receive no follow-up care from health care professionals in the community following discharge. Nurses endeavour to provide support as far as is possible within the hospital but this is determined by their practice as there is no recognised guideline for bereavement care following perinatal death in South-Western Nigeria. Thus, there is a lack of consistency in care and support. Nonetheless, nurses recognise the need for post-discharge follow-up and provide this within their own leisure time, outside of their role.

Conclusion

Overall, bereavement care following perinatal death is limited in South-Western Nigeria; rather nurses provide care and support based on their own practice. There is a need for further research into and a development of sufficient bereavement care in Nigeria for women who experience perinatal death. In addition, the experience of other health care professionals and family members including partners of care and support also requires further research.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application

for another degree or qualification of this or any other university or other institute of learning.

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over and over again as my sister. For all you have done, and you do for me, thank you. I cannot thank you enough sis, God bless you immensely for me. Thank you.

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Preface

I qualified as a Registered Mental Health Nurse after my studies at the University of Leeds. I commenced my career as a Staff Nurse in working age adult psychiatry. As a Staff and Charge Nurse, I worked in various clinical settings such as Forensic, Perinatal, and Elderly psychiatry. I obtained a master's degree in applied psychology (Therapies) at the University of Salford. My research interest is in improving maternal mental health outcome in the perinatal period in sub-Saharan Africa but not limited to this setting. I aim not only to conduct applicable research but contribute to interventions and innovations in improving the health outcome of women following perinatal death in Africa.

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1   Chapter 1 – Introduction

This thesis aims at exploring the lived experience of care and support in women, families and health care professionals following perinatal death in South-Western Nigeria. This chapter focuses on introducing the phenomena of interest, aim and objectives, and an outline of the thesis.

1.1   Perinatal Death

Perinatal death is a prevalent issue that affects many individuals globally, particularly in sub-Saharan Africa and South Asia (UNICEF, 2020c). Sub-Saharan Africa and South Asia carry the highest number of the global perinatal death burden of 81% of neonatal death and 77% of stillbirths (Akombi and Renzaho, 2019; Hug et al., 2019; UNICEF, 2020c; UNICEF, 2021a; Gage et al., 2021; Suzuki and Kashiwase, 2020). Perinatal death is defined as the death of a baby between 22 weeks gestation and 7 days after birth (World Health Organisation, WHO, 2006). Perinatal death includes stillbirths and neonatal death. Stillbirth is the death of a foetus over 28 weeks gestation, while (early and late) neonatal death is the death of a baby within 0-6 days, and before 28 days of life respectively (WHO, 2022b; WHO, 2022c). However, classification varies in different settings globally. As of 2020, there were 2.4 million neonatal deaths within the first month of life and 2 million stillbirths in 2019 globally (UNICEF, 2021; UNICEF, 2020d). Perinatal death has significant physical and psychological impact on women and their families including post-traumatic stress, depression, anxiety, distress and lower quality of life (Boyle et al., 1996; Campbell-Jackson and Horsch, 2014; Adeyemi et al., 2008; Sutan et al., 2010). This also triggers feelings of guilt, sadness, emptiness, worthlessness and isolation in women (Campbell-Jackson and Horsch, 2014; Cacciatore, 2009). The impact of perinatal death also extends to the social aspect of their life such as long-term difficulties with coping with employment and family life (Downe et al., 2013; Gausia et al., 2011). These effects

of perinatal death have been extensively studied in high and low-income settings. Many women and their families are exposed to the impact of perinatal death in sub-Saharan Africa and South Asia due to its high prevalence in these regions. Nigeria is one of the countries carrying the highest burden of perinatal death with a rate of 41 per 1000 live births (neonatal mortality rate of 39 deaths per 1000 live births, and stillbirth rate of 43 deaths per 1000 live births) (Ezeh et al., 2019; UNICEF, 2020a, 2020b).

The majority of studies into the experience of care and support following perinatal death have been conducted in high-income countries. There has been minimal research on this topic in low and middle-income countries as identified in the metasynthesis conducted in this thesis. However, there remains a lack of sufficient studies, and none conducted in Nigeria on the lived experience of care and support following perinatal death.

1.2 Outline of the Thesis

This thesis is presented in an alternative (journal) format and has seven (7) chapters. Chapter 1 presents an introduction to the thesis, explaining perinatal death as a phenomenon, and highlighting the study aim and objectives. Chapter 2 provides a background and describes the context of the studies within this thesis, and rationale for conducting them. Chapter 3 discusses the methodology and methods adopted in this thesis. Chapter 4 presents the literature review in the form of a metasynthesis. Chapters 5 and 6 present the studies on the lived experience of care and support following perinatal death from women and health care professionals in South-Western Nigeria. Chapter 7 provides the discussion of all studies, including strengths, limitations, and implications for policy and practice, and research. This thesis is submitted in alternative format because the researcher aims for the findings to reach a wider audience and be used in improving the provisions for bereaved mothers and their families in sub-Saharan African countries. Thus, the studies have been presented in journal format and will be

submitted for publication to peer reviewed journals. The metasynthesis in this thesis (Paper 1, Chapter 4) has been published in a peer reviewed journal (*Women and Birth: The Australian Midwives Journal*) and is currently in press. The qualitative studies (Paper 2 – Chapter 5, and Paper 3 -Chapter 6) are in preparation for submission for publication.

2   Chapter 2 – Background

2.1   Introduction

This chapter provides a description of the country under study, Nigeria, a brief explanation of its demography and health care system, and an overview of maternal health care provision. The significance of the study is explained, along with a rationale for choosing Nigeria as the setting.

2.2   Research Study Setting: Nigeria

The Federal Republic of Nigeria is a country in sub-Saharan Africa, located precisely in West Africa (Figure 1) with its capital in Abuja (Nigeria High Commission, 2022). It has an area of 923,770 km^2 and is bordered by Benin in the west, Cameroon and Chad in the east, Niger in the north, and has its coast on the Gulf of Guinea in the south (Chukwuonye et al., 2018; UCLA African Studies Center, 2022; Nigeria High Commission, 2022). Nigeria is made up of 36 states, categorised into six geopolitical zones, namely South-East, South-South, South-West, North-Central, North-East and North-West (Figure 2) (Chukwuonye et al., 2018; Wong et al., 2018). Its government is structured into three tiers, namely one federal government, 36 state governments and 768 local governments (Nigeria High Commission, 2022). Nigeria comprises 250 ethno-linguistic groups of which Yoruba (21%), Igbo (18%) and Hausa (29%) are the most recognised amongst others (32%) (Minority Rights Group International, 2022). There are numerous languages spoken in Nigeria including Pidgin, Igbo, Yoruba, Hausa, Igala, Ijaw, Fulani, and English which is the official language. In this country, there are different religions practised namely Christianity (47%), Islam (51%), and Traditional Beliefs (1%) (Nigeria High Commission, 2022; Minority Rights Group International, 2022). The average age for finishing education is 16 years, with a total of 62% of 15-year-olds and above who are literate as of 2018, yet many particularly in the north of the country do not have access to education (UNESCO Institute of Statistics, 2022; Nasir, 2022).

Nigeria has a total population of 216 million people, making it the most populated country in Africa (World Bank, 2022a; United Nations Population Fund, 2022; World Population Review, 2022a). Lagos is the most populated state in Nigeria with an estimated 24.6 million people (Lagos State Government, 2022). Nigeria can be described as a "middle aged" country as 54% of its population are aged between 15 and 64 years, 43% aged between 0 and 14 years, and 3% aged 65 years and above (World Bank, 2022f). Nigeria has a birth rate of 37 live births per 1000 people per year and total fertility rate (TFR) of 5.2 births per woman, significantly higher than the United Kingdom (UK) which has 10 births per 1000 people and 1.6 births per woman respectively in 2020 (World Bank, 2022c). The life expectancy is 55 years (males) and 57 years (females), which is low compared to the UK with 79 years and 82 years for male and females, respectively (Abubakar et al., 2022; Office of National Statistics, 2021; United Nations Population Fund, 2022). The national currency is Naira (₦). In Africa, Nigeria has the largest economy with a Gross Domestic Product (GDP) of $441 billion in 2022, with a GDP growth of 3.6% (World Population Review, 2022b; World Bank, 2022b; Abubakar et al., 2022). According to the Nigeria Poverty Assessment 2022 conducted by the World Bank (2022e), one (1) in four (4) (approximately 40%) Nigerians live below the national poverty line of ₦137,430, particularly in rural areas where many lack access to basic amenities such as electricity, safe drinking water and sanitation facilities (Nasir, 2022).

Figure 1: World map indicating the location of Nigeria (Burning Compass, 2022)
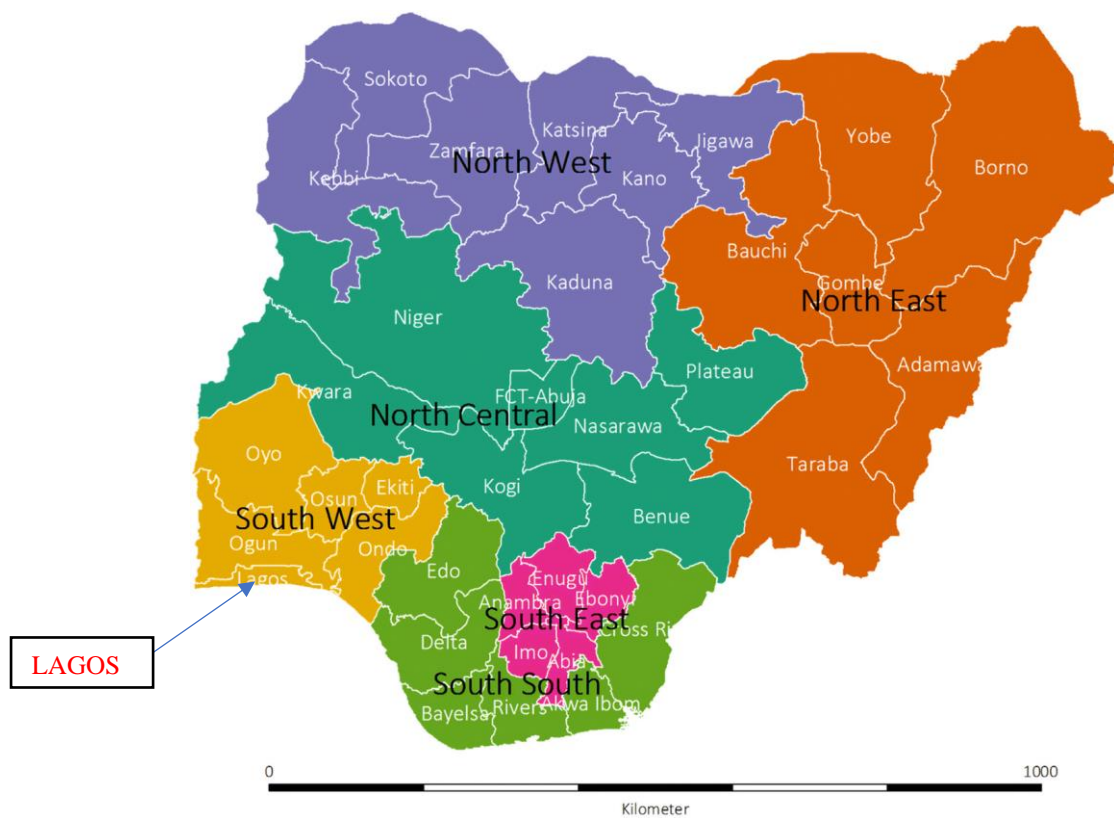
Figure 2: Map of Nigeria including all geopolitical zones (Wong et al., 2018)

2.3   Nigeria's Healthcare System

In Nigeria, the health care sector consists of public and private providers. The health care system is predominantly driven by the public sector, while the private sector substantially augments the service provision (Uzochukwu, 2017). Health care in Nigeria is split into three tiers: primary (local dispensaries and health centres), secondary (general hospitals) and tertiary (university teaching hospitals and federal hospitals) (Oyedeji and Abimbola, 2014). These tiers are managed by local, state and federal governments, respectively (Wellcome, 2011). Primary health care facilitates are located in rural areas, and secondary and tertiary facilities are situated in urban areas (Uzochukwu, 2017). The public sector has three tiers, namely Federal, State and Local Government areas, which are autonomous and have the authority to allocate and distribute health care resources (Uzochukwu, 2017). The Federal Ministry of Health houses the Division of Hospital Services, which supervises Teaching Hospitals, Federal Medical Centres and Specialty Hospitals in Nigeria (Federal Ministry of Health, 2022).

Healthcare in Nigeria is funded via the National Health Insurance Scheme (NHIS), government budget allocation, donors and private funding (Odunyemi, 2021; Adeniji, 2017). The expenditure on health by the Nigerian government remains at 1%, even with a 4% allocation in the federal budget, significantly below the 15% that was committed to at the Abuja Declaration of 2001 (Gatome-Munyua and Olalere, 2020; Abuja Declaration 2001; Odunyemi, 2021; Olatubi, 2018). In 2014, the National Health Bill was passed into law by the government of Nigeria to improve the access of vulnerable population to health care (Edeh, 2022; National Health Bill, 2014). However, this has not been effective, as many Nigerians continue to pay out of their own pocket, and approximately 97% of the population are exposed to significant health care bills, which contributes to poor health care consumption and inequality in access (Edeh, 2022; Adebiyi and Adeniji, 2021).

As with other states, the Lagos State Ministry of Health initially had the accountability and responsibility for the health and social welfare of its residents. However, the social welfare division was removed and placed under the Ministry of Youth and Social Development (Lagos State Ministry of Health, 2022). In Lagos State, there are 26 registered general hospitals, 256 primary health centres, 2886 private and specialist hospitals, laboratories/diagnostic centres, and approximately 160 traditional medicine centres (Musbau, 2017). There are approximately 386,000 annual births in Lagos State, of which only 62% were registered, as of 2013. Of these annual births, there were 15,000 neonatal deaths (39 neonatal deaths per 1000 live births) and 2000 maternal deaths (576 maternal deaths per 100,000 live births) yearly (Healthy Newborn Network, 2014). There remain inconsistencies and a lack of accurate data for maternity and newborn outcomes in Lagos State, which hinders the ability to understand health care provisions. The health care system in Lagos, and Nigeria, is poorly developed with various lapses and a lack of adequate and functional monitoring systems. There are numerous agencies commissioned under the Federal Ministry of Health, which makes it difficult to understand the key avenues or agencies responsible for regulating the hospitals and providing data.

2.4 Maternal Health Care in Nigeria

Maternal health refers to the health of a woman during pregnancy, childbirth and the postnatal period (WHO, 2022). Maternal mortality occurs at an alarming rate in low and middle-income countries, specifically sub-Saharan Africa with a rate of 435 deaths per 100,000 live births which is significantly higher than in high income countries with a rate of 11 deaths per 100,000 live births in 2015 (Olamijulo, Olorunfemi and Okunola, 2022; World Bank, 2022h). As of 2017, the maternal mortality rate (MMR) was 917 per 100,000 in Nigeria, that is a 1 in 22 lifetime risk of dying during pregnancy, childbirth or postpartum/post-abortion (WHO, 2022; World Bank, 2022g). Nigeria ranks second in the world of countries with the highest MMR, as

it is estimated to account for 23% of the global maternal mortality (Ope, 2020; WHO, 2017; Roser and Ritchie, 2017). The high MMR in Nigeria is linked to delays in attending, and accessing services, inequalities and poor health care provisions (Olamijulo, Olorunfemi and Okunola, 2022; WHO, 2022). Some other causes of maternal mortality in Nigeria include obstetric haemorrhage, eclampsia, sepsis and complications from abortions (Meh et al., 2019).

A total of 39% of births occur in health facilities in Nigeria (26% in public hospitals and 13% private hospitals), 59% of women birthed at home and a national total of 42% of these births are registered (Adedokun and Uthman, 2019; National Population Commission, 2019). The Federal Government of Nigeria made birth registration with the National Population Commission compulsory by law under the Births and Deaths (Compulsory Registration) Decree No. 69 of 1992 within 60 days, after which a penalty will be issued. However, this penalty was never implemented due to the National Population Commission's aim to widen the coverage of registering births across the country, but this has proved ineffective (Canada: Immigration and Refugee Board of Canada, 2011). Birth registration is higher amongst the wealthier population and in urban areas in Nigeria (National Population Commission, 2019).

Maternal and perinatal mortality are part of the public health concerns that have remained prominent globally. This led to the development of Millennium Development Goals (MDG) (Table 1, page 29) by the United Nations in 2000, setting 8 targets in tackling global health and wellbeing concerns by 2015 (WHO, 2018). Despite global efforts and good progress that has led to a decrease in maternal and perinatal death (MDG 4 and 5), African countries continued to carry the highest global burden thus MDGs 4 and 5 were not met in this region (United Nations Economic Commission for Africa, 2015). The MDGs were replaced in 2015 by Sustainable Development Goals (SDGs) (Table 2, page 31) under the 2030 Agenda for Sustainable Development (United Nations, 2022b). There are 17 SDGs (Table 2, page 31)

calling for urgent actions from all developed and developing countries to address the global concerns and achieve a sustainable future (United Nations, 2022b). The SDG3 continues to address the global health concerns as commenced in the MDGs by focusing on "ensuring healthy lives and promoting well-being at all ages" (United Nations, 2022b). This is the goal which applies to this study, particularly targets 3.1 and 3.2. Target 3.1 focuses on reducing the global maternal mortality ratio to less than 70 per 100,000 live births by 2030. On the other hand, target 3.2 focuses on ending preventable death of newborns and children under 5 years of age with all countries aiming to reduce neonatal mortality to as low as 12 per 1000 live births and under-5 mortality to at least as low as 25 per 1000 live births (United Nations, 2022a). The findings of this study will contribute to the efforts of improving the care and support for women and their families following perinatal death in Nigeria and in achieving the SDG3.

Table 1: Millennium Development Goals

	Millennium Development Goal	Targets
MDG1	Eradicate extreme poverty and hunger	To halve the proportion of people whose daily income is less than $1.25 To achieve full and productive employment, as well as decent work for all, including young people and women To halve the proportion of individuals suffering from hunger in the period between 1990 and 2015.
MDG2	Achieve universal primary education	To ensure that children universally – including both boys and girls – will be able to complete a full course of primary education by 2015.
MDG3	Promote gender equality and empower women	To eliminate gender disparity in primary and secondary education by 2005, and in all levels of education by 2015.
MDG4 and MDG5	Reduce child mortality and improve maternal health	To reduce the under-five mortality rate by two-thirds in the period between 1990 and 2015. To reduce the maternal mortality ratio by 75 percent To achieve universal access to reproductive health.
MDG6	Combat HIV/AIDS, malaria and other diseases	To halt by 2015 and have started to reverse the spread of HIV/AIDS To achieve global access to treatment for HIV/AIDS for those who need it by 2010 To have ceased and started reversal of the incidence of malaria and other major diseases by 2015.

MDG7	Ensure environmental sustainability	To integrate the principles of sustainable development into every nation's policies and programmes, and also reverse the depletion of environmental resources
		To reduce biodiversity loss and achieve a substantial reduction in the rate of loss by 2010
		To halve the proportion of the universal population without sustainable access to clean and safe drinking water and basic sanitation by 2015
		To achieve substantial improvement in the lives of a minimum of 100 million slum dwellers by 2020.
MDG8	Develop a global partnership for development	To further develop an open, predictable, rule-based, non-discriminatory trading and economic system
		To address the special needs of the least developed countries
		To address the special needs of small island developing states and landlocked developing countries
		To deal exhaustively with the debt problems of developing nations
		To provide access to affordable essential drugs in the developing world – in collaboration with pharmaceutical companies
		To avail benefits of new technologies, especially information and communications, in collaboration with the private sector

(MDG Monitor, 2016).

Table 2: Sustainable Development Goals

Number	Aim	Targets
Goal 1	No poverty	End poverty in all its forms everywhere
Goal 2	Zero hunger	End hunger, achieve food security and improved nutrition and promote sustainable agriculture
Goal 3	Good health and well-being	Ensure healthy lives and promote well-being for all at all ages
Goal 4	Quality education	Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all
Goal 5	Gender equality	Achieve gender equality and empower all women and girls
Goal 6	Clean water and sanitation	Ensure availability and sustainable management of water and sanitation for all
Goal 7	Affordable and clean energy	Ensure access to affordable, reliable, sustainable and modern energy for all
Goal 8	Decent work and economic growth	Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all
Goal 9	Industry, innovation and infrastructure	Build resilient infrastructure, promote inclusive and sustainable industrialisation and foster innovation
Goal 10	Reduced inequality	Reduce inequality within and among countries
Goal 11	Sustainable cities and communities	Make cities and human settlements inclusive, safe, resilient and sustainable
Goal 12	Responsible consumption and production	Ensure sustainable consumption and production patterns

Goal 13	Climate action	Take urgent action to combat climate change and its impacts
Goal 14	Life below water	Conserve and sustainably use the oceans, seas and marine resources for sustainable development
Goal 15	Life on land	Protect, restore and promote sustainable use of terrestrial ecosystems, sustainably manage forests, combat desertification, and halt and reverse land degradation and halt biodiversity loss
Goal 16	Peace and justice strong institutions	Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels
Goal 17	Partnerships to achieve the goal	Strengthen the means of implementation and revitalize the global partnership for sustainable development

United Nations (2022b)

2.5   Study Significance

The metasynthesis in Chapter 4 (Paper 1: Women's experiences of care and support following perinatal death in high burden countries: A metasynthesis.) revealed that there is limited research into care and support following perinatal death in high burden settings. However, the impact of perinatal death on the psychological and physical health and wellbeing of women had been widely studied globally. It is evident from the literature that women are exposed to potential short- and long-term negative effects as a result of the death of their baby (Fernandez-Sola et al., 2020; Das et al., 2021). This is further worsened in the absence of adequate care and support. There has been no study into the lived experience of care and support following perinatal death in Nigeria.

Perinatal death is prevalent globally with ongoing efforts to reduce the rates, but this remains concerning in sub-Saharan Africa and South Asia, with Nigeria having a significantly high rate (Tiruneh et al., 2021; Ezeh et al., 2019). There are numerous factors that contribute to Nigeria carrying a very high burden not only of perinatal death but maternal mortality. Some of these include poor health care provisions, inequality in access to care, lack of knowledge and education in the population, financial barriers, and inadequate health care facilities (Adedini et al., 2014). There has been some research into these areas particularly using quantitative methodology, but the experience of care and support has not been given adequate consideration. This is an important area to study because of the detrimental impact that perinatal death can have on women and their families. Thus, conducting this hermeneutic phenomenological study (Paper 2: An exploration of women's lived experiences of care and support following perinatal death in South-Western Nigeria: A phenomenological study, and Paper 3: An exploration of health care professionals' lived experiences of care and support provision following perinatal death in South-Western Nigeria: A phenomenological study)

allowed an in-depth exploration of the lived experience of care and support for greater understanding and interpretation. This contributes to the improvement of outcomes for women and families who experience perinatal death in Nigeria, and also achieves the SDG3. Overall, this study is a valuable contribution towards creating an awareness of the importance of adequate bereavement care and support following perinatal death. The findings will be disseminated to maternal health care facilities and support groups in Lagos, Nigeria, with a view to widening the reach and impact.

This study setting (Lagos, Nigeria) is unique because it is a state in one of the countries with the highest rate of perinatal death, currently ranked second in the world. Thus, this means that the study was conducted in a setting that has a large population that is highly impacted by perinatal death.

This thesis has contributed to the knowledge and literature on the experience of care and support in areas with the highest burden of perinatal death. It revealed that the experience of care and support from the perspective of mothers is insufficient and inadequate. However, nurses believed they provided the best care and support to these mothers within the limited resources available within the hospital. Some nurses also went beyond their role by providing follow-up support in the community following discharge as they recognised that this is required. Thus, this thesis revealed that there is a need for better bereavement support for mothers following perinatal death in Nigeria.

2.6   Personal Rationale for Choosing this Research Topic and Context

I was born in Nigeria and lived there for over a decade, and in this time, I developed an awareness of the state of its healthcare system. I have always had an interest in babies, they fascinate me so much so that I had an ambition of becoming a paediatrician and later a midwife, although I never pursued this, the passion still remains. When I was 14, a family member

experienced neonatal death at a federal government hospital in Lagos which was very traumatic and the approach to care and support was insufficient and inadequate. As a teenager, I felt unable to help and from my observation the health care professionals were absent therefore the majority of care and support, particularly psychological, was offered by family. Over the years, this experience has remained with me. The awareness of this experience created a desire in me to ensure that other women and their families are given sufficient care and support following perinatal death in Nigeria. I trained as a mental health nurse in the UK, and my interest in maternal mental health in Nigeria was reflected in my undergraduate dissertation where I focused on interventions to improve interactions between mothers with depressive illness and their babies. However, I remained interested in the country of Nigeria.

I have a deep awareness of the state of health care in Nigeria, particularly in relation to maternal health. On one of my visits to Nigeria, I observed that the healthcare system remained underfunded and inadequate, and the birth rate in the country was still high according to statistics. Thus, this sparked my desire to study the care and support that is offered to women following perinatal death in South-West Nigeria particularly Lagos State which is densely populated and yet has a high rate of poverty and inequality. As my PhD study progressed, it became apparent that this is a topic that is not much recognised or studied in Nigeria. This revealed to me the importance of undertaking this study as it made me relive my family member's experience. In addition, the reality that many women and their families continue to have the same experience spurred my interest in studying this phenomenon.

2.7   Aim and Objectives of the Studies

These studies aimed to explore the views of women, their families and health care professionals about their lived experience of care and support following perinatal death in South-Western Nigeria.

In achieving this aim, the objectives were:

1. To synthesise and critically interpret existing qualitative studies on women's lived experience of care and support following perinatal death in high burden settings by conducting a metasynthesis to identify gaps in the literature and develop new interpretation of findings.

2. To conduct a hermeneutic phenomenological qualitative study using semi-structured interviews to explore the lived experiences of women, families and health care professionals of care and support following perinatal death in South-Western Nigeria.

2.8   Conclusion

Overall, this chapter provided a description of Nigeria, including its demography, population, and health care provisions. Within this, the challenges facing the population and health care system in Nigeria including poor access, inequality and the financial impact were explored. The MDGs and SDGs were also discussed in relation to the studies within this thesis. The rationale for conducting these studies in Nigeria, and the aims are also provided.

3   Chapter 3 – Research Methodology and Methods

3.1   Introduction

The aim of this chapter is to discuss, in depth, the methodological approach adopted in the metasynthesis and research studies. This chapter provides a rationale for utilising the chosen research methods and a description of the data collection methods. An explanation of the philosophical underpinning and its influence of the methodological approach is also provided.

3.2   Research Paradigm

A research paradigm is the way of thinking and describing a worldview informed by philosophical assumptions about the nature of social reality (ontology), and knowledge (epistemology) (Thomas Kuhn, 1962 cited in Kivunja and Kuyini, 2017 p.26; Chilisa and Kawulich, 2012; Patton, 2002; Guba and Lincoln, 1994). These assumptions determine how researchers understand and interpret a phenomenon/reality (Thomas Kuhn, 1962 cited in Kivunja and Kuyini, 2017, p.26; Mackenzie and Knipe, 2006; Schwandt, 2001). Crotty (1998) explained that it is imperative for a researcher to have a proper understanding of these stances to ensure that the research process is appropriate in achieving the aims and objectives of a proposed study. Ultimately, a research paradigm informs the approach (methodology and methods) used in studying a phenomenon of interest (Given, 2008; Guba and Lincoln, 1994). A research paradigm is made up of four components namely ontology, epistemology, methodology and methods (Scotland, 2012; Khatri, 2020).

Ontology is the study of nature and essence of reality, that is, "what is the nature of the "knowable?" or "what is the nature of "reality?" (Mason, 2002; Guba and Lincoln, 1994; Guba, 1990, p. 18). On the other hand, epistemology is the study of the nature of knowledge, concerned with how we know what we know about the world/reality and what forms the

foundation of knowledge, that is, "what is the nature of the relationship between the knower (the inquirer) and known (or knowable)?" (Mason, 2002; Guba and Lincoln, 1994; Guba, 1990, p.18). Ontology and epistemology are made up of various theoretical perspectives, not limited to those explained below. Ontological stances include realism and relativism while epistemology includes positivism, constructivism and interpretivism (Levers, 2013). These stances influence the theoretical perspectives of researchers and are explored further below.

3.2.1 Ontological Stances

Realism posits that a single reality exists independent of human consciousness and can be studied, understood and experienced as "truth" (Moon and Blackman, 2014; Levers, 2013; Proctor, 1998). In other words, a clear distinction exists between how the world is and individuals' meaning and interpretation of it (Ritchie et al., 2014). Realism is in two categories namely empirical or naïve and critical realism. Empirical or naïve realism proposes that internal underlying factors such as emotions and beliefs do not contribute to an experience or reality (Moran, 2019). Rather it holds that reality is created and exists external to the human mind thus making empirical realism superficial in its view (Bryman, 2008; Moran, 2019). Critical realists argue that a single reality exists but cannot be perfectly understood or observed because it is created by invisible structures of human views and experience (Guba and Lincoln, 1994). Thus, reality should be critically examined, as it can only be understood if these structures are fully understood (Guba and Lincoln, 1994; Bryman, 2008; Bhaskar, 1989).

On the other hand, relativism suggests that reality is constructed in the mind hence a single reality does not exist but rather is relative to those who experience it (Moon and Blackman, 2014; Proctor, 1998; Guba and Lincoln, 1994; Ritchie and Lewis, 2003; Scotland, 2012). Furthermore, relativism argues that reality is individually created when our consciousness interacts with objects that already carry meaning and is moulded by language to achieve an

interpretation (Crotty, 1998; Frowe, 2003; Schwandt, 2000; Andrews, 2012; Scotland, 2012). Hence, realities are influenced by senses and consciousness, without which we are unable to understand the world (Scotland, 2012; Bradshaw et al., 2017).

3.2.2 Epistemological Stance

Positivism suggests that only one reality exists and can be understood objectively as *"hard facts"* independent of human behaviour, thus not created by the mind (Crossan, 2003; Antwi and Hamza, 2015; Hudson and Ozanne, 1988; Carson et al., 2001; Guba and Lincoln, 1994). Developed by Auguste Comte (1758 -1857), positivism proposes that deductive logic and observed behaviour can be amalgamated to produce probabilistic causal laws to be used in predicting patterns of human activity (Neuman, 2014). Positivism asserts that in gaining reliable knowledge, natural phenomenon/human behaviour must be directly observed and manipulated using an experimental or empirical approach to find laws and causal relationships on social phenomena (Antwi and Hamza, 2015; Don-Solomon and Eke, 2018). Hence, positivism is suited to quantitative studies (Carson et al., 2001; Churchill, 1996). However, it is criticised for viewing humans as objects and not acknowledging their subjectivity to influences such as emotions and beliefs, thereby hindering its ability to examine them and their behaviours/experiences in-depth (Crossan, 2003; Scott and Usher, 2011; Elshafie, 2013).

In opposition to positivism, the philosopher Kant explained that there are ways of knowing about the world other than using direct observation/senses. He described that human reasoning and perception not only relate to senses but also to interpretation of what they tell us (Kant, 1781 cited in Ritchie et al., 2014, p.11). This is because we experience the world as it presents and interpret it hence interpretivism was developed (Flick, 2014; Dharamsi and Scott, 2009). Interpretivism suggests that truth and knowledge are subjective and not objective, as positivism proposed (Ryan, 2018; Williams and May, 1996; Grix, 2004; Scotland, 2012). It explains that

knowledge does not originate from *just* having an experience but rather when individuals reflect on an occurrence (Ritchie et al., 2014; Iofrida et al., 2014). Thus, interpretivism focuses on how individuals understand and interpret their subjective reality (Levers, 2013; Fossey et al., 2002). According to Wilhelm Dilthey, to develop an understanding (Verstehen) of the meaning of a phenomenon (interpretation), the researcher must have access to that experience (Schwandt, 1998). This can only be attained by observing and listening to individuals and becoming a part of them to grasp the meaning of their experience (Singh, 2019). Therefore, interpretivism claims that researchers cannot completely detach their personal beliefs and values, which positivism refutes, but rather this influences how data is gathered, interpreted and analysed (Ryan, 2018). Interpretivism shares a similar view with constructivism.

Constructivism emphasises that social phenomena and their meanings do not exist externally to individuals, rather they are *socially constructed* in their minds as they engage with the world and remain in a state of constant revision (Schwandt, 2000; Bryman, 2008; Crotty, 1998; Creswell, 2009). Therefore, each individual will construct meanings of the same phenomena in different ways influenced by their cultural, historical and social perspectives (Moon and Blackman, 2014; Creswell, 2009). This epistemological stance shares a similar view with the ontological stance of relativism. Constructivism suggests that researchers should aim at understanding the complex world of a lived experience from the standpoint of individuals who live or have lived it (Schwandt, 2000; Mertens, 2019). This is because the knowledge and the "knower" cannot be separated, as the experience of interest is within them (Mertens, 2019).

Overall, from exploring research paradigms, the epistemological stance of interpretivism is well suited to achieving the aims of this study which is focused on exploring the lived experience of women, families and health care professionals of care and support following perinatal death in South-Western Nigeria. This is because the researcher's stance is that without

understanding the subjective reality as experienced by these individuals, the lived experience of interest cannot be sufficiently explored in depth. Furthermore, as has been highlighted in interpretivism, reality can be different for each individual. Therefore, interpretivism was adopted in this study (see figure 3) because it allows individual realities to be explored in their own rights and contexts.

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RESEARCH PARADIGM
    ├── Ontology
    │     ├── Realism
    │     └── Relativism
    └── Epistemology
          ├── Positvism
          ├── Interpretivism
          └── Constructivism
```

Philosophical Stance/Theoretical Perspective

Realism | Relativism | Positvism | Interpretivism | Constructivism

Methodology

Qualitative Phenomenology

Methods

Purposive sampling and semi-structure interviews
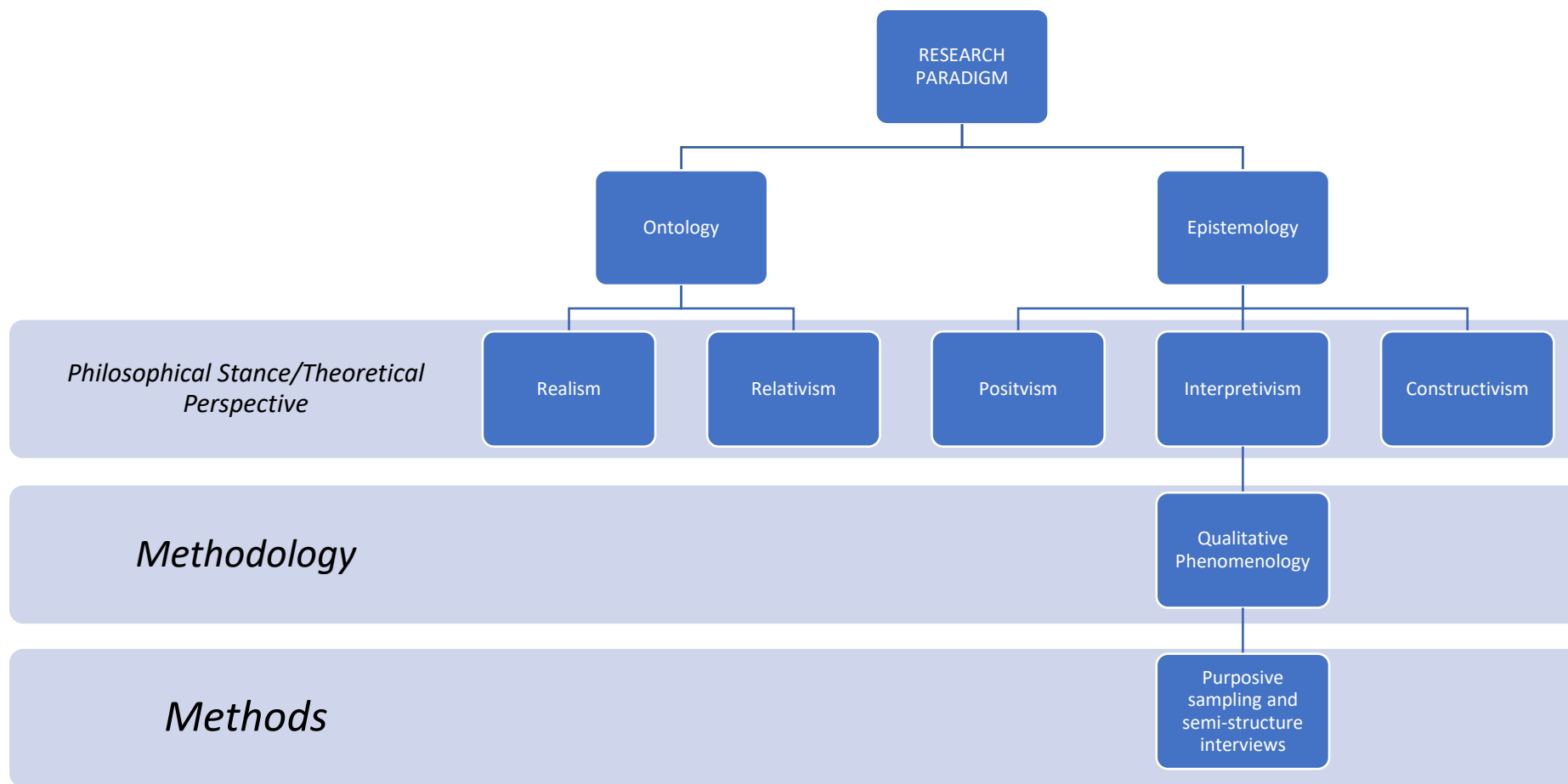
Figure 3: Diagram illustrating the research paradigm.

3.3 Qualitative Research Methodology

In this study, the philosophical stance of interpretivism informed the use of qualitative methodology. Qualitative research methodology is concerned with studying the nature of a phenomenon in its original context or the perspective of individuals who are living or have experienced it (Busetto, Wick and Gumbinger, 2020; Yilmaz, 2013; Isaacs, 2014; Mohajan, 2018; Hammaberg et al., 2016). This methodology was adopted because it allows exploration of lived experiences of care and support following perinatal death in their natural context as experienced by women, families and as provided by health care professionals (Malterud, 2001; Grossoehme, 2014). There are various approaches used in qualitative methodologies including metasynthesis for reviewing and synthesising existing literature, grounded theory, ethnography and phenomenology for conducting research studies (Sayre, 2001; Grossoehme, 2014). These approaches share a similar aim of gaining an in-depth understanding of experiences, but they differ in their method of achieving this (Sayre, 2001; Teherani et al., 2015; Rodriguez and Smith, 2018). Nonetheless, it was imperative to explore other approaches to ensure the most appropriate method is used.

3.3.1 Metasynthesis

Metasynthesis was adopted in synthesising existing studies and critically reinterpreting their findings to identify gaps in the literature and develop new interpretation. Metasynthesis uses a systematic approach to identify qualitative literature and to appraise, analyse and synthesise findings to yield richer and in-depth critical reinterpretation of a phenomenon of interest (Erwin et al., 2011; Flemming et al., 2019; Sandelowski and Barroso, 2007; Nye, Melendez-Torres and Bonell, 2016). The critics of the field of qualitative research have argued that individual studies give rich and in-depth description of a topic of study but connections between their findings are not drawn thereby limiting their use in gaining further understanding of a

phenomenon and its application to practice and theory development (Nye, Melendez-Torres and Bonnell, 2016; Jensen and Allen, 1996; Estabrooks, Field and Morse, 1994). This led to the development of metasynthesis as an approach to the synthesis and interpretation of findings of individual studies thereby creating a new perspective via "third level" findings (Jensen and Allen, 1996; Nye, Melendez-Torres and Bonnell, 2016, p.70). The aim of metasynthesis is not to be aggregative by summing findings, rather it is interpretative in nature (Jensen and Allen, 1996). There are different approaches to metasynthesis including meta-study, meta-ethnography, and "thematic analysis". Meta-study made up of meta-theory, meta-method and meta-data synthesis, is the approach that involves "simultaneously meta-synthesising and reciprocally translating methods, results and discussion" (Nye, Melendez-Torres and Bonnell, 2016, p. 68) to develop an understanding of interactions between these sections to achieve a theory of a phenomena (Paterson et al., 2001; Lee et al., 2015; Dixon-Woods et al., 2005; Barnett-Page and Thomas, 2009). In addition, meta-data synthesis shares the same approach with meta-narrative, which examines how different epistemologies contribute to the results and understanding of a phenomenon and is often used in mixed-methods reviews (Nye, Melendez-Torres and Bonnell, 2016; Greenhalgh et al., 2005). Thematic synthesis, developed by Thomas and Harden (2008) is an adaptation of 'thematic analysis', concerned with identifying obvious/recurring themes in quantitative and qualitative studies and providing a summary of study findings under thematic headings (Dixon-Woods et al., 2005; Ryan et al., 2018). This is an approach of synthesis that brings together qualitative evidence focused on practice and intervention development and evaluation. This approach uses line-by-line coding in analysing study findings to achieve a hypothesis for systematic reviews (Nye, Melendez-Torres and Bonnell, 2016).

Grounded formal theory analysis which has been adapted by researchers (Kearney, 1998; Eaves, 2001; Finfged, 1999) from the research methodology, grounded theory initially

developed by Glaser and Strauss (1967) and Strauss and Corbin (1998). This approach views qualitative research as being concerned with theory generation thus focuses on extracting theory from existing study findings that used grounded theory methodology (Charmaz, 2006; Atkins et al., 2008). It is used in a "like for like" manner by using the same approach of constant comparative method adopted in primary studies (theory) to synthesise findings (Barnett-Page and Thomas, 2009; Noble and Mitchell. 2016). Grounded formal theory analysis displays good potential in synthesising studies because it has written procedures to guide researchers in conducting a synthesis of studies (Strauss and Corbin, 1998). However, a lack of transparency persists in grounded formal theory analysis even with its clarity of procedures. In addition, the existing unresolved epistemological issues with grounded theory as a methodology such as uncertainty about varying credibility of accounts and how to manage them, also affects grounded formal theory analysis as a method (Dixon-Woods et al., 2005).

Meta-ethnography is an inductive and interpretive approach to synthesising qualitative data and interpreting the findings developed by Noblit and Hare (1988) (Paterson et al., 2001; Sattar et al., 2021; Chrastina, 2018). It uses a set of specific strategies (reciprocal translational analysis, refutational synthesis and line of argument synthesis) in analysing findings of existing studies. Reciprocal translational analysis is the direct comparison of the study findings with each other to identify similarities while refutational synthesis is concerned with identifying the differences/conflicts within these studies. These therefore yield a line of argument synthesis of bringing the findings of these parts to make a whole, that is a new interpretation (France et al., 2019; Tavish et al., 2019; Britten et al., 2002). These strategies help in creating a re-interpretation of the data findings from primary studies to develop new and deeper conceptual insights (Malpass et al., 2009; Pope, Mays and Popay, 2007). This makes it different from other methods of synthesis such as narrative, thematic and grounded formal theory analysis because it does not seek to be aggregative or to identify theory, but rather aims for interpretation of

existing knowledge. Thus, meta-ethnography is better suited to synthesising phenomenological studies in contrast to the other synthesis methods and is often utilised because of its suitability to developing a higher level of analytic as opposed to descriptive findings and generating new research questions (Dakar-White et al., 2015; Atkins et al., 2008). However, meta-ethnography has been criticised for offering no guidance on sampling and quality appraisal of included studies and being solely applicable for use as method of synthesis (Dixon-Woods et al., 2005). Nonetheless, meta-ethnography was chosen in synthesising qualitative studies because it is best suited to developing conceptual understanding of specific phenomena such as the experience of care and support among women and their families following perinatal death in high burden countries (Sattar et al., 2021).

In line with the study focus on lived experience of care and support following perinatal death, qualitative studies were most suited to being synthesised. Synthesising and critically reinterpreting qualitative literature poses a concern of diminishing the integrity of individual studies (Ring et al., 2011; Bearman and Dawson, 2013). In addressing this concern, Noblit and Hare's (1988) meta-ethnography guided the metasynthesis because it gives clear methodological steps for literature search and identification, data analysis and synthesis whilst preserving the context and meaning of individual studies. This approach was suited because of its inductive and interpretive nature which promotes developing new and deeper insights and knowledge from existing qualitative studies (Dakar-White et al., 2015; Sattar et al., 2021; Chrastina, 2018).

3.3.2   Primary Research Studies

Hermeneutic phenomenology was used in conducting the original research studies (Paper 2: An exploration of women's lived experiences of care and support following perinatal death in South-Western Nigeria: A phenomenological study, and Paper 3: An exploration of health care

professionals' lived experiences of care and support following perinatal death in South-Western Nigeria: A phenomenological study) however prior to adopting this, other approaches were explored. For example, grounded theory, developed by Glasser and Strauss (1967) aims at generating explanatory theories embedded in the data to reveal social processes (Noble and Mitchell, 2016; Corbin and Strauss, 2015; Punch, 2014; Astalin, 2013). Although grounded theory is valuable as it avoids assumptions and takes a neutral view towards individuals' actions in social contexts, it is suited to studying social processes (Simmons, 2006; Milliken, 2010). Thus, it was rejected because this study was not aimed at social processes and theory generation. Ethnography was also considered which focuses on studying socio-cultural interactions where the researcher actively immerses themselves and engages with the group to gain an insider's perspective and experience on a culture to develop better understanding (Astalin, 2013; Allen, 2017; Morgan-Trimmer and Wood, 2016; Jones and Smith, 2017). This poses some ethical challenges where the researcher's presence may also influence actions of bereaved women and health care professionals (reactivity) thus interfering with retrieval of true lived experiences of care and support following perinatal death (Neuman, 2003; Sangasubana, 2011). Hence, ethnography did not suit the aim of the study. Phenomenology focuses on understanding and interpreting the lived experience of women, and health care professionals of care and support following perinatal death in its natural context and directly from the stance of those who experienced the phenomena (Neubauer et al., 2019). This approach was adopted as it matches the aim of the study. Phenomenology is made up of different approaches which the researcher explored to develop understanding and identify the most suited approach for this study. This led to the adoption of Heideggerian (Hermeneutic) phenomenology. Phenomenology is explored in more details below.

3.3.3 Phenomenology

Phenomenology was initially developed by German philosopher Edmund Husserl (1859 -1938) as a philosophy that focused on the study of structures of consciousness or experiences of a phenomena (Eberle, 2014; Smith, 2018; Wojnar and Swanson, 2007). It is concerned with the world as lived and experienced by individuals and does not view it or reality as separate from the individuals (Valle et al., 1989; Vamanu, 2012). In explaining this philosophy, Spiegelberg (1984) divided phenomenological movement into three phases, preparatory, German and French. These three historical phases (preparatory, German and French) also influenced phenomenology as a research method (de Chesnay, 2015; Spiegelberg, 1984).

Husserl's work was influenced by Franz Brentano's (1874) notion of intentionality, that is the directedness or consciousness of experience toward things in the world (Smith, 2018; Drummond, 2015). According to Brentano, mental phenomena are acts of consciousness that occur in one's mind and physical phenomena are the objects of external perception (Smith. 2018). Therefore, individuals' experience is formed by their intentional perception, thoughts, memory, imagination and emotions, of a particular occurrence (Crotty, 1996; Rodriguez and Smith, 2018, p. 96). These structures of consciousness form the foundation of knowledge (Racher and Robinson, 2003; Valle et al., 1989). Therefore, Husserl's phenomenology aims at knowing and understanding the lived experience of a phenomenon as perceived by individuals and not only their reaction to it (Munhall, 2007; Teherani et al., 2015; Van Manen, 1997). Building on the foundations of this philosophy, Husserl developed transcendental (descriptive) phenomenology as a research method in studying lived experiences (Creswell, 2009; Neubauer et al., 2019; Teherani et al., 2015). This focused on describing the conscious lived experience of a phenomenon in its natural state as understood by those who experienced it (Husserl, 1962; Polit and Beck, 2008; Crotty, 1996; Dowling, 2007). However, the researcher must set aside ("bracket") their pre-conceived knowledge about the phenomenon to allow them to explore the

experience of individuals without prejudice thereby maintaining objectivity (Polit and Beck, 2008; Creswell, 2013). This process in transcendental phenomenology is known as "epoche" or phenomenological reduction (de Chesnay, 2015). Husserl's main contributions to phenomenology were his refute of positivism, as he suggests that knowledge arises from senses, the concepts of intentionality, and epoche/phenomenological reduction of particular facts to general essence (Cohen et al., 2000). In addition, Husserl developed the concepts of "intersubjectivity" and "lifeworld" which refer to the plurality of subjectivities that make up a group sharing a similar world, and the world of lived experience, respectively (Cohen et al., 2000). Husserl's work influenced by Brentano, was the first step in introducing phenomenology thus known as the preparatory phase.

Phenomenology further evolved when Husserl's student, Martin Heidegger (1889-1976) brought an ontological approach by focusing on the nature of being in the world (Dasein) (Heidegger, 1962; Rodriguez and Smith, 2018; Laverty, 2003). This went against Husserl's epistemological stance as he focused on how we understand our world/experiences. Heidegger refuted the notion of bracketing in transcendental phenomenology. He argued that researchers cannot bracket because they are deep-rooted "beings-in-the-world" who are unable to set aside their preconceptions and are inseparable from their backgrounds. Rather embracing their preconceptions helps derive enhanced understanding and meaning of a phenomenon of interest when placing it in context with their own life experiences (Cooper, 1999; Wimpenny and Gass, 2000; Hellman, 2016; Heidegger, 1962; Wilson and Hutchinson, 1991). Heidegger's refutation of bracketing further affirmed his ontological stance. This led to Heidegger developing another phenomenological research method known as interpretive (hermeneutic) phenomenology, using Husserl's work as a foundation. This focuses on *understanding* rather than only describing individuals' experiences of a phenomenon, how they make sense of it, and uncovering aspects of it that are taken for granted (Heidegger, 1962; Laverty, 2003; Polit and

Beck, 2008). As a concept, hermeneutics is the study of human activities as text with a focus on interpretation to reveal meanings (Gadamer, 1983; Kvale, 1996; Oerther, 2020). It is focused on theory and practice, meaning and understanding of interpretation (meanings behind and hidden in everything) (Keshavarz, 2020, p. 30). Hermeneutics is made of principles of historicity of language and comprehension, understanding existing literature by translating them into new expressions, representation of texts on meaning (semantics) and effectiveness of linguistic representation (interpretation) (Keshavarz, 2020; Budd, 1995, Budd, 2005). Hermeneutics was developed in opposition to positivism and posited that different research topics such as humanities, natural and social sciences require a different approach which needs individual distinction (Hansson, 2005; Keshavarz, 2020). This is because human knowledge is understood by introspection and the researcher assuming the place of participants to know their experiences (interpretivism) while natural knowledge is learned via external experience and objectivism (positivism) (Hjorland, 2003). That is, nature is explained but humans are understood (Keshavarz, 2020). Therefore, the goal of hermeneutic phenomenology is to enter the world of participants and uncover practical understanding enclosed within it (interpretation) (Polit and Beck, 2008). In achieving this interpretation, Heidegger explained that the researcher must move between parts of the experience and the whole experience, repeatedly, to increase depth of understanding, known as the "hermeneutic circle" (Laverty 2003; Annells, 1996; Polkinghorne, 1983). Heidegger's hermeneutic phenomenology has been criticised because it posits the notion that knowledge is dependent on interpretation, therefore research findings are not regarded as "true" or "valid"; it thus requires a robust evaluation criterion (Draucker, 2001 p. 361; Koch, 1996). This is to enable the reader to audit steps taken and influences of the researchers' actions that led to interpretive findings (Draucker, 2001). However, since this criticism, there have been steps implemented in hermeneutic research to enable readers to evaluate the process of the researcher moving from the narrative to interpretation, in the form

of rigour (Koch, 1996). Heidegger's approach was called the German phase of the phenomenological movement. Gadamer (1900 - 2002) was a supporter of Heidegger's hermeneutic phenomenology. He refutes the notion that hermeneutics is concerned with developing processes of understanding. He explains a notion that hermeneutics is a procedure to further clarify the conditions in which understanding occurs (Laverty, 2003). Gadamer agrees with Heidegger that language and understanding cannot be separated, and bracketing was impossible (Annells, 1996). Hence language is the medium in which interpretation of an understanding occurs (Laverty, 2003). Following Husserl's death, the French phase of the phenomenological movement began as led by Gabriel Marcel (1889 -1973), Jean-Paul Sartre (1905 -1980), and Maurice Merleau-Ponty (1908 -1961) (Cohen et al., 2000). These philosophers focused on existence and perceptions. Sartre was most influential in this phase and argued that an individual's consciousness and behaviour make up their existence and this precedes their character, which is their essence (Cohen, 1987).

In conclusion, it appears that Husserl and Heidegger were involved in a debate of phenomenology being of an epistemological or ontological nature. These debates spanned various philosophers. Nonetheless, phenomenology has been described as a strong and invaluable approach as it permits the development of a new interpretation of experiences to allow an in-depth understanding of a phenomenon (Laverty, 2003). Thus, the researcher remained confident that phenomenology was the appropriate methodology to use in achieving the aims of this study. Heidegger's hermeneutic phenomenology convinced the researcher because of its in-depth approach and focus not only on describing but also interpreting a phenomenon whilst embracing the researchers' pre-conceptions. Nonetheless, the researcher's stance matched Heidegger's hermeneutic phenomenology as it lends itself to an interpretivist paradigm, because it suggests that each individual has their own subject reality of a phenomenon, and this does not exist separately from each person (Qutoshi, 2018; Laverty,

2003). Hence, studies in this thesis adopted interpretive (hermeneutic) phenomenology because it allows the researcher to gain a deeper understanding and interpretation of the lived experience of care and support after perinatal death from the view of the participants by entering their world (Polit and Beck, 2008). Furthermore, this methodology is utilised because it does not adopt bracketing, therefore permits a rich interpretation of the data as it embraces the researcher's understanding and preconceptions. Hermeneutic phenomenology encourages the researcher to move repeatedly between interpretation of parts and the whole text respectively in a circular motion (hermeneutic circle) and question every part of the text to gain an emerging understanding of the experience of care and support following perinatal death in women and their families (Gadamer, 1976; Rodriguez and Smith, 2018).

3.4   Research Methods - Metasynthesis

This section provides a description of the methods used in the metasynthesis.

3.4.1   Research Question and Aim

The metasynthesis aimed to explore women's experience of care and support following perinatal death in high-burden settings. The aim of this review was to synthesise the findings of existing studies and conduct a critical reinterpretation to reveal gaps in the literature and new knowledge. The findings of this metasynthesis informed the primary studies in this thesis that explored the lived experience of women, families and health care professionals of the care and support following perinatal death in South-Western Nigeria.

3.4.2   Search Strategy

Systematically searching for qualitative studies can be challenging but it is a critical component of metasynthesis to promote transparency thereby giving readers clarity on steps taken to identify included studies (Cooper et al., 2018). A systematic approach was used in searching and identifying relevant studies. An initial scoping search was completed to ensure there was no existing systematic review on the topic of interest and create a broader knowledge on search terms. Search terms were established using the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research Type) tool developed by Cooke et al. (2012) because of its specificity to qualitative studies (Methley et al., 2014). Using the search terms (Table 1 – page 89), a strategy was established in searching the databases. An electronic database search was conducted on EMBASE platform, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychInfo, Applied Social Sciences Index and Abstracts (ASSIA), and African Journals Online from inception to July 2019. The search was repeated in July 2022 to ensure it was up to date. The search was not limited by time, but by English language. There was no time limit set for inclusion or exclusion to widen the search scope to retrieve eligible

studies. In enhancing and optimising the search, Boolean operators ('OR' and 'AND') were used in combining search terms. A hand search of the reference lists was also undertaken for a wider coverage of existing literature. For a study to be eligible for inclusion in the metasynthesis, they were: (i) primary qualitative studies (ii) exploring views and experiences of women of their care and support following perinatal death; (iii) conducted in high burden settings. Mixed-methods studies were eligible to be included if the qualitative data on women's experience was made explicit. Grey literatures were excluded due to time and financial constraints in retrieving them. It is recognised that the exclusion of grey literature from literature reviews could potentially mean that data/findings that could offer more insight into the experience of women in high burden settings have been omitted. However, the lack of resources of time and finances was the main hinderance to its inclusion (Adams, Smart and Huff, 2016). Nevertheless, valuable data was still gained from the included studies.

3.4.3 Quality Appraisal

Critically appraising studies contributes to the robustness and trustworthiness of the metasynthesis. The included studies were quality appraised with a view to assessing rigour of the research, methodological and reporting processes. Quality appraisal of qualitative research has been debated and reported to be non-essential as studies with applicable findings may be excluded if methodological processes are deemed to be of poor quality (Pearson et al., 2011; Dixon-Woods et al., 2005; Garratt and Hodkinson, 1998). Furthermore, quality appraisal tools may improve transparency and validity, but it takes a one size fits all approach in its criterion which is not compatible in assessing the broadness of qualitative studies (de Jong et al., 2021). Thus, to prevent the exclusion of studies that have valuable findings, quality was not a basis for exclusion in this metasynthesis because useful studies may be graded as being of low quality

but may contain valuable findings (Majid and Vanstone, 2018). However, included studies were quality appraised to identify their strengths and flaws, and reflect to the reader their impact on the synthesis thereby contributing to the rigour of the metasynthesis (Table 3 – page 108). There was a critical consideration of existing quality appraisal tools including Critical Appraisal Skills Programme (CASP) checklists, Consolidated criteria for Reporting Qualitative research (COREQ), Grading of Recommendation Assessment, Development, and Evaluation (GRADE) which either had limitations such as lacking sufficient depth or were not suited to the study aim thus hindering their use in metasynthesis (Guyatt et al., 2011; Buccheri and Sharifi, 2017; Tong et al., 2007; Booth et al., 2014; Hannes et al., 2010; Long et al., 2020; Dixon-Woods et al., 2007). The COREQ tool provides a set of closed questions within its checklist to enable the researcher clearly examine aspects of the study in assessing quality under three domains respectively namely, research team and reflexivity, study design, and analysis and findings (Tong et al., 2007). This is similar to the CASP tool for qualitative studies which also assesses quality using a set of closed questions under three headings *"are the results valid?"*, "*what are the results*", and "*will the results help locally*?" (Critical Appraisal Skills Programme, 2021). The questions in the CASP tool are superficial, therefore does not promote an in-depth approach into assessing the quality of studies. In addition, the use of closed questions in the COREQ and CASP tools although makes analysing, scoring and ranking of the quality of studies easier, they do not encourage an inductive approach at quality appraisal as Walsh and Downe's (2006) tool does (Crowe and Sheppard, 2011; Remington, 2020). GRADE tool was not suitable to be used as it is suited to assessing controlled studies and drawing recommendation for systematic reviews and intervention guidelines (Long, 2013; Meader et al., 2014).

Following these considerations, the Walsh and Downe (2006) appraisal tool was adopted. This was chosen as it provides a structured approach towards critically appraising the integrity,

transparency and transferability in qualitative studies specifically. It allows the researcher to widely critically assess stages of the study such as methodology, data analysis and interpretation using twelve (12) essential criteria statements (Porritt et al., 2014; Downe et al., 2009). These stages include scope and purpose, design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions, relevance and transferability (Walsh and Downe, 2006). The approach of the Walsh and Downe (2006) tool helps the researcher appraise the quality of studies flexibly as opposed to using rigid criteria which may omit aspects that contribute to rigour (Majid and Vanstone, 2018). The studies were assigned a grade from A-D using Downe et al's (2009) grading system (Appendix 1). Studies that comprehensively or satisfactorily reported all, or a majority of the 12 criteria thereby demonstrating a few or some flaws unlikely to affect credibility, dependability and confirmability (rigour) were assigned grade "A" or "B" respectively, connoting high quality. If they sufficiently reported on the 12 criteria but demonstrated some or significant flaws respectively that compromise rigour, they were assigned grade "C" or "D". The researcher (OK) and research supervisors (TM and KL) quality appraised the included studies independently, conflicts were resolved in a meeting and consensus was attained. There were no studies that did not report on the 12 criteria.

3.4.4   Data Extraction and Analysis

Data was extracted under the categories of study aim, participants, study and recruitment setting, methodology, method of analysis and findings. These categories also informed description of study characteristics (Table 3 – page 108). Noblit and Hare's (1988) meta-ethnography was used in analysing the data after critically exploring different approaches to data analysis in qualitative synthesis. Findings were categorised according to similarities and differences in the experience of care and support following perinatal death across studies. Themes and subthemes in each study were compared with each other, and core concepts were

retrieved (Noblit and Hare, 1988; Tavish et al., 2019; Polit and Beck, 2014). The data was analysed using Noblit and Hare's (1988) meta-ethnography. This is described in detail in Chapter 4 (Paper 1 Women's experiences of care and support following perinatal death in high burden countries: A metasynthesis.).

3.5 Methods for Qualitative Studies

This section explores the methods used in the qualitative studies including sampling, data collection, management and analysis, settings, and ethical processes. In addition, the approaches to reflexivity and ensuring trustworthiness are explained.

3.5.1.1 Aims and Objectives

The qualitative studies were focused on examining the experiences of women, their families and health care professionals in South-Western Nigeria, of care and support following perinatal death. This was achieved by conducting hermeneutic phenomenological qualitative studies using semi-structured interviews.

3.5.1.2 Study Setting

In selecting the study setting, Lagos is the most populated state in Nigeria, and a previous area of residence for the researcher who has good knowledge of the health care system within the state. Lagos was chosen because of its large and diverse population. There were other states considered for the study but due to the ongoing security concerns in Nigeria, it would have been difficult and unsafe for the researcher to work in unfamiliar states/settings in the country. Thus, it was most appropriate for the research to be conducted in a state with great diversity in its residents, and a place of familiarity and safety for the researcher. Participants were recruited from a federal government hospital (Lagos Island Maternity Hospital), and postpartum support group (Postpartum Support Network Africa) in Lagos, Nigeria. The women were recruited via

Postpartum Support Network Africa and the hospital. The health care professionals were recruited via the federal hospital. Lagos Island Maternity Hospital, also known as the "baby factory", is the largest specialised maternity unit which has been serving the population of Lagos since 1960 (International Hospital Federation, 2022; Lagos Island Maternity, 2020). Using a facility that is widely accessed by a large and mixed population aided the recruitment of women from diverse socioeconomic and ethnic backgrounds. This hospital also works with Postpartum Support Network Africa which is a support group for women in the postnatal period who have experienced perinatal death or mental health difficulties. This support group based in Lagos offers their services to women across federal hospitals in Lagos and neighbouring states.

Prior to commencing this research, the researcher visited the hospital and support network to gain further understanding of the setting and to meet with staff. This visit allowed the researcher to develop links with the Apex Nurse (Chief Nursing Officer) and gave her the opportunity to liaise with the lead co-ordinator at Postpartum Support Network Africa and attend some of their support group meetings which gave an insight into the population of women they cater to. At this time, the research proposal was being developed. Therefore, the proposed study was explained to the Apex Nurse and lead co-ordinator and the possibility was explored of recruiting participants from their facility and groups, respectively. Both individuals were interested in undertaking the study and supporting the recruitment of participants thus they became contact persons. It was agreed that they would support recruitment by identifying eligible participants and referring them to the researcher, with their consent.

3.5.1.3 Sampling Method and Size

Non-probability sampling was used in this research as it is not focused on participants being representative of the larger population, but rather aims to examine a phenomenon using a small sample (Taherdoost, 2016; Vehovar et al., 2016). In qualitative research, non-probability

sampling is used because studies using this design are not aimed at statistical generalisability (Guest et al., 2013). Qualitative research focuses on gaining rich contextual and explanatory data. Therefore, utilising probability sampling was not beneficial in achieving the study aim and may have negatively impacted the validity of findings by omitting individuals able to provide rich and useful data relative to the research aim/topic (Guest et al., 2013). In non-probability sampling, participants are deliberately selected based on their characteristics as they relate to the study topic, without the intent of being statistically representative of the population of interest (Ritchie et al., 2003; Etikan and Bala, 2017). There are different types of non-probability sampling methods, but the study's aims and objectives determine the sampling approach, size and population characteristics (Mack et al., 2005). The types of sampling methods mainly used in qualitative studies are purposive, convenience, snowballing and theoretical, which are explained in more detail below.

Convenience sampling involves selecting and using samples based on the ease of accessing them (Ritchie and Lewis, 2003). This sampling method is classed as the least credible because it may not be representative of the larger population and may yield poor quality data, however it is suited for use in research studies where there are difficulties in recruiting (Guest, Namey and Mitchell, 2013; Marshall, 1996). Snowballing or chain referral sampling is a method utilising participant in the study to recruit others that fit the selection criteria, through their social network (Archarya et al., 2013; Emerson, 2015). This method is suited to recruiting "hard to reach" participants with specific characteristics that are not widespread or very sensitive populations (Streeton et al., 2004). However, this sampling method would not allow full exploration of the phenomenon of interest because participants are likely to refer likeminded individuals with similar views to take part in the study thereby leading to a one-sided understanding being gained (Streeton, Cooke and Campbell, 2004; Kemp, 2013).

Theoretical sampling (also known as inductive sampling) is more associated with grounded theory, which refers to "seeking pertinent data to developing an emerging theory" (Charmaz, 2006, p.96). The researcher jointly collects, codes and analyses data and identifies data that is needed to be collected next and where to find them to develop their emerging theory (Glaser and Strauss, 1967). In other words, theoretical sampling involves the researcher sampling participants based on their potential to contribute to theory development. This is by selecting an initial sample and analysing the data, and then choosing another sample to refine emerging categories and theories, and this continues until data saturation is attained (Charmaz, 2006; Ritchie and Lewis, 2003).

Finally, purposive, also known as judgemental sampling, refers to selecting samples using specific characteristics/features such as age, socioeconomic status and gender to allow the researcher to explore and gain in-depth understanding of the phenomenon of interest (Etikan and Bala, 2017; Guest et al., 2013). Ritchie and Lewis (2003) explained that deliberately selecting participants is not reflective of prejudice, but rather an objective method of ensuring that the sample is able to stand up to independent scrutiny. Qualitative studies on the experience of care and support following perinatal death have mostly utilised purposive sampling because of its focus on ensuring that the population of interest is represented which will allow the retrieval of a well-rounded understanding (Modiba and Nolte, 2007; Simwaka et al., 2014; Mills et al., 2020; Onaolapo et al., 2020; Conry and Prinsloo, 2008; Palinkas et al., 2015). Thus, for this reason and because it aligns with the chosen research methodology – interpretative phenomenology, purposive sampling was used in the primary studies to gain rich data in understanding and interpreting the experience of care and support from women, families and health care professionals in South-Western Nigeria (Onwegbuzie and Leech, 2007; Connolly, 1998; Denzin and Lincoln, 2005). In addition, sampling method in this reserach was

informed by the metasynthesis, and exploration of other existing qualitative studies on lived experiences. The sampling criteria is presented in section 3.5.1.4.

Researchers have long debated the issue of appropriate sample size in qualitative study because this has been based on individual studies (Dworkin, 2012). However, some researchers have given guidelines of a sample size from 6 to 10 in phenomenological studies to gain rich in-depth data (Ritchie and Lewis, 2003; Patton, 2002; Creswell et al., 2007; Denzin and Lincoln, 2005; Morse, 2000). In phenomenological studies, data saturation which is the point in research data collection and analysis where no new information is gained thereby indicating to the researcher that data collection can end, is not relevant or considered (Vasileiou et al., 2018; Faulkner and Trotter, 2017). This is because sample size in phenomenology is determined by richness of data from participants as required by the researcher (Sim et al., 2018; Malterud, Siersma and Guassora, 2016; Sebele-Mpofu and Serpa, 2020). Thus, a sample size of 15 in each participant category was selected using other phenomenological studies as a guide, with the aim of retrieving in-depth data on the experience of women, families and health care professionals.

3.5.1.4   Study Sampling Criteria

The inclusion criteria used for sampling participants were:

Women:

- Aged 18 years or over and have experienced perinatal death (stillbirth or early neonatal death) in Nigeria within the last 5 years.

- Have been cared for at a hospital in South-Western Nigeria.

Partners and family:

- Aged 18 years and above.

- Be identified by the woman as the person who supported them during the time of perinatal death.

According to the Child Rights Act (2003), the age of consent in Nigeria is 18 years therefore recruiting below this age would mean that minors are being included in the research (Stand to End Rape Initiative, 2023). This study was not focused on examining the experiences of minors. However, this is an area of research to be explored in the future.

Health care professionals:

- Nurses, midwives, doctors, psychologists, or maternity ward attendants who provide care for women who have experienced perinatal death in the healthcare setting.

- Work at a hospital in South-Western, Nigeria with over a year's experience of caring for women who have experienced perinatal death. This is to ensure that the healthcare professionals have a good understanding and experience of caring and supporting women within this setting to provide rich narrative for the study.

3.5.2 Participant Recruitment

This section describes the initial recruitment plans and adaptations made due to COVID-19 impact.

3.5.2.1 Initial Recruitment Plan

The researcher planned to travel to Lagos, Nigeria to recruit participants in person but was hindered by restrictions introduced in the country and in the UK as a result of the global COVID-19 pandemic. Recruitment was initially scheduled to be carried out in collaboration with the Apex Nurse (Chief Nursing Officer) at the hospital and lead co-ordinator at PSN Africa as contact persons. Information sessions on the study were to be provided to the Apex

Nurse and other nurses, and lead co-ordinator respectively explaining the study aims, inclusion and exclusion criteria in person. These nurses and lead co-ordinator were to identify eligible participants and complete consent to contact forms (Appendix 12) with them. The forms were to be given to the researcher to make contact to provide more information about the study and gain consent for participation. Health care professionals were to be recruited via Apex Nurses who would inform the nurses about the study and provide them with participant information sheets (Appendices 4, 5 and 6). Nurses who were interested in taking part were to voluntarily contact the researcher via text or phone call to express their interest. In return, the researcher would contact them to provide further information and gain consent for participation. However, the COVID-19 pandemic led to an adaptation of the consent to contact process and recruitment plan as participants had to be recruited remotely. The adaptations are explained below.

3.5.2.2   Adapted Recruitment Plan due to COVID-19

Information sessions were provided to the contact persons via telephone call, participant information sheets (Appendices 4, 5 and 6) and consent forms (Appendix 12) were sent electronically to them. PSN Africa were unable to hold support groups in person which prevented physical recruitment of participants due to imposed lockdown in Nigeria. Thus, the contact person for this group provided details about the study from the participant information sheet at virtual support group meetings and on their WhatsApp platform. The participant information sheet which also had the research contact details was distributed electronically to support group members by the contact person. Due to the limit on physical contact, potential participants were informed to contact the researcher directly to express their interest in participating in the study.

The contact persons at the hospital identified potential participants meeting the inclusion criteria and provided them with verbal explanation of the study and participant information

sheet (Appendices 4 and 5). Due to the time and resource limitations and COVID-19 restrictions, consent to contact forms could not be completed, rather potential participants were invited to contact the researcher directly. In relation to health care professionals, they were informed by contact persons to express their interest directly to the researcher via the provided contact details. The researcher contacted those who expressed their interest to provide more information about the study. Following this contact, the participant information sheet (Appendix 5) and consent form (Appendix 13) were sent to participants electronically. Interviews were also planned with partners and family members to understand the experiences of the main provider of support to the mother. The family members were to be recruited via the women.

3.5.3   Data Collection Method and Tools

Data collection commenced in October 2020 and ended in July 2021 via telephone interviews using a topic guide (Appendices 2 and 3) due to the COVID-19 pandemic restrictions. Prior to selecting semi-structured interview, different approaches to interviews such as structured and unstructured were explored. A structured interview is the approach to data collection involving the use of strictly predetermined questions with no variation and scope for participants to be asked follow-up questions to elaborate on the responses they have given (Gill et al., 2008; Denzin and Lincoln, 2008; Stuckey, 2013). Unstructured interviews take the form of a conversation rather than an interview where participants express themselves without restraint and at their own pace, and the researcher does not have or use pre-planned questions to steer the conversation (Jamshed, 2014). However, this approach was not utilised, although it has the potential to yield copious data, which can be an advantage; it may lack the focus required on a phenomenon and be difficult to handle particularly in time-constrained studies such as this, while structured interviews prevent exploration of the experience of care and support following

perinatal death due to their rigid approach (Seale, 2012; Mueller and Segal, 2015; Al-Busaidi, 2008). The chosen data collection method of semi-structured interviews was determined by the methodology – phenomenology. Although unstructured interviews seem to be suited to phenomenological studies, they were not used because of the time -constraints. Semi-structured interviews are widely used in qualitative studies because they allow researchers to set an outline of questions using a topic guide beforehand. They also give participants liberty to express their experiences of care and support following perinatal death, and their responses determine interview direction (Stuckey, 2013; DeJonckheere and Vaughn, 2018; Al-Busaidi, 2008). This method assumes an open-ended stance in questioning and is less rigid in contrast to structured interviews as participants do not answer questions in order, and the researcher can adapt questions to fit participants and their context (DeJonckheere and Vaughn, 2018; Bevan, 2014). Ritchie and Lewis (2003) also explained that this approach is best suited to qualitative studies as it allows exploration of participants' perspectives and gains an in-depth understanding of a phenomenon within the personal context of their experience. Thus, the semi-structured interview was the most appropriate data collection method to use in these qualitative studies because of its flexibility and suitability to the study aim. The researcher intended to observe participants' non-verbal cues such as facial expressions and body language during interviews for deeper and richer understanding and interpretation of their experiences (Denham and Onwuegbuzie, 2013). However, this could not be achieved as the data collection had to be conducted virtually using WhatsApp due to the global pandemic (see COVID-19 impact statement). Nevertheless, the researcher paid close attention to other non-verbal cues during the interview such as rate and tone of speech, gaps in conversation, and hesitance or eagerness to speak, and this was recorded in the field notes.

3.5.3.1 Interviews

Phenomenology traditionally utilises face-to-face interviews to explore and develop understanding and meaning of a phenomenon (Van Manen, 2016; Lauterbach, 2018). However, due to the impact of the COVID-19 pandemic restrictions, alternative methods were used in conducting the interviews. Thus, with ethical approval, interviews were conducted virtually using WhatsApp calls, and audio recorded securely on an encrypted recorder. WhatsApp is a free audio and video cross-platform messaging mobile phone application (McLaughlin, 2022). There were concerns about the researcher being able to establish rapport with participants, observe and respond to non-verbal cues via telephone interviews (Drabble et al., 2016). Considerations were made to mitigate these concerns, such as the use of WhatsApp video function. This option was made available to participants, but they preferred to use WhatsApp audio calls. The majority chose this option because of the cost of WhatsApp video calls, which they reported use more internet data than voice calls. There were other factors that influenced participants' choice of voice calls including time of day, need for privacy, and lack of electricity. The interviews lasted between 20 and 60 minutes. One interview lasted for 20 minutes because the participant (woman) responded in a succinct manner and the use of prompts to expand on the points also yielded the same response. In addition, it was observed that the environment within which they were having the conversation may not have been permissive of their ability to express themselves in more detail. The researcher due to the virtual of the interview was not able to influence the participant's environment. However, the data that was gained was valuable and therefore was included in the study.

 Prior to the interview, the researcher provided another explanation of the study and offered opportunities to participants to have their questions answered before proceeding. Demographic information was collected before commencing the interview; because of the emotive nature of the topic of discussion, it did not feel appropriate to do this at the end (Demographic form

Appendices 6 and 7). Verbal consent was gained and recorded with the approval of the participants due to the virtual nature of interviews. The researcher also completed a paper copy of the consent form and labelled them with the participants' identifier.

All interviews were conducted in English except two in Yoruba, of which the researcher is a fluent speaker. The interviews were audio recorded with participants' consent. The rationale for audio recording interviews was to ensure accuracy in the data when transcribed and analysed, which was explained to participants (Tessier, 2012; Rutakumwa et al., 2019). The researcher conducted interviews in a private room to maintain confidentiality. The participants were also advised to use a room that was private and convenient for them to speak freely. However, as interviews were conducted remotely, it was difficult to ensure that participants were in a space that was private.

As it was a telephone interview, the researcher commenced by developing a rapport and creating a comfortable space where participants could speak about their experiences freely by having a brief casual conversation. They were asked informal questions such as "how are you", "is this still a good time to talk?", and if they were ready and it was explained to them that they are leading the conversation while the researcher is there to listen and guide the conversation. The questions commenced with speaking about the experience of pregnancy for the women, and a typical day at work as a health care professional. The subsequent questions focused on the experience of care and support from the view of health care professionals and the women. The interview was led by the participants, and there were minimal prompts from the researcher to seek elaboration on points as required. Participants were also given the opportunity to speak about other relevant aspects of their experience which may not have been covered by the topic guide. The researcher made some notes as the interview progressed but was conscious not to allow this to disturb her from listening and engaging in the conversation with participants. One

of the participants refused to have their interview audio recorded, therefore the researcher made notes as they spoke. At the end of the interview, time was spent in completing the field notes. These notes have been used to guide the data analysis to ensure accuracy.

There were some challenges with using WhatsApp audio call for interviews due to the network. This led to difficulties hearing the participant, calls being abruptly ended and delayed connection which at times resulted in loss of time as interviews had to be rescheduled. In some cases, interviews took much longer as the calls had to be placed repeatedly whenever they cut out.

3.5.3.2 Topic Guide

The semi-structured interviews were conducted using topic guides for women and health care professionals respectively (Appendices 2 and 3) focused on open-ended questions representative of main aspects in exploring the phenomenon of interest. The topic guide was developed from findings of the metasynthesis, aims and objectives of the studies, and wider reading of existing studies on women and health care professionals. It ensured that main points of interest were covered along with providing sufficient flexibility to elaborate on the responses given by participants. The topic guides commenced with questions to ease participants into the interview and develop a rapport between both parties and make them comfortable. Prompt questions were included to aid further probing of participants' experience (van Selm and Helberger, 2019; DeJonckheere and Vaughn, 2019). A pilot interview was conducted with two mothers who had experienced perinatal death and a nurse to test the questions to ensure they were appropriate and effective in producing sufficient responses from participants. This allowed the researcher to refine the topic guide adequately. The data from these pilot interviews was also included in the data analysis because of the relevance of the experience that was narrated.

3.5.3.3 Field Notes and Reflexive Diary

During the interviews, field notes were written to document the researcher's observations such as change in tone of voice, or silence, for instance, and their context. The field notes were vital in contributing contextual information to the data and research process as a whole and contributed to reflexivity in the study (Tessier, 2012; Maharaj, 2016; Flick, 2014; Miles and Huberman, 1994; Onwuegbuzie et al., 2010). Reflexive accounts of the researchers' thoughts and feelings were also documented (see reflexivity section) to promote the rigour and quality and create further depth of understanding of the studies (Teh and Lek, 2018; Dodgson, 2019).

3.6 Data Analysis

In the qualitative studies, the data was analysed using Van Manen's approach to analysis in hermeneutic phenomenology. Demographic data was collated manually and presented in Tables 1 (page 130 and 163). There are different approaches to analysing qualitative data dependent on the focus of the studies, which were explored by the researcher prior to adopting Van Manen's approach. According to Smith and Firth (2011), qualitative data analysis can be subdivided into three categories and provided a succinct description for each one as follows:

1. Discourse and conversation analysis: which aim at exploring the use and meaning of language (Hodges, Kuper and Reeves, 2008).

2. Grounded theory: which aims to generate theory.

3. Content and thematic analysis: which aims at describing and interpreting the views or lived experiences of participants on a topic of interest.

Of the three categories, thematic analysis fits the aim of the studies to explore the lived experience of participants of care and support following perinatal death. Thematic analysis is an inductive approach that allows derivation of themes grounded in the experience of participants (Sundler et al., 2019). This approach to analysis identifies patterns of meanings

and organises them into themes. It aims at understanding complex meanings embedded in the data, whilst encouraging the researcher to delve deeper into the experience to draw out meanings (Sundler et al., 2019). This approach shares similarity with Van Manen's approach to analysis rooted in hermeneutic phenomenology. Van Manen (1990) expressed that phenomenology aims at transforming lived expression into textual expression of its meaning. Thus he developed a six-step approach to hermeneutic phenomenology which involves (1) formulation of the research topic, (2) investigating the lived experience via methods such as semi-structured interviews, (3) retrieving the meaning of participants' experience from themes derived from the data using a holistic, selective and line-by-line approach, (4) describing the phenomenon to reveal participants' experience through writing, (5) maintaining the focus on the phenomenon of interest, and (6) ensuring a contextual balance by moving between parts and whole of the text (hermeneutic circle) (Molley et al., 2018; Van Manen, 1990). The data analysis process commences from step 3 and is explained in section 3.6.1.1. On critical exploration of these approaches and their philosophical underpinnings, Van Manen's approach to analysis was adopted in analysing the qualitative data on the lived experience of care and support following perinatal death.

3.6.1   Data Management and Analysis

Consent and interviews were audio recorded separately using an encrypted audio recorder. These recordings were transferred from the recorder and stored securely on the P drive of the University of Manchester, secured with a password, and only accessible by the researcher. The recordings were stored using codes only identifiable by the researcher to maintain confidentiality and anonymity of participants. Pseudonyms were allocated for each participant for use in reporting the data. The interviews were transcribed by the researcher which promoted

immersion in the data through repeated listening. This also led to retrieval of more points that were noted in the field notes. An example of a field note for a participant (woman) is as follows;

> *"Remide was very warm and open. We seemed to develop a rapport very quickly. She seemed very keen to talk about her experiences and was driven to partake in this study with a view of helping other women be support. She seems very mature, passionate about this topic from the tone of her voice, and content of the conversation. Remide was very quick to respond to questions and it was very conversational. She freely shared her experience and communicated as though she had known me for a long time. She seemed a bit detached from the baby as she referred to them as "the baby" as opposed to him or her, or my baby. I could not see her as it was a virtual interview, but she came across as very relaxed. She strongly communicated that she wants other women who may have experienced or will experience perinatal death in Nigeria to be adequately supported. Remide was very passionate about this study and topic."*

Two interviews were conducted in Yoruba at the request of the participant and were translated and transcribed into English by the researcher. Transcription is the process of transforming recorded audio into written narratives for use in analysing data (Duranti, 2006; McMullin, 2021). Transcription in qualitative studies has been categorised as "naturalized (intelligent verbatim)" where the narrative is adapted and corrected at the discretion of the researcher to written norms and "denaturalized (full verbatim)" where all text is written as said with no corrections (Bucholtz, 2000). This is because the researcher needs to subjectively decide based on the focus of their study, what should or should not be included, and if grammatical or repetition corrections should be made to transcripts (McMullin, 2021). The interviews in this research were transcribed verbatim to ensure and promote rigour in the data and research process, and prevent loss of vital information (Easton et al., 2000). In transcribing each

interview, the researcher paid close attention to the data by carefully listening to each audio and typing the conversation out, including repetitions, grammatical errors, gaps in the conversation as it was presented by both participant and researcher. Each transcript was anonymised, and pseudonyms and identifier numbers were used. They were stored separately to the audio recordings to protect the identity of participants and uphold ethical principles of confidentiality and anonymity.

3.6.1.1 Generation of Themes

Van Manen's (1990) approach follows three main manual steps namely "[w]holistic", "selective" and "detailed" approach. These steps were followed in analysing the data. The researcher immersed herself in the data by repeatedly reading the transcripts and listening to the audio recording simultaneously for familiarisation and to ensure accuracy. Although this was time consuming, the researcher did this to enhance rigour in the analysis. Van Manen (1990; 1984) explained this step as the wholistic approach where thematic aspects are uncovered (Ritruechai et al., 2018; Abbasi et al., 2014). Secondly, the salient phrases, sentences and words that were revealing of participants' experience were identified and highlighted and underlined with notes made for understanding, known as the selective/highlighting approach. Following this, the detailed/line-by-line approach was undertaken where the text was explored line by line and categorised based on similarities to reveal the experience of interest enclosed within. This step required the researcher to repeatedly interact with the parts and whole of the text to ensure accurate understanding and interpretation which is reflective of Heidegger's hermeneutic circle (Gadamer, 1975, 1976; Longxi, 2018). The hermeneutic circle connotes that the researcher can only understand the "whole" experience of an individual by examining "parts", that is repeatedly moving between embracing our preconceptions, interacting with the new knowledge and interpreting the phenomenon (Sebold et al., 2017). The themes were

developed by writing and rewriting thematic statements that emerged from the data using short phrases. These phrases were continuously checked against the data and refined to ensure that they reflect the true experience/narrative as given by participants to attain appropriate themes. The researcher had constant interactions with her supervisory team (KL and TM) in refining the themes. Finally, a description of themes was developed whilst ensuring that they remained close to the core meaning of the lived experience of care and support as narrated by participants.

3.7 Rigour

Rigour is an essential aspect in research which ensures legitimacy of processes, and confidence in study findings by demonstrating integrity and competence (Thomas and Magilvy, 2011; Morse et al., 2002; Tobin and Begley, 2004). Rigour differs in qualitative and quantitative studies. In quantitative studies, rigour is expressed as validity and reliability (Heale and Twycross, 2015). However, focus is placed on rigour in qualitative studies which is demonstrated using the concepts of credibility, transferability, dependability and confirmability (Thomas and Magilvy, 2011; Lincoln and Guba, 1985). These concepts were applied to demonstrate the rigour in this study.

3.7.1 Credibility

Credibility is concerned with ensuring that analysis of the data is accurate and credible (Forero et al., 2018). It seeks to ensure that participants' views and researchers' interpretations are a good fit by clarifying that explanation matches description (Schwandt, 2007; Janesick, 2000; Tobin and Begley, 2004). In ensuring credibility, the researcher undertook research modules to attain the right level of knowledge and skills in undertaking the study. Furthermore, the step-by-step process of conducting the primary research and metasynthesis provided a clear audit trail. Regular meetings were held with the supervisory team during data collection and analysis to ensure that they were appropriately conducted. The topic guide was tested, reviewed and

changes were made by the researcher and supervisory team to ensure its effectiveness. The initial two transcripts were reviewed during the data collection by the supervisors and amendments to the approach were made to improve data collection. Verbatim quotes from the data were used to buttress findings thereby reflecting transparency. The researcher also kept field notes, a reflexive diary, and documented discussions from supervision which contributed to the development of an audit trail of the decisions and processes (Forero et al., 2018). In addition, the researcher consulted with the supervisory team who also reviewed the data analysis processes (Holloway, 1997; Thomas and Magilvy, 2011).

3.7.2 Dependability

Dependability ensures that the study findings can be repeated on participants within the same context at a different time using exact processes (Schwandt, 2007; Farrelly, 2013). Therefore, the researcher must establish a clear, logical and traceable audit trail of the process of the study and how findings were achieved (Lincoln and Guba, 1985; Nowell et al., 2017). However, it has been argued that dependability places some reliance on credibility and cannot be achieved without it (Lincoln and Guba, 1985; Shenton, 2004). This can be achieved using an audit trail to ensure that study processes are described in detail to allow readers or other researchers to assess the extent to which appropriate practices have been adhered to (Shenton, 2004). Thus, as explained in credibility, an audit trail was maintained, and the methods section also detailed steps taken in the studies thereby attaining dependability.

3.7.3 Confirmability

Confirmability is concerned with ensuring that interpretations of findings are derived directly from data and not fabricated in the imagination of the researcher (Tobin and Begley, 2004; Schwandt, 2007). In achieving confirmability, the researcher ensured that the voice of participants was made clear using verbatim quotes from the data. Furthermore, the researcher

also engaged in reflexivity where feelings and thoughts during data collection and analysis as suggested by Lincoln and Guba (1985) were expressed and documented. Justification was also provided for methodological and analytical decisions used in the studies for readers to understand, and as a form of audit trail (Koch, 1994; Moon et al., 2016). Guba and Lincoln (1989) explained that confirmability is achieved when credibility, transferability and dependability are attained.

3.7.4 Transferability

Transferability refers to the extent to which methods and findings of the study can be transferred to other participants or contexts (Lincoln and Guba, 1985; Thomas and Magilvy, 2011; Wang et al., 2006; Farrelly, 2013). This was achieved in this study by providing an in-depth description of the demographics of the population, the research context, methods and data analysis approach so that the readers can make an appropriate judgement of its applicability to other participants or context. However, transferability is regarded as the responsibility of the reader in judging the appropriateness of transferring findings to another group of people or context (Farrelly, 2013). The researcher also has a responsibility to ensure that the description is detailed enough for readers to understand and make their judgement. Thus, it can be said that there is a joint responsibility between the reader and researcher in transferability.

Lagos is regarded as the melting pot of all cultures and ethnicity in Nigeria, as it is a state that experiences a high level of migration from other states within the country due to better socioeconomic prospects (Ofuafo, 2019). The study was made up of women from different tribes who shared very similar experiences of perinatal death and the subsequent care and support. Therefore, although phenomenology is not aimed at transferability but this study findings are transferable across tribes and states (Frechette et al., 2020). However, these

experiences may be different in rural area where the healthcare provision is significantly different to the urban areas. In relation to transferability to other LMICs countries, the metasynthesis revealed that there are similarities in the experiences of bereaved mothers. Therefore, the studies in this thesis contribute to the literature as the findings were also like other LMICs and can be used as a foundational basis in understanding the experience of bereaved mothers and healthcare professionals in other countries across Africa and across the world. The use of a support group in recruiting mothers may pose a view that majority of the women who utilise their services are of high socioeconomic status in contrast to those who were recruited from the hospital. However, the findings are transferable across these groups of women because they all utilised federal government hospitals and have shared similarities.

3.8   Reflexivity

Researchers need to sensitively identify their pre-conceived ideas, beliefs, experiences and biases and how these influenced the study, and sufficiently communicate this to the reader (Berger, 2015; Dodgson, 2019; Sloan and Bowe, 2014). There have been debates about the possibility of a researcher being reflexive and how this contributes to research quality (Pillow, 2003; Finlay, 2002; Lynch, 2000). Reflexivity has been also argued to be of benefit to qualitative studies by not only ensuring trustworthiness but by adding to the integrity of the research processes and findings (Probst, 2015; Teh and Lek, 2018). It encourages self-awareness of one's own stance as a researcher and helps put personal reactions and emotions in context, thereby aiding in achieving appropriate interpretation of participants' views (Probst, 2015; Gilgun, 2008; Sloan and Bowe, 2014). Thus, I maintained a reflexive diary (see 3.8.1) where I documented my feelings, thoughts and opinions, to separate them from participants' data, decisions and processes through the study.

3.8.1   Personal Reflection

3.8.1.1   Research Approach and Methodology

My aim was to explore in an in-depth manner, the views of women, their families and health care professionals on the lived experience of care and support following perinatal death in South-Western Nigeria. In achieving this, I explored various approaches and methodologies that would be suitable. I noted that a quantitative approach would not be appropriate because it would not allow the lived experience of interest to be explored in sufficient depth. I found that qualitative study using a hermeneutic phenomenological methodology was most appropriate. Although descriptive phenomenology was considered, it was not deemed as appropriate because the study was not simply describing the lived experience but also interpreting it. Thus, hermeneutic phenomenology which permits interpretation was adopted. Other qualitative methodologies that were explored include ethnography, and grounded theory which have been explained in the methodology section. However, they were not appropriate in achieving the aim of this study.

3.8.1.2   Data Collection

I am a registered mental health nurse by background and came into this research with an understanding of the psychological impact of perinatal death on individuals. Thus, I can be said to have brought my experience and knowledge from a personal, clinical and educational perspective into this research. However, I realised that there was a need for me to be aware of my experience and knowledge, and how it could impact the study as is encouraged by hermeneutic phenomenology (Moran, 2000; Neubauer et al., 2019). When conducting interviews with the women who were participants in this study, I identified that some participants tended to view me as knowledgeable because of their awareness of me as a nurse, and a researcher from an international institution. I was conscious of this and reiterated to

participants that I was not functioning in the capacity of a nurse, but as a researcher. Also, I explained that being from an international institution does not place me at an advantage rather I am there to understand their experiences. I did identify at times that I may have been thinking as a nurse rather than a researcher. I must say at times it was difficult to separate the conflicting roles of nurse and researcher because naturally I felt very empathetic towards the women. I often fell into the mode of identifying what could have been done to support women but consciously encouraged myself to remain open minded and listen to what they had to say. I was conscious not to put my ideas into the minds or words of participants. This is something that Kemp (2013) also found in her study where she experienced a conflict between the roles of nurse and researcher. This was buttressed with Holloway and Wheeler's (2002) view that the role conflict is a result of the nurse being interested in the research at hand, and the wellbeing of participants. However, I do feel that my thoughts are helpful as I believe these are pointers to the recommendations to be made. Furthermore, my empathy led to the development of a warm rapport with the participants which also helped them feel comfortable with sharing their experiences with me. In addition, the participants' awareness of my background as a nurse led them to feel able to ask me clinical questions about their medical situations or seek advice, at which I encouraged them to return to their healthcare providers for full assessment. For example, one of the women asked after the interview:

> "*If I'm pregnant again, do you advise I go to traditional birth attendants or register with the hospital*" [Jemila].

This also appeared to confuse participants at times, as they did not understand my reluctance to give clinical advice and assessment. Holloway and Wheeler (2002) also indicated that the role conflict causes confusion for participants as they may not fully understand that the researcher is functioning solely in that role and not that of a nurse, and an attempt to demarcate

these roles may impact the relationship between both parties (Kemp, 2013; Chesney, 2001). Also, I believe that conducting the interview virtually also helped with managing the balance of power as they were not able to see the researcher and vice versa. The interviews also took place in an environment of their own choice, and not a clinical setting.

Being a nurse conducting research with other nurses in a completely different country was also daunting. The majority of the nurses that took part had been in the profession for much longer than the researcher. Therefore, there was a worry that this could create an imbalance in power as they could be regarded as senior in relation to the researcher. Furthermore, some nurses were also quite senior in their ranks at the hospital. So, there is a chance that they may have spoken about best-case scenarios. In addition, the participants' awareness of the researcher being a nurse created a level of familiarity in relation to experiences of working within a healthcare organisation and the pressures that come with this. This seemed to establish a rapport between both parties as there was common ground to relate on. There appeared to be a belief that because I am nurse in the UK, I have an advantage over them. This often stemmed from their experience of working in disadvantageous environments, with poor staffing levels and increased clinical pressures. Thus a few of them passed a comment reflecting this such as:

> "*At least it's better over there (in the UK), me too I want to come and work there oh*"
> [Sanye, Nurse]

> "*Let me to come and work in UK oh, this Nigeria. The work is much. The stress is much*"
> [Latifa, Nurse]

3.8.2 Data Analysis, Handling and Management

The data was analysed using Van Manen's approach to hermeneutic phenomenology as also discussed in section Paper 2 (Chapter 5). The analysis moved through the three stages of wholistic, selective and detailed/line-by-line steps of the approach to develop an understanding

and interpretation of the lived experience of women and health care professionals. In line with the hermeneutic circle, these steps were moved through repeatedly to achieve an understanding and interpretation. This approach to data analysis was new to me, therefore I spent time reading to understand the process. All interviews were transcribed by me. There were two interviews in Yoruba, which were translated by me. There was no divergence observed or noted in the Yoruba translation and the researcher ensured that there were no nuances lost in the data by utilising English words in the transcription that matched exactly the narrative being presented in Yoruba to further protect the context and meaning.

I transcribed the interviews simultaneously with recruitment and data collection. This was at times labour intensive as transcribing took numerous hours. However, it was beneficial to have transcribed all interviews by myself as it allowed me to immerse myself even more in the data. Following transcription, I printed all transcripts out and whilst reading them made highlights and comments prior to cutting them out. I placed each cut out on a large sheet of paper and arranged them in order of differences and similarities which helped in the formulation of themes. The data analysis is discussed in detail in section 3.6. I enjoyed the data analysis process, particularly the transcribing, and going through the Van Manen steps in achieving a new understanding and interpretation of the experiences of women and health care professionals. Van Manen and his phenomenological stance seemed to unravel as I conducted the data analysis which was very interesting. Through the data analysis, I was keen to ensure that the voices of the women and health care professionals were prominent as they were most knowledgeable about their experiences. I preferred to not allow my personal and previous clinical knowledge and preconceptions to overshadow theirs. The experience of my family member of perinatal death was put in better context by the narratives of the nurses. This personal experience helped me understand the experience of the women as I could relate with the narrative of their encounters with healthcare professionals. Therefore, I had a practical in

addition to the narrative understanding provided by the participants, contributing to a well-rounded interpretation of their experiences. Thus, my personal experience was of advantage towards the interpretation of the findings.

3.9   Ethics

Ethics is a fundamental aspect of research as it addresses ethical challenges that may arise and ways to adequately address them with the aim of protecting individuals and society (Doody and Noonan, 2016). Ethical approval was sought and gained from the University of Manchester (ref: 2020-9052-16039, Appendix 10) and Lagos State Government (ref: SUB/LIMH/78/VI/892 Appendix 11). The conduct of this research was guided by ethical principles of beneficence, autonomy, non-maleficence and justice as identified by Beauchamp and Childress (2001). The ethical considerations in this study will also be discussed further, later in this section. These ethical principles are described briefly for clarity as follows. Beneficence and non-maleficence share some similarities, and refer to the obligation of a researcher to act for the benefit of research participants, minimising or completely preventing where possible the chances of harm towards them (Varkey, 2021). These are important principles as the researcher ensures that possibilities of harm such as emotional distress, physical harm, loss of privacy, time and/or money, but not limited to these, are sufficiently assessed, analysed and addressed (Johansen et al., 2008; Barrow et al., 2020). In studies within this thesis, there was no identified risk of physical harm or loss of time or money to participants, however, due to the emotive nature of the topic, the possibility of emotional distress could not be eliminated. Therefore, if any participants showed signs of emotional distress, the researcher offered support over the phone at the time and gained their consent to refer them to a specialist service. They were also contacted the following day after the interview by the researcher and offered further follow-up support as required. There was also a risk of loss of privacy to participants as the interviews were conducted via telephone call. Thus, to mitigate this risk, an encrypted software called WhatsApp was used as approved by the University of Manchester ethics committee. The researcher also ensured confidentiality and anonymity as the interviews

were recorded on an encrypted audio recorder, and securely transferred to the University's P Drive, and saved with a password.

Secondly, autonomy is concerned with respecting participants' right to make rational decisions and moral choices, and have opinions based on their personal values and belief system (Varkey, 2021; Guyer, 2003). This principle was upheld via gaining ethical approval to undertake the research from the University of Manchester and Lagos State government ethics committee. Informed consent was also gained from participants after providing them with adequate information about the study, and sufficient time to decide on their participation in the study. Finally, justice is concerned with the obligation to treat participants fairly and equitably by ensuring anonymity, privacy and equal opportunities (Doody and Noonan, 2016). The researcher aimed for utmost equal opportunity in these studies by adopting a recruitment strategy where participants partook in the study voluntarily and there was no disadvantage in choosing to take part or not, or dropping out at any point. Thus, in line with the ethical principles, there were key ethical considerations surrounding qualitative research that were considered in the studies within this thesis such as confidentiality, informed consent, and participant and researcher safety (Sanjari et al., 2014).

3.9.1   Informed Consent

This is integral in research as it entails giving participants sufficient information such as the objectives of the study, their role as a participant, identification of the researcher, data to be collected and how it would be used, in a manner that can be easily comprehended (Orb et al., 2001). This aids participants' ability to make a decision on either taking part in the study or not (Sanjari et al., 2014). Thus, in these studies, the researcher provided an information sheet (Appendices 4 -5) to all participants which provided in-depth details about the study. Informed consent was gained after giving participants sufficient time to read the information sheet.

Verbal consent (Appendix 14) was gained before the commencement of each interview and audio recorded, and participants' responses were also recorded on a hard copy consent form due to the virtual nature of data collection. According to Hoeyer, Dahlager and Lynoe (2005), informed consent is a continuous process through data collection to ensure that participants remain in agreement with the study terms. Thus, consent was also checked at intervals during the interview, particularly when participants presented with emotional distress, to ensure that they were not feeling coerced to continue with the data collection.

3.9.2   Confidentiality and Anonymity

Confidentiality and anonymity are an important aspect of research concerned with ensuring that participants' identities are appropriately protected and cannot be easily uncovered in the study (Fleming and Zegwaard, 2018). As interviews were conducted via telephone call, the researcher ensured that the conversation was held in a confidential room and encouraged participants to do the same. However, this could not be ensured by the researcher due to virtual nature of the data collection. Furthermore, participants were partly anonymous as their physical identity was hidden because they were not seen by the researcher, which may have contributed to participants feeling comfortable speaking about their experiences. However, this may also have made participants apprehensive towards sharing their experiences. The interviews were audio recorded with permission from the participants. These recordings were transferred from the encrypted audio recorder securely on to the P drive of the University of Manchester with only the researcher having access to this using a password. The P drive is the researcher's student drive on the University of Manchester's computer server system, accessible to them only. The researcher transcribed all interviews and anonymised all transcripts using pseudonyms and participant identification codes. Any information within the data that could make participants easily identifiable were also anonymised with careful consideration to ensure

the narrative and its meaning are not impacted. Consent forms were also anonymised, by assigning participant identification codes only known to the researcher.

3.9.3   Researcher and Participant Safety

Physical safety risks were mitigated as data collection was conducted virtually. Hence, the researcher and participants were less likely to come to harm as they were in their own individually identified safe places (Fleming and Zegwaard, 2018). However, as this research is on an emotionally sensitive topic, the emotional wellbeing of researcher and participants was considered. For the researcher, arrangements were made that in the instance of emotional distress, they would have contacted their supervisory team for support. Due to the sensitive nature of the research topic, there was an awareness of the possibility of participants becoming distressed. Hence, participants were informed of the process that would be followed according to the distress protocol (Appendix 9) if they required support. One woman experienced distress where she became upset and cried through the interview. The researcher regularly asked the participant if she wished to stop the interview due to how upset she was, but she chose not to. Following the interview, the researcher remained with the participant on the telephone call offering assurance and a debrief (Appendix 16) was conducted. This led to the researcher suggesting referring the participant to a service (PSN Africa) for further support. The participant chose to refer themselves therefore they were given the contact information of the support network.

3.10 CONCLUSION

In this chapter, the methodology and methods utilised in this study have been discussed along with the justification for adopting them. The approach of metasynthesis that was used in reviewing the literature was discussed, and the methods used, to including literature search, quality assessment of included literature and data analysis. The research paradigm was

discussed in detail, with an examination of the different ontological and epistemological stance, for understanding and justification of adopting interpretivism as the philosophical underpinning for the qualitative studies. Different qualitative approaches were explored such as grounded theory, prior to selecting phenomenology. Phenomenology was explored to provide foundational knowledge for choosing a qualitative approach of hermeneutic phenomenology. This chapter also provided an in-depth explanation of the methods adopted in qualitative studies such as sampling, data collection, data analysis, approaches to ensuring rigour, and ethics. The sampling and recruitment of participants were explained, including the justification of the sample size, and the inclusion and exclusion criteria used to ensure that appropriate individuals were recruited. The steps taken and tools used in collecting data via interviews were also explained. The data analysis approach and steps to achieving the themes and interpretation were also detailed in this chapter. Ethical considerations such as confidentiality and anonymity, informed consent, researcher and participant safety in this study were also discussed.

4   Chapter 4: Paper 1 – Metasynthesis

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

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4.1 Abstract

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

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

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

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

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

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

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

Keywords: perinatal death, high burden settings, care and support, metasynthesis, meta-ethnography.

4.2   Statement of Significance

Problem

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

What is already known about the topic?

Women in high burden settings have poorer psychological and health outcomes following perinatal death.

What this paper adds

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

4.3 Introduction

Stillbirth is the death of a fetus of or over 28 weeks prior to or during birth however its classification and definition vary in different countries (World Health Organisation WHO, 2021a; Sharma et al., 2019). Neonatal death is the demise of a baby within the first 28 days of life, subdivided into early and late neonatal death (within first seven (0-6) days and before 28 days of life respectively (WHO,2021b). Perinatal death is a prevalent issue worldwide, as of 2019, there were 2 million stillbirths per year, and a further 2.4 million deaths within first month of life, 75% occurred in the first week of life and 1 million newborns died in the first 24 hours (WHO 2020; Hug et al., 2021). Low and middle-income countries (LMICs) particularly in Sub-Saharan Africa and South Asia carry the highest percentage of the global burden, 77% of stillbirths, and 81% of neonatal death (Akombi and Renzaho, 2019; Hug et al., 2019; UNICEF, 2020c; UNICEF, 2021a; Gage et al., 2021; Suzuki and Kashiwase, 2020). The United Nations, and UNICEF and World Health Organisation under the Sustainable Developmental Goals (SDG3) and Every Newborn Action Plan (ENAP) respectively aim for a global reduction of perinatal death to 12 stillbirths or fewer per 1000 live births and 12 neonatal deaths or fewer per 1000 total births in all countries by 2030 respectively (Hug et al., 2019; United Nations, 2021; WHO, 2015).

After the death of a baby, women experience grief, described as complex, unique, and long lasting which is worsened by lack of societal acknowledgement (Fernandez-Sola et al., 2020; Kingdon et al., 2015). Adequate and effective bereavement care from healthcare services is essential to limiting negative outcomes for women in the short and long-term (Heazell et al., 2016; Shakespeare et al., 2018). High-income countries continue to improve bereavement care through health education, interventions, enhancing healthcare professionals' knowledge and approach (Ellis et al., 2016; Shakespeare et al., 2018). However, less is known about women's experience of care and support provided following perinatal death in LMICs. Shakespeare et

al.'s (2018) metasummary of parents and healthcare professionals' experience of care following stillbirth in LMICs identified that parents' grief was unrecognised by healthcare professionals and communities in these settings. Therefore, negative experiences such as stigma, blame, loss of value and social status are worsened. Thus, this calls for a deeper understanding of the experience of care and support following perinatal death in high burden countries. This metasynthesis aimed to build on existing understanding, with a focus on women's experience of care and support following perinatal death in high burden countries. This understanding will contribute to effort of ensuring appropriate bereavement care is offered to those who experience perinatal death in such settings.

4.4 Methods

4.4.1 Search Strategy and Data Sources

The search strategy was informed by an initial scoping search of qualitative studies on women's experience of care and support following perinatal death. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research Type) tool developed by Cooke et al. (2012) was used in formulating search terms (table 1), because of its specificity to qualitative studies (Methley et al., 2014). Search terms were combined using Boolean operators of "And" and "Or". Truncations were also used for a wider search. Six electronic databases including EMBASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychInfo, Applied Social Sciences Index and Abstracts (ASSIA), and African Journals Online were searched. The search was initiated in July 2019 and repeated in July 2022 to ensure it was up to date. No date limit was applied on the databases because older studies may give valuable insight into changes in care and support provisions following perinatal death and experiences of women over time. Hand searching of reference list was adopted to supplement and enhance

database search as applicable terms may not be used in titles and abstracts resulting in relevant studies being missed (Higgins and Green, 2011).

SPIDER	SEARCH TERMS
SAMPLE	"Women" or "mothers" or "parent*" or "Famil*"
PHENOMENON OF INTEREST	"Perinatal death" or "baby death" or "neonatal death" or "neonatal loss" or "neonatal death" or "death of a baby" or "neonatal bereavement" or "neonatal mortality" or "fetal loss" or "Stillbirth" or "Neonatal bereave*" or "Stillb*"
DESIGN	"qual*" or "qualitative" or "mixed methods"
EVALUATION	"Experience" or "views" or "perceptions" or "perspectives" or "feelings" or "opinions" or or "Narrative" or "Thoughts"
RESEARCH TYPE	"interpretive" or "descriptive"

Table 1: Search Terms.

4.4.2   Study Selection

Author 1 completed the literature search and imported all references to COVIDENCE software (www.covidence.org), a systematic review management software. All titles, abstracts and full text were screened independently by all authors to ensure rigour in the process (Stoll et al., 2019). Conflicts were resolved via the COVIDENCE software and a discussion between all authors. A summary of characteristics on included studies is provided in Table 3.

4.4.3   Inclusion Criteria

Primary qualitative studies, in English using descriptive and interpretative methodology, in exploring the experiences of women following perinatal death on the care and support in high burden setting were included. Mixed-method studies were eligible for inclusion if the qualitative data was clearly reported and applicable. Studies including experiences of other family members were also eligible for inclusion if women's experiences could be extracted. The ENAP and SDG3 targets reducing stillbirths to 12 deaths per 1000 live births, and neonatal deaths to 12 deaths per 1000 live births globally by 2030 respectively (UNICEF, 2021; WHO 2021). Thus, in this metasynthesis, high burden settings were defined as countries with perinatal death rates above the ENAP and SDG3 target rates.

4.4.4   Exclusion Criteria

Studies focused solely on miscarriage (loss of pregnancy before 28 weeks of gestation and termination of pregnancy) were excluded (WHO, 2021). Grey literature such as thesis were also excluded due to financial and time constraints in retrieving these resources. Families of different sexual orientation/gender identity outside of heterosexual orientation were not included as this is not recognised in Nigeria and is regarded as illegal under the Same-Sex Marriage (Prohibition) Act (2013) (Refworld, 2022). Thus, including participants of the Lesbian, Gay, Bisexual and Transgender (LGBT) has the potential of putting this group at risk,

and there will be a need for a highly sensitive approach in studying the experience of care and support following perinatal death in this group of individuals. The wider family was not included in this metasynthesis as the aim was to explore the experience of mothers in high burden countries.

4.4.5   Quality Appraisal

Quality was appraised in this review to gain an insight into the strengths and flaws of each study and how they may impact the findings and new interpretation. It was important to appraise the quality of included studies as it contributes to the credibility of a metasynthesis (Carroll and Booth, 2014). Walsh and Downe's (2006) appraisal tool which evaluates rigour by assessing integrity, transparency and transferability, and Downe et al., (2009) grading system were used in quality appraising included studies (Downe et al., 2009; Carroll and Booth, 2014). All three authors independently appraised the included studies, and assigned a grade between 'A' and 'D' according to Downe et al., (2009) grading system. A study by author 2 was appraised by authors 1 and 3. Conflicts in grading was resolved in a meeting between authors. No study was excluded on the basis of grade because although a study may be graded as 'poor', it may contain valuable qualitative findings (Majid and Vanstone, 2018).

4.4.6   Data Extraction and Synthesis

The researcher read and re-read included studies for understanding and immersion in the data. Data was extracted under the categories of study aim, participants, study and recruitment setting, methodology, method of analysis and findings. These categories also informed description of study characteristics (Table 3). Noblit and Hare's (1988) meta-ethnography was adopted in analysing the data. Five steps were followed; analysis commenced with author 1 reading and re-reading each study to identify key concepts and themes within the findings. Key concepts in the included studies were highlighted, and written out by hand, cut out and arranged

on a large paper. The concepts and themes were organised, along with the first and second order constructs (direct quotes of participants and interpretation of original research authors respectively) identified from each study to preserve their original contexts (Tavish et al., 2019). These finding were synthesised by comparing the themes and concepts to identify similarities (reciprocal findings), and highlight the conflicts (refutational findings). The reciprocal and refutational findings were converged from which a line of argument was developed. This approach advocates that synthesis should be interpretive not just descriptive, and its steps aid the development of interpretation of women's experiences of care and support following perinatal death (Polit and Beck, 2014).

4.4.7   Reflexivity

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

4.5   Findings

4.5.1   Search Outcome

A total of 1882 studies was retrieved from the database search of which 744 duplicates were removed. After title and abstract screening of 1138 studies, 177 studies moved to full text review and 940 papers were excluded as they did not meet the inclusion criteria. At full text review, of the 177 studies, 7 were eligible for inclusion in the metasynthesis from the database

search. 2 studies were retrieved from hand search of reference lists, of which 1 study was eligible for inclusion. Of the 170 studies that were excluded, 20 were not retrievable due to either paywall restrictions or not being available, 7 were dissertations, 9 were not focused on women, 1 was not in English, 48 were not of qualitative or mixed method design, 85 were from low burden settings. Overall, a total of 8 studies was included in this metasynthesis (7 studies from the database search and 1 study from the hand search of reference lists) (Refer to PRISMA diagram below for the database search).

Identification of studies via databases and registers

Identification

Records identified from:
Databases (n = 1882)
Registers (n = 0)

Records removed *before screening*:
   Duplicate records removed (n = 744)
   Records marked as ineligible by automation tools (n = 0)

Screening

Records screened
(n = 1138)

Records excluded
(n = 940)

Reports sought for retrieval
(n = 177)

Reports not retrieved
(n = 20)

Reports assessed for eligibility
(n = 157)

Reports excluded:
   Low burden settings (n = 85)
   Not qualitative or mixed methods study (n = 48)
   Not in English Language (n = 1)
   Dissertation (n=7)
   Wrong population e.g. fathers, healthcare

Included

Studies included in review
(n =7)
Reports of included studies
(n = 0)

From: Page MJ, et al (2020).

Figure 1: PRISMA Diagram of database search

4.6   Characteristics of Included Studies

The eight (8) included studies were of interpretive, descriptive and grounded theory qualitative methodology, except one which was mixed-methods. Studies were undertaken in Uganda (1), South Africa (2), Ghana (2), India (1), Malawi (1), and Kenya (1) (Table 3 for characteristics of studies), all high burden settings in Sub-Saharan Africa and South Asia, and were conducted between 2007 and 2020. The sample sizes ranged from 8 – 134 participants. All of the studies focused on women's experiences of care and support following stillbirth and/or neonatal death but some included other participants such as partners (Kiguli et al., 2015; Mills et al., 2020), grandparents and traditional birth attendants (Kiguli et al., 2015). All the studies utilised interviews as their data collection method. In relation to the quality appraisal, four studies (Kiguli et al., 2015; Mills et al., 2020; Onaolapo et al., 2020; Roberts et al., 2012) were graded B, three (Meyer et al., 2016; Simwaka et al., 2014; Conry and Prinsloo, 2008) were graded C and one (Modiba and Nolte, 2007) was graded a D (Table 3).

Subthemes	Relevant Studies	Main Themes	Example Quotes	Core Concept
My baby died, I embarked on a wasted journey it's my fault	Kiguli et al., (2015), Simwaka et al., (2014), Modiba and Nolte, (2007), Roberts et al., (2012), Onaolapo et al., (2020), Mills et al., (2020), Meyer et al., (2016)	Mothers' reaction to their baby's death	*I was filled with sorrow because I was expecting something, I was eagerly waiting, and I was also happy that I would have a baby. I was heart-broken… I become depressed (Simwaka et al., 2014).*	Perinatal death causes a range of emotions in mothers, particularly feelings of guilt which is compounded when others blame them for the loss. There is an understanding amongst mothers that the absence of a living baby makes them of less concern to healthcare professional. Family and communities contribute to the grief due to lack of support. Consequently, coping strategies are adopted by women to help in managing their experience of perinatal death and its impact. There is a need for appropriate bereavement support for mothers.
I don't have a live baby so staff don't care	Simwaka et al., (2014), Modiba and Nolte, (2007), Roberts et al., (2012), Onaolapo et al., (2020), Mills et al., (2020), Meyer et al., (2016), Conry and Prinsloo, (2008)	Care and support following perinatal death	*"nurses … should try hard to comfort patients... They should try hard to look at the other person's problem, try to comfort her the way they have been taught, and according to their capability, because most of the time, at home there is no time for this" … "The doctor avoided me, and when I pressured him, he said: 'These things happen and you should try to put that behind you'. He really offered no support, he was so cold". (Modiba and Nolte, 2007)*	
Lack of support from partners, family and community	Kiguli et al., (2015), Modiba and Nolte, (2007), Roberts et al., (2012), Onaolapo et al., (2020), Mills et al., (2020), Meyer et al., (2016)		*"they all acted as if I intentionally killed the baby myself. People's attitude sometimes can make someone's situation worse" (Onaolapo et al., 2020)*	

Stoicism and acceptance	Onaolapo et al., (2020), Meyer et al., (2016)	Coping strategies in the absence of care and support	*Because I knew that, actually, the baby is gone and there's nothing that I can do. So there's no need for me to cry and scream and shout for people to know . . . (Meyer et al., 2016).*	
Living children and faith as a protective factor	Kiguli et al., 2015, Mills et al., (2020), Meyer et al., (2016), Onaolapo et al., (2020)		*"I think I have to concentrate on how to help raise my children to get to somewhere in life than to think of bringing another one into the world." (Meyer et al., 2016)* *"I believe God has a purpose for everything, he allowed this to happen for a reason" (Onaolapo et al., 2020)*	
Avoidance	Kiguli et al., 2015, Meyer et al., (2016)		*"even the pictures we took of the baby have been seized by my uncles, in a bid to help me not talk or remember the event, to prevent me from crying or being sad…They [my family] said if I talk or think about it so much, I will be so depressed and also that chances of having another baby will be so slim" (Meyer et al., 2016)*	

Table 2: Themes, subthemes and core concepts

4.7   Themes

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

Mothers' reactions to their baby's death

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

The anticipation of welcoming a living baby was dashed by their death causing mothers to experience a range of negative emotions including guilt, heartbreak, confusion, sadness, numbness, emptiness, lack of fulfilment and emotional pain which were worsened by different factors (Modiba and Nolte, 2007; Onaolapo et al., 2020; Simwaka et al, 2014; Roberts et al., 2012; Kiguli et al., 2015).

> *"I just felt confused. I could not cry, I really felt empty ...When a child is born dead, there is nothing. The world remembers nothing and the gap in the womb is replaced by an emptiness in your arms. You are not recording a birth or a death".* (Modiba and Nolte, 2007).

Women described the experience of perinatal death as having embarked on a pregnancy journey with its accompanying emotional and physical demands in vain without a reward of a living baby (Simwaka et al., 2014; Mills et al. 2020; Modiba and Nolte, 2007).

> *I felt very sorry for myself because it was as if I had worked for nothing.* (Simwaka et al., 2014)

The feeling of guilt was heightened when others such as healthcare professional or family inferred that mothers were responsible, and they also blamed themselves for their baby's death due to actions they may have or not taken whilst pregnant or during labour (Meyer et

al., 2016; Onaolapo et al., 2020; Roberts et al., 2012; Simwaka et al., 2014; Modiba and Nolte, 2007).

> *"I felt myself it was my fault. I felt it was something wrong with me…I feel it's my body rejecting the baby". I think really I am blaming myself for going into labour, for getting out of bed. If only I had stayed in bed that extra day, would it have made any difference?"* (Modiba and Nolte, 2007).

Care and Support after Perinatal Death

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

The care from healthcare professionals (staff) had a direct impact on mother's grief experience. The level and quality of interaction and communication from healthcare professional were perceived as inadequate, limited and in some instances absent particularly from doctors. The included studies show that most mothers had an understanding that they were not appropriately cared for and supported by healthcare professional due to the absence of a living baby (Meyer et al., 2016, Mills et al., 2020; Modiba and Nolte, 2007, Simwaka et al., 2014).

> *Nurses don't communicate with you". "Doctors don't have time for the patients. Just a few. But they don't have time for the patients! Most of them don't have time for the patients.* (Modiba and Nolte, 2007).

Consequently, many mothers were left to construct their own explanation of the reasons and circumstances leading to their baby's death which contributed to their grief (Simwaka et al., 2014; Modiba and Nolte, 2007; Mills et al., 2020; Meyer et al., 2016; Onaolapo et al., 2020). Some of which included; medical negligence, partners' infidelity, witchcraft.

> *I think it is the nurse's negligence because if she had attended to me a way could have been found to save my baby...* (Simwaka et al., 2014).

Some meaningful interactions were reported where healthcare professional offered verbal encouragement and sensitive approach to care such as nursing bereaved mothers on separate wards to those with living babies (Conry and Prinsloo, 2008; Meyer et al., 2016; Mills et al., 2020; Simwaka et al., 2014; Robert et al., 2012).

> *"She [healthcare professional] said I should not worry too much because that is how God planned it, He gives and takes away so maybe God will give me another gift at a later time"* (Simwaka et al., 2014)

However, healthcare professional were mostly unsupportive of mothers as they did not provide opportunities for discussion, were insensitive, absent, rude, unapproachable, lacking in compassion, warmth, and enthusiasm in their care duties (Conry and Prinsloo, 2008; Mills et al., 2020; Onaolapo et al., 2020; Simwaka et al., 2014; Modiba and Nolte, 2007). This is reflected in an example of healthcare professional's conversation as narrated by a mother;

> *'What do you want us to help you with? Your thing has already died, for us we save those who are still alive, if your baby was still alive, we could have saved him. So, on that note, help yourself because we also have no way of saving you.'(Mills et al., 2020).*

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

> *'. . . then after that delivery[sic] and the incident of losing my child I was being put in the same room with other women holding their baby. I felt very bad because I too wanted to hold mine and feel like them.'* (Mills et al., 2020)

Lack of support from partners, family and community

Relationships between women, partners and families and with the community were impacted either positively and negatively by perinatal death. Many reported that the bond with their partners was strengthened as they lived through and coped with the grief jointly (Kiguli et al., 2015; Mills et al., 2020; Roberts et al., 2012). The sustenance of relationships was in some cases reliant on its quality prior to perinatal death (Kiguli et al., 2015).

> *"I have the most amazing and supportive husband in the whole world…he did not let me feel bad. He is so funny and dramatic that all his dramatic acts in the house make me forget my loss"* (Onaolapo et al., 2020).

However, breakdown in relationships occurred as perinatal death caused strife and sadness for some couples thereby drawing them apart. This was also precipitated in a few cases where mothers were blamed by partners, and extended family members for the baby's death. Thus, mothers experienced marital strife, separation, emotional and verbal abuse from partners, family members including co-wives and stigmatisation in and by communities (Kiguli et al., 2015; Mills et al., 2020; Roberts et al., 2012; Onaolapo et al., 2020; Meyer et al., 2016; Modiba and Nolte, 2007).

> *I had a previous [perinatal] loss, and this again! At a point my husband started frustrating me, coming back home late at night…he even threatened to bring in another woman as a wife (Onaolapo et al., 2020).*

The family and community particularly stigmatised mothers in the case of repeated perinatal death, often accusing them of witchcraft or being possessed by demons (Meyer et al., 2016; Kiguli et al., 2015). They withdrew their care and support for mothers as they were seen as responsible for their baby's death. This reinforced sense of guilt carried by most mothers. Mothers responded by isolating themselves, enduring the blame and ill-treatment due to lack

of understanding of their grief experience, and support from their families and communities (Meyer et al., 2016; Mills et al., 2020; Roberts et al., 2012).

Coping Strategies in the Absence of Care and Support

Stoicism and Acceptance

Perinatal death was not adequately acknowledged in communities and by families, majority of mothers were unable to openly express their grief. Therefore, the absence of care and support led to the adoption of personal coping strategies to manage their experiences. Stoicism was described as "being strong for themselves" by some mothers who endured the emotional pain and impact with an assurance that they will live through the grief (Onaolapo et al., 2020; Meyer et al., 2016).

> *All mothers have to be strong for themselves especially during their loss because whatever loss or pain or tragedy we are experiencing we would always get through it. I know it hurts but my Allah will do another one, I know* (Onaolapo et al., 2020).

Living Children and Faith as Protective Factors

Older living children were a protective factor to a few mothers who were grateful to be alive to care for and see them grow (Kiguli et al., 2015; Meyer et al., 2016; Mills et al., 2020).

> *Do I even have the time [to dwell on the death of the baby]? Look at the children around me. If I lost one, will I not get on my feet to support the rest that are alive? . . .* (Meyer et al., 2016)

There was a reliance on religious belief as a few mothers accepted their baby's death as the will of God/Allah who will provide a living baby for them in the future (Kiguli et al., 2015; Meyer et al., 2016; Mills et al., 2020; Onaolapo et al., 2020).

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

(Onaolapo et al., 2020).

Avoidance

Avoidance was used as coping strategy by mothers but this was not always by choice rather enforced by others such as family or as a result of cultural beliefs. Certain cultures discourage mothers speaking or thinking about a deceased baby as it is believed to be an effective method of coping and preventing future fertility issues (Meyer et al., 2016). Consequently, mothers avoided thinking or speaking about their baby's death by placing focus on others things or engaging in activities, although some longed to speak about it.

"even the pictures we took of the baby have been seized by my uncles, in a

bid to help me not talk or remember the event, to prevent me from crying or being

sad…They [my family] said if I talk or think about it so much, I will be so depressed

and also that chances of having another baby will be so slim (Meyer et al., 2016).

Line of Argument Synthesis:

After the death of their baby, mothers in high burden settings were isolated in their loss. The experience of perinatal death was perceived as a 'fruitless journey'. This invoked a range of emotions such as sadness, emptiness, lack of fulfilment, which was compounded by the feelings of guilt and responsibility for their baby's death. There were expectations of understanding of the impact of their loss and support in managing their grief from healthcare professional, family and community. However, there was mostly a lack of communication, supportive interactions, and care from healthcare professional who were insensitive, unapproachable and lacking in compassion. Relationships between mothers and their partners

were strained, and families also stigmatised them, as they were often regarded as responsible for the loss. Thus, mothers were reliant on their own coping strategies in managing their emotions and grief.

4.8   Discussion

4.8.1   Main Findings

This metasynthesis aimed to increase the understanding on women's lived experience of care and support following perinatal death by synthesising the findings of existing studies in high burden settings. In this review, there was a perception amongst mothers that they had embarked on a journey to motherhood without a positive outcome. This experience of perinatal death was characterised by intense grief which manifested in negative emotions such as anger, emptiness, and lack of fulfilment. There was a sense of guilt in mothers which was further worsened when blamed by others such as healthcare professional, families and communities as responsible for the death. There was an expectation of care and support from healthcare professional, families and communities which some mothers received. However, most mothers expressed dissatisfaction as they had a negative experience with healthcare professionals who were thought to place them as less of a priority due to the absence of a living baby. Mothers reported negative experiences following perinatal death such as blame, stigmatisation, relationship breakdown, and lack of avenue to express their emotions from healthcare professional, family and the society which worsened their grief responses. Family members and the community lacked understanding of support needs of mothers; they were driven by cultural beliefs in their approach. Family members were a concern for mothers as they blamed them and contributed to the breakdown of their relationships/marriages, experience of abuse and ostracization. Thus, many felt unsupported and left to cope with their experience of perinatal death alone. Consequently, in this synthesis, mothers sought other ways of coping and managing their grief.

They utilised caring for their other children, and isolating themselves from others, avoidance, acceptance and faith as there is often no opportunity to express their grief.

4.8.2 Interpretation

This metasynthesis highlighted that the experience of care and support following perinatal death in mothers is shaped by the response of the healthcare setting, partners, family and community. The response stems from a lack of understanding on acknowledgment of perinatal death, recognition of deceased babies and cultural norms thereby leading to disenfranchised grief (Obst et al., 2020; Kersting and Wagner, 2012). Mothers were affected by negative responses thus can be said that they experienced multiple losses; of their baby, relationships, family and also social status (Camacho-Avila et al., 2019; Mills et al., 2014). They yearned for opportunities to express their grief experience, but were hindered by the response of others, and cultural beliefs and practices. Healthcare professionals' approach was inadequate as there was a lack of communication, attention and sensitivity in interactions following perinatal death. A high level of expectation was placed by mothers on healthcare professional in being physically and emotionally supportive and present but this was not the case, which worsened their experience and its accompanying grief. Support and ongoing encouragement from healthcare professional is often of paramount importance to bereaved mothers (Ellis et al., 2016; Gauchi et al., 2011; Gopichandran et al. 2018; Nordlund et al., 2012). Healthcare professionals are to support mothers by having consideration for their feelings, helping relieve their negative emotions and feelings of guilt (Salgado et al., 2021; Das et al., 2021). However, it will be beneficial to understand from the perspective of healthcare professionals the rationale behind their approach of care and support towards bereaved mothers in high burden settings following perinatal death.

On the other hand, mothers also had negative responses from family and the community thus they had no source of support leading to adopting other ways of coping with their experience of perinatal death. This has been reported to be more prevalent in high burden in contrast to low burden settings (Burden et al., 2016). These negative responses stemmed from cultural beliefs and practices held by families and communities such as not being allowed to hold or see the deceased baby to avoid future fertility issues. In addition, perinatal death impacts on the relationship of mothers and their partners positively and negatively, and thus not limited to high burden settings as also found in studies in low burden settings by Gausia et al., (2011) and Fernandez-Sola et al., (2020). However, the quality of relationship prior to perinatal death has been reported to determine the sustenance following perinatal death. Some bereaved mothers reported a strengthened bond with partners but others experienced more friction between themselves. Educating communities and families on the causes and impact of perinatal death on bereaved mothers will be beneficial in limiting the negative responses such as blame, and relationship breakdown in high burden settings. However, this links back to healthcare professionals who are best placed to provide adequate medical explanations to mothers and families about the cause of perinatal death. Thus, there is a need for adequate explanations when perinatal death occurs to bereaved mothers and families (Reinebrant et al., 2018). This will contribute to increasing the acceptance of bereaved mothers by family and communities as individuals who experienced rather than caused a loss.

4.8.3   Strength and Weaknesses

This is the first metasynthesis exploring the experience of care and support following perinatal death in high burden settings. Shakespeare et al (2018)'s study provided key foundational understanding for this review. However, Shakespeare et al (2018) conducted a metasummary which is the quantitatively-oriented approach to aggregating frequency and intensity effect of

qualitative findings (Erwin et al., 2011). This review is inductive as it utilised metasynthesis which takes a broader approach towards synthesising qualitative studies through integration and interpretation rather than amalgamation of findings to uncover deeper insight into the phenomenon of interest (Erwin et al., 2011; Sandelowski and Barrosso, 2007). Although metasynthesis has been criticised for producing interpretations three times removed from the original owners of an experience (participants), its findings remain firmly grounded in the primary studies (Sandelowski and Barrosso, 2007; Bearman and Dawson, 2013; Toye et al., 2014). Another strength of this metasynthesis is its use of meta-ethnography in analysing and synthesising study findings which is very efficient at generating new interpretation in a rigorous and systematic manner (Noblit and Hare, 1988; France et al., 2019). The expertise and experience of each author also contributes to the strengths of this metasynthesis. Although authors brought differing views based on their expertise which can be challenging, it worked positively as it opened up channels of allowing each open their minds to new angles from the data. Furthermore, the processes in undertaking this metasynthesis was rigorous with numerous discussions between the authors thus creating confidence that the interpretations are reliable.

A majority of included studies in this review (6) were conducted in Uganda, South Africa and Ghana, and the rest were India and Malawi. One of the studies was conducted in two countries, Uganda and Kenya. This reflects continuing gaps in research in perinatal death in high burden countries. The studies were also mostly conducted in rural areas, meaning experiences of women in urban areas in these countries were less represented. Furthermore, the studies had some commonalities in cultural responses to perinatal death from family and communities but practices differ within healthcare settings even in, the same and, different countries. Cultural beliefs and healthcare practices often vary widely between and within high burden countries, which have to be individually understood (Gopalkrishnana, 2018).

4.9   Conclusion

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

4.10   Implication for Research

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

Table 3: Characteristics of Included Studies

Authors, Date, Country	Aim	Methodology	Sampling Strategy	Recruitment setting	Data Collection Method	Data Analysis Approach	Quality Assessment Grade
Conry and Prinsloo, (2008), South Africa	To explore access of bereaved mothers to services following perinatal death.	Exploratory study	Purposive sampling (n=15) 15 women	Hospital	Interviews	Mixed methods (dominant/less dominant approach).	C
Kiguli et al. (2015), Uganda	To explore local definitions and perceived causes of stillbirths as well as coping mechanisms used by families affected by stillbirth in rural eastern Uganda.	Interpretive phenomenological research	Convenience sampling (n=29) 14 women (who experienced stibirth) 6 men (husbands of women who experieed stibirth) 11 4 Grandmothers 1 Grandfather 4Traditional Birth Attendants	Hospital maternity ward register, and village community leaders.	In-depth interviews and observation	Content analysis using Granheim and Lundman approach	B
Modiba and Nolte (2007), South Africa	To describe the experience of mothers with the loss of a baby during pregnancy (stillbirth included) and the professional care received during the time.	Interpretive phenomenological research	Purposive sampling (n=10)	Maternity ward in a hospital.	In-depth unstructured interviews	Tesch's data analysis approach.	D

			10 women who had experienced perinatal death.				
Meyer et al. (2016), Ghana	To further understand the notion that suggests that women in sub-Saharan Africa are discouraged from publicly mourning a perinatal death and discussing their loss for fear of social ramifications such as stigma, gossip and blame.	Mixed methods	Convenience sampling (n=8) 8 women	Mother and baby Unit in a hospital	Interview and quantitative survey for demographics.	Content Analysis	C
Mills et al., (2020), Nairobi, Western Kenya, Kampala and Central Uganda.	To explore the lived experience of care and support following stillbirth in urban and rural health facilities.	Qualitative interpretative design (Heidegerrian phenomenology)	Purposive sampling (n=134) 75 women and 59 men	Hospital and postnatal clinics	Interviews	Van Manen's reflexive approach	B
Onaolapo et al. (2020), Ghana	To explore experiences, coping strategies and support systems available for perinatally bereaved mothers.	Descriptive phenomenological design	Purposive sampling (n=12) 12 women	Hospital	Interviews	Thematic analysis using Colaizzi's approach	B
Roberts et al. (2012), India	To explore how poor, rural central Indian women perceive and cope with stillbirths.	Grounded theory	Snowballing sampling (n=33) 17 women 16 health care professionals and hospital staff	General hospital	Interviews and focus groups	Standard qualitative data analysis	B
Simwaka et al., (2014), Malawi	To explore women's perceptions of and satisfaction with nursing care they received following stillbirth and neonatal death.	Qualitative exploratory study	Purposive and snowballing sampling (n=20) 20 women	Villages around the community hospital	Interviews	Thematic analysis using Colaizzi's approach	C

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5   Chapter 5: Paper 2 – Qualitative Study (Women)

An exploration of women's lived experiences of care and support following perinatal death in

South-Western Nigeria: A phenomenological study.

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(In preparation for submission)

5.1   Abstract

Background

Perinatal death results in long-lasting intense grief for bereaved mothers and their families which can negatively impact on their short- and long-term outcomes and quality of life if inadequately supported in coping with and managing their experience.

Aim

This study aimed at exploring the lived experience of women, their partners and families of care and support following perinatal death in South-Western, Nigeria.

Methods

A qualitative methodology using Heideggerian phenomenology was used. Fourteen women who had experienced perinatal death in South-Western Nigeria within the last (5) five years were interviewed, and Van Manen's approach to hermeneutic phenomenology was used in analysing the data.

Findings

Four main themes were identified: "*they did not tell me the baby died*", "*response of health care professionals after the baby died*", "*moving on from hospital*", and "*support from family*". The physical health status of mothers determined how health care professionals informed them of the death of their baby. In cases where there were physical health concerns in mothers, deceptive measures such as stating that their baby was being cared for in another facility was used by health care professionals, particularly following caesarean section. This was to limit further risks of medical complications. Health care professionals were distant, rude, non-empathetic and did not offer emotional support, in some cases. Mothers were given

123

the opportunity to see and hold their babies but many did not find health care professionals supportive in their approach. However, nursing care was mostly regarded as good by mothers. Following hospital discharge, there was no routine follow-up support in the community provided by health care services, besides a postnatal check-up appointment which was offered to all mothers regardless of their birth outcome. Family provided emotional support for mothers on discharge.

Conclusion

Overall, this study was the first to explore the lived experience of women of the care and support following perinatal death in South-Western, Nigeria. The emotional support of mothers is not sufficient at present as there appears to be little to no provisions and no recognised approach to supporting them within the health care system. Thus, there is a need for healthcare systems to review bereavement care and support provisions for women, partners and families who experience perinatal death.

Keywords

Perinatal death, mothers, support, care, sub-Saharan Africa, bereavement care

5.2 Introduction

Perinatal death (stillbirth and neonatal death) is prevalent globally, with 2.4 million neonatal deaths within the first 28 days of life and 2 million stillbirths occurring in 2020 (UNICEF, 2021; WHO, 2022). The majority of these deaths occur in low- and middle-income countries (LMIC), with South Asia and sub-Saharan Africa including Nigeria, carrying the highest global burden (Adebayo et al., 2019). Nigeria ranks second and third in the world, with 42.9 stillbirths per 1000 births and 35 neonatal deaths respectively, accounting for a large share of the global total (UNICEF, 2021b; UNICEF 2022; Ezeh et al., 2019). Efforts have been made towards reducing these rates in Nigeria, such as, but not limited to, promoting antenatal care uptake amongst pregnant women, improving access to maternal and newborn health care services by introducing community midwifery, and increasing health education (Fasina et al., 2020; Okereke et al., 2019). Despite the effort, high rates of perinatal death remain, reflects that many women in Nigeria continue to experience complex, intense and long-lasting grief as a result of the death of their baby (Fasina et al., 2020; Popoola, Skinner and Woods, 2021). Existing literature from LMICs show that women's grief is not always acknowledged, and many are significantly stigmatised due to cultural beliefs in their community thereby causing them to feel isolated in their experience because of a lack of social support (Adebayo et al., 2019; Popoola, Skinner and Woods, 2021; Kuti and Ilesanmi, 2011; Kiguli et al., 2015, Kuforiji, Mills and Lovell, 2022). Some of the long-lasting effects of perinatal death on women besides poorer physical health outcomes include depression, anxiety and fear of subsequent pregnancy (Camacho-Avila et al., 2019). The care and support following perinatal death can determine the grieving process, and short and long-term outcome for mothers, partners and their families. Health care professionals should offer support by being sensitive to their care, cultural and faith needs, by adapting adequately, being emotionally present, person-centred, and communicating

in a compassionate manner, acknowledging their grief and empowering them in facing the future (Hendson, 2018; van Aerde, 2001). Following discharge, appropriate follow-up support from health care professionals helps promote healthy grieving outside of the hospital (Hendson, 2018). Support from the family also contributes to improving the grief experience of mothers (Bennett et al., 2007). Adequate care and support as detailed above contributes to fewer symptoms of grief, less posttraumatic stress disorder (PTSD), depression and anxiety. It also prevents the development of maladaptive coping mechanisms thereby promoting a healthier approach to coping with their grief. However, there is insufficient knowledge about the care and support that women, partners and their families receive in Nigeria following perinatal death. There is a need to explore in-depth the experience of women, partners and families in terms of care and support, to identify current provisions, what would be beneficial and to improve health outcomes. Thus, this study aimed at exploring the lived experience of care and support of women, partners and families following perinatal death in South-Western Nigeria.

5.3 Methodology and Methods

5.3.1 Study Design

This qualitative study was guided by Heideggerian (hermeneutic) phenomenology (Heidegger, 1962). Hermeneutic phenomenology is concerned with understanding and interpreting experiences (Matua and Van Der Wal, 2015). Researchers use this approach in delving deeper into human experience as it is lived to identify meanings rooted within them (Lopez and Willis, 2004). Hermeneutic phenomenology emerged from Martin Heidegger's (1889-1976) rejection of Husserl's notion of understanding beings. Husserl focused on describing the experience as lived by individuals. However, Heidegger was interested in understanding and interpreting individuals' experience as lived by them (Laverty, 2003). Heidegger recognised the limitation of Husserlian phenomenology's bracketing thus he rejected this notion (McConnell-Henry, Chapman and Francis, 2009). This is because he believed that understanding lived experience was an interpretative process which is augmented by preconceptions which cannot be bracketed, but rather embraces it, promoting deeper understanding and interpretation (Reiners, 2012; Gearing, 2004; McConnell-Henry, Chapman and Francis, 2009).

5.3.2 Patient and Public Involvement

The Postpartum Support Network Africa (PSN), a non-governmental organisation in Lagos, Nigeria, provides psychological support to women who experience perinatal death, and mental health difficulties in the postnatal period. They contributed to the recruitment by facilitating the distribution of the study information on their WhatsApp group regularly to widen the reach for potential participants, as this had been made more difficult by the COVID-19 pandemic. The topic guide was piloted with two mothers who had experienced perinatal death in Nigeria. Based on their responses and feedback, the topic guide was amended to improve prompts and

questions to aid gaining in-depth data. The researcher aimed for more patient and public involvement in the development of this study such as in the design of participant information sheets and data collection method. However, this was not possible due to the COVID-19 pandemic preventing travel to Nigeria and physical contact with participants.

5.3.3 Ethics

Ethical approval (ref: 2020-9052-16039, Appendix 10) was gained from The University of Manchester in the United Kingdom (UK) and the Lagos State Government research ethics committee (ref: SUB/LIMH/78/VI/892 Appendix 11). Audio-recorded verbal consent using a script (Appendix 14) was obtained from all participants. Participants' identity was concealed by assigning pseudonyms. Recognising the sensitivity of the research topic, a distress protocol was developed before data collection commenced (Appendix 9). This highlighted steps to follow, should a participant experience distress during the interview, such as the researcher offering support, being a trained mental health nurse. If this was not sufficient, a referral with their consent would have been made to appropriate support services for adequate support. One participant experienced emotional distress as they recalled their experience during the interview and was signposted to PSN Africa as opposed to being referred by the researcher because they preferred to make contact themselves. The researcher made telephone contact with this participant the following day after the interview and after another twenty-four (24) hours for additional support at which they confirmed that they contacted the support network.

5.3.4 Setting and Participants

A purposive sample of 14 women who had experienced perinatal death in South-Western Nigeria was recruited via PSN Africa and Lagos Island Maternity hospital, a federal government hospital in Lagos State. Participant recruitment commenced in November 2020

and ended in July 2021. Participants were recruited virtually because of the COVID-19 global pandemic travel restrictions which prevented the researcher from being in Nigeria. Women were eligible to take part in the study if they were 18 years of age and above, had experienced perinatal death within the last five years and received care at a hospital in South-Western Nigeria. Partners and families were also to be included in the study. However, there were difficulties in recruiting this group virtually as no one expressed interest in participating. Interviews in this study were conducted by telephone due to the COVID-19 pandemic restrictions.

The Apex Nurse (Chief Nursing Officer) at the hospital and lead co-ordinator at Postpartum Support Network were contact persons for this study. Information sessions about the study were provided to contact persons via telephone call, and participant information sheets and consent forms were sent electronically by the researcher. The Apex Nurse at the hospital identified potential participants who met the inclusion criteria and provided them with a verbal explanation of the study and a participant information sheet (Appendices 4 and 5). PSN Africa were unable to hold support groups in person due to the imposed lockdown in Nigeria. Thus, the contact person explained the study at virtual support group meetings and on their WhatsApp platform. Due to the time and resource limitations, and COVID-19 restrictions, consent to contact forms could not be completed, rather potential participants were invited to contact the researcher directly. Following this contact, participant information sheets (Appendices 4 and 5) and consent forms were sent to participants electronically by the researcher. The participants were contacted after 24 hours to gain their consent to participate and schedule a time for interview.

5.3.5 Data Collection

Face-to-face interviews were initially planned however due to the COVID-19 pandemic, data collection was altered to telephone interviews via WhatsApp, a communication app. A questionnaire designed by the researcher was used to collect demographic data (Appendix 8). A topic guide was developed based on the metasynthesis (Paper 1, Chapter 4) conducted prior to this study, and in discussion with the supervisory team (TM and KL). The interview commenced with broad opening questions to initiate the conversation inviting women to share their lived experience of care and support following perinatal death. Prompts were used to guide the conversation, probe further and clarify aspects of their experiences. Most interviews were conducted in English, and two were in Yoruba, which the researcher is fluent in. All interviews were audio recorded and transcribed verbatim, except one, as the participant did not consent to be recorded. For this interview, written notes were taken contemporaneously by the researcher. The researcher made attempts at summarising key points at the end of each interview to the participant but was often hindered by some issues such as network difficulties and time constraints. Field notes and a reflexive diary were completed after each interview to capture non-verbal data and personal thoughts about the participants' experience.

5.3.6 Data Analysis

Data analysis was guided by Van Manen's approach to hermeneutic phenomenology which aided transformation of the lived experience, as narrated by participants, into textual expressions of meanings which were structured by the themes (Van Manen, 1990; Abbasi et al., 2014). Analysis occurred in three stages; (1) "Wholistic approach" – where text was examined by reading and re-reading transcripts to become immersed and familiar with the data.

(2) Selective approach – as the text was read, salient aspects were highlighted, and underlined with explanatory notes attached. (3) Detailed/line-by-line approach – texts were related with each other line by line and based on their similarities were grouped in clusters (Ritruechai et al., 2018; Abbasi et al., 2014, Van Manen, 1990). These steps were to uncover thematic aspects and isolate thematic statements to achieve linguistic transformations and thematic descriptions (Ritruechai et al., 2018; Abbasi et al., 2014; Van Manen, 1990). Heidegger advocated adopting the hermeneutic circle in analysing the text where we consider how parts of the text interact with each other and the whole (Gadamer, 1975, 1976; Longxi, 2018). Thus, the researcher followed the hermeneutic circle, moving repeatedly between the whole text and parts to ensure accuracy and achieve an in-depth and subjective interpretation (Longxi, 2018). From the analysis, the researcher generated themes and subthemes, and achieved the final interpretation from regular discussion and guidance of the supervisory team.

5.4   Findings

Interviews were conducted with 14 mothers who were all married and lived with their immediate family. Table 1 (page 130-132) shows the characteristics of participants, 43% (6) between 22 and 31 years old and 57% (8) were between 32 and 41 years old. Of these mothers, 10 had living children either before or after they experienced perinatal death while 4 had no living children at the time of the study. In addition, of the babies that died, 7 were the first, 5 were the second, and 2 were the third child or above. The participants were of Yoruba (12), Igbo (1), and Edo (1) tribe, practised Christianity (11) and Islam (3), and their highest educational qualification was higher national diploma/ordinary national diploma (HND/OND) (7), bachelor's degree (5) and high school certificate (2). They were self-employed (8), unemployed (4) and employed (2). It was noted that majority of the mothers were Christians, this is because the population in South-Western Nigeria predominantly practice Christianity

compared to the Northern region of the country where Islam is mostly practised (Harvard Divinity School, 2022; Adibe, 2022). Four main themes emerged in the interpretation of women's experience of care and support following perinatal death. Theme 1 *"They did not tell me the baby died"* gives a summary of how women became aware of the death of their baby in three subthemes; *"waiting to be told", "they didn't tell me the baby died, they deceived me"*, and "*They told her immediately that the baby died, and she gave up [died]*" which described the timing and approach used by health care professionals in breaking the news. Theme 2, *"Response of health care professionals after the baby died",* detailed the women's experiences of care from health care professionals following perinatal death and was made up of four subthemes: "*I need to see a live baby, not a dead baby", "Culture of little talk", "The health care professionals were too busy to support us", and "They were very very supportive"* which reflected a mixed experience amongst women of the care and support they received. Theme 3 *"Moving on from hospital",* discussed the provision of follow-up care for women under three subthemes: *"No emotional support or counselling", "That's my problem…it's not their business"* and *"Nurses' follow-up outside of healthcare system"*. Theme 4: *"Support from family"* explored family support under two subthemes: "*Partners support towards mothers"* and *"Gaining support from other family members"*.

Table 1: Characteristics of Study Participants (Women)

Characteristics	Women	Total
Age	22-31	6
	32-41	8
Marital status	Single	0
	Married	14
	Civil Partnership	0
	Divorced/Separated	0
Ethnicity	Yoruba	12
	Igbo	1
	Hausa	0
	Other (Edo)	1
Living status	Alone	0
	With immediate family	14
	With extended family	0
Educational level	High School Certificate	2
	HND/OND	7

	BSc	5
Religion	Christianity	11
	Islam	3
Employment status	Full time	2
	Part time	0
	Self-employed	8
	Homemaker	0
	Unemployed	4
Occupation	Business owner - baker, seamstress, grocer, hairdresser, clothier, public relations consultant	
	Nurse	
Living children	Yes	10
	No	4
Gender of deceased baby *includes one who lost 2*	Male	8
	Female	6
	Unknown	1
Parity	1st	7

	2nd	5
	3rd and above	2
Type of death	Stillbirth	5
	Neonatal death	9
Cause of death	Known (Vein of Galen, necrotising enterocolitis (NEC), Prolonged labour, infection, Hepatitis C, breech birth)	6
	Unknown	8
Physical health conditions related to pregnancy	Yes (Gestational diabetes)	1
	No	13
Medical condition before or after pregnancy	Yes	0
	No	14

Theme 1: "They did not tell me the baby died"

Communication was a key aspect for women, as being aware of the health status of their baby was of utmost importance when they had concerns. There were delays and lapses in the communication from health care professionals which caused distress and upset for mothers. They expressed their preference to be informed promptly of concerns or of the death of their baby.

"Waiting to be told"

There was a delay in informing mothers when antepartum stillbirth occurred. This resulted in a feeling of anxiety and uncertainty about the status of their baby. When mothers presented with pregnancy concerns, referrals were made by health professionals for a diagnostic ultrasound scan. All mothers reported being fully informed about the rationale for the referral. The concern and dissatisfaction amongst mothers arose from the scan results not being communicated by the sonographer. Rather they were given the results in an envelope for the referring healthcare professional to interpret and inform them of their baby's death. On receipt of the scan results, health care professionals informed mothers of the outcome and concerns. A few mothers described being informed by health care professionals and aware of the concerns about the health status of their baby prior to or at onset of labour. They felt emotionally prepared when their baby was birthed and did not survive. The death of the baby was also verbally communicated immediately after birth by health care professionals to mothers.

> *"They have prepared my mind already. I was having contractions like [at] 5mins, [and] 2 mins interval. The doctors said with this condition [frequency of contractions] the baby's breathing [was] dropping…and the baby was not feeling good [well]. They had told me this is what [was] going to happen with the baby even if I deliver this baby, it*

might not live. The following morning baby was coming, and I was rushed to the labour

room and they brought out the baby, it was already dead." [Sege].

Mothers expressed a preference to have been informed immediately of the results as opposed to waiting to be told by the referrer. The delay and feeling of uncertainty were difficult to bear for some mothers who chose to read the result before handing it to a healthcare professional.

"... when the [sonographer] did the scan, with the look of the man when he was asking me what hospital I was using. I said "general hospital"…. He said I guess you will go there today and show them this report. I said what happened? He said nothing, that I should just show them… I opened the [scan] result myself…I saw fetus not (alive)…. So, I had to go through the [internet] and read about it so I came to notice that its meaning that the baby is not breathing" [Banky].

In some cases, such as when unexpected intrapartum stillbirth occurred in vaginal birth, mothers were often aware as they either did not hear the baby cry, and/or witnessed resuscitation attempts. Thus, they were often informed immediately of the baby's death by health care professionals.

"After I gave birth then the doctor told me [immediately] that I can see that the baby is not alive." [Yanu]

"They didn't tell me the baby died, they deceived me"

Some mothers identified that deception was used by health care professionals to delay informing them about their baby's death where there were potential risks to their own health following birth. This was common amongst mothers who birthed via caesarean section (CS) under general anaesthetic and experienced neonatal death or intrapartum stillbirth. Mothers

were informed that their babies were being cared for at a different facility or department. Partners and family members maintained the same story, although they were already aware of the baby's death.

> *"When one delivers [gives birth], they will place the baby by their side so [I asked] where my baby was? The nurses were telling me that the baby is okay, and that they were giving them oxygen. When it was morning, I asked where is the baby, why can I not go and see the baby. They now said that they have taken the baby to the general hospital, that when I get better, they will take me there."* [Koko]

A few mothers sensed that their babies had died, and the truth was being hidden, when they were repeatedly prevented by both nurses and family members from seeing them for several days.

> *"I told my husband that the baby is gone because every time I attempt to make a move to see the baby, they will discourage me."* [Bidemi]

The use of deception initially caused upset and anger in most mothers as it created a false sense of having a living baby. They would have preferred to have been informed sooner of the death of their baby.

> *Ah! When they didn't tell me, I was angry. I was telling my husband that they should have told me on time ..."* [Koko].

"They told her immediately that the baby died, and she gave up [died]"

Most mothers realised that delay and deception were adopted by health care professionals to reduce the risk of physical deterioration and allow sufficient time to recuperate medically. A

few mothers appreciated this approach because of their awareness of health complications that may occur if informed about their baby's death whilst medically unfit.

> *… I had a friend, she went to give birth and she was even operated [had a caesarean section], after giving birth the baby was not alive then they told her immediately [about the baby's death] then she gave up [died]… So I thank God that they did not tell me immediately. I was so happy and I thank God* [Yanu]

Theme 2: *Response of health care professionals after the baby died*

There was an expectation that health care professionals would offer robust emotional support following the death of a baby. Mothers were mostly dissatisfied with the interactions and approach from these professionals. They highlighted that most of their input was to uphold hospital policies and avoid litigation rather than being supportive. Nonetheless, they were satisfied with the physical care provided by nurses.

"I need to see a live baby, not a dead baby"

Mothers' anticipation and hopes of welcoming a living baby were dashed when their babies died. Regardless of their feelings of grief, for many mothers seeing and holding their deceased baby was important. This was facilitated by some health care professionals prior to transferring them to the mortuary or being given to partners/fathers for burial.

> *"The baby was handed over to me [to see and hold], once I was ready, they [health care professionals] said they'll take the baby off me…, they gave me all the time I needed. I was touching her, touching her face, touching her eyes, touching her nose, touching every part of her body. I kept touching every part of her body."* [Remide]

A few mothers found seeing and/or holding their deceased baby unbearable and preferred not to do so to avoid having a negative memory of them.

> *"I need to see a live baby. They wanted to show me…but I said no. I don't want to see. So far he [the baby] has gone his own way, let him go. I don't want to [see him] because if I see, I will keep remembering and it will cause something else [sadness and sickness] into my body and I don't want that."* [*Banky*]

However, this was an issue where health care professionals imposed seeing and holding their babies on some mothers. This was not with a view of managing their grief but as a way of confirming the identity of their babies. It was noted from mothers' narrative that regardless of their choice, fathers were shown the baby. Some mothers were prevented by partners and family due to cultural beliefs discouraging contact with dead babies as it is often regarded as a taboo/bad omen to bury one's child. The majority of the mothers were not involved or present at the burial of their babies because of cultural beliefs. This was also a source of distress for some mothers who had wished to see and be present at the funeral of their baby.

"Culture of little talk"

Following being informed about their baby's death, many mothers were keen to discuss their loss and feelings in-depth with health care professionals. Although some had the opportunity to have this discussion, disappointment arose where health care professionals were insensitive and engaged in minimal to no communication and interaction with mothers when there was no living baby. *"Nobody spoke to me about anything"* [Bidemi]. The majority of mothers had an expectation of extensive support including counselling and discussions around their baby's death from doctors in particular but their direct input ended immediately after birth.

"It's supposed to be the doctor that is meant to be giving me hope, you understand? [They should be reassuring me that] this is not the end of the world, … [instead] The doctor just left." [Bankole].

A mother labelled this as a "*culture of little talk"* based on their understanding that health care professionals had better communication and interactions with those with living babies.

"…often times people say that it's almost like the health care professionals go about their [duties]…they kind of revert back to business as usual. But if the baby did make it [survived], it's almost like they're [health care professionals] more present…" [Remide]

In contrast to doctors, mothers perceived that nurses had more contact and communication with them where they offered some empathy in the form of condolences and words of encouragement. This seemed superficial and remained dissatisfactory for most mothers.

"…the nurse-in-charge came to meet me and offered her condolences and said a short prayer that hopefully the next one would come and stay. And also, when I was taken back to my ward, the nurse-in-charge there came and offered her condolences." [Remide].

Notably, the level of mutual rapport was a determinant of the interaction a few mothers received from nurses. This seems to suggest that nurses favoured women with whom they had better rapport. For instance, a mother expressed that she received more interactions with a particular nurse because she shared the same last name with them which created a stronger rapport between both individuals.

> *"It was a woman [nurse] that was there, we are bearing the same surname, that was consoling me that it's okay, it's okay."* [Tania]

However, there was dissatisfaction expressed by some mothers who found that health care professionals' behaviour was of concern as they were rude, non-empathetic and harsh.

> *"They [health care professionals] don't know how to relate with people. They talk anyhow like trash."* [Bankole]

"The health care professionals were too busy to support us"

The workload of health care professionals was seen to interfere with their ability to offer support. The work priorities of health care professionals were seen as responsible for the lack of adequate interaction and emotional support as "*they were too busy*" [Kanyinsola]. Thus, efforts were made to gain answers to their concerns and worries independently either from doctors where possible or other sources.

> *"...I was even the one bringing up more questions about the baby with the doctors. As soon as when can I have another, as soon as when can I conceive or as soon as when can I go for another round of the procedure and all of that. I was the one bringing up this with the doctors than vice versa"* [Remide].

"They were very very supportive"

Physical care from health care professionals, particularly nurses, was positive for most mothers who felt adequately cared for. For instance, nurses administered medication and ensured that they were made comfortable on the wards.

> *"After I delivered my baby, they came around, gave me my drugs [medication], they served me urinary pan . They were very very supportive."* [Kanyinsola]

142

There were some negative experiences of care where mothers felt neglected by nurses. These appeared to be isolated occurrences particularly where there were disagreements and poor rapport between mothers and nurses. The personality of nurses was also blamed for a negative care experience.

Theme 3: Moving on from hospital

"No emotional support or counselling"

Mothers described that the contact from health care professionals ceased immediately after discharge from the hospital except if they returned for a routine postnatal appointment. Provision was made for a follow-up appointment by health care professionals but there was more focus on physical health than emotional wellbeing. On discharge from hospital, all bereaved mothers were offered a routine 2- or 6-week postnatal appointment, the same as for women with a living baby. Many mothers found that attending health care professionals were unaware that their babies had died, and some chose to inform them. This reflected a lack of sensitivity to the experience and needs of bereaved mothers. Some mothers felt hurried during their appointment and were unable to discuss their experience or needs further with the doctor. It was disappointing to them that health care professionals did not acknowledge their baby's death, lacked empathy and did not offer emotional support or counselling.

> *"They gave me [an appointment for] 2 weeks after to come for postnatal check-up. I got there; I was expecting the doctor to say something [about the baby's death]. He did not even say anything. He just checked me [medical assessment]. I even mentioned to the doctor that "doctor when can I try again [for another baby]?" I feel maybe he didn't know [that the baby died]. I now told him, he said oh sorry madam, as in just sorry madam. As in he didn't even [show], no remorse, no pity."* [Bidemi]

"That's my problem…it's not their business"

There was an expectation from most mothers that they would receive a follow-up contact for further support in the community such as a phone call from staff members at the hospital. This expectation stemmed from the belief amongst mothers that they had suffered the death of a baby and should be offered emotional support beyond their hospital stay. There was no offer or provision of further follow-up after the postnatal appointment and all input/care from health care professionals ceased.

> *"There's nobody that called me oh. Nobody called me. They [health care professionals] left it that that's my problem, it's happened so it's not their business. They didn't even call me. They didn't even call me at all."* [Koko].

"Nurses' follow-up outside of health care system"

There appeared to be a lack of formal follow-up from the hospital, but some nurses made efforts as a voluntary gesture to offer support and encouragement after hospital discharge. A few mothers received follow-up phone calls from nurses on a personal level, which was outside of their role and dependent on the rapport between both parties. Some mothers also initiated contact with nurses by asking for their phone numbers.

> *"It was one nurse. She was the one that used to call me [to ask] "ah how are you feeling?" I purposely collected her number."* [Bankole]

In the absence of a formal follow-up, many mothers independently sought support outside of the hospital setting from individuals with a health care professional background to address their concerns and gain emotional support. For instance, Sege approached a retired matron as a source of support and follow-up following her discharge.

"...[It was] a matron in my church [who has been supportive]. We do talk...she's a retired matron. She came home and I explained things to her. She told me things to do" [Sege]

Theme 4: Support from family

Family members, mothers of bereaved mothers, and partners were a source of emotional and physical support.

Partners' support towards mothers

Mothers who received support from their partners expressed the belief that men were "stronger" and were able to suppress their grief to be present for them. They identified that their partners were grateful that they survived and used this in reassuring mothers of hope for future pregnancies and living babies.

"He was always there to encourage me that ...thank God you're alive, the most important thing here is your life and thank God you're alive and now that you're alive there is hope, we can make other babies and I know this that happened God knows the reason why he had to take the baby and all." [Kanyinsola]

This reflects mothers' understanding that partners felt compelled to support them while managing their own experience of grief.

"my husband too, he did not leave me. It's not as though he was not affected [by the baby's death] but if he sees that I'm alone or I've gone somewhere to cry. He'll say I know you'll go to the corner and start crying by yourself. He would come and find me and then pull me out and realise that I've cried, cried, cried there. He'll tell me lets go out and do things so that I don't dwell on it." [Koko].

However, a few mothers did not receive support from their partners, with some partners choosing to end the relationship and marriage due to the baby's death.

> *"I and my husband are as good as not being together now because he is angry that he spent too much and he also borrowed and at the end, we lost the baby. He abandoned me. He said lets not pretend, that he sef [too] is tired of the marriage."* [Adedoyin]

Gaining support from other family members

Most mothers consistently expressed that besides partners, their own mothers or mothers-in-law were a strong and constant source of support. Other family members such as siblings also offered support. These women and family members often lived with the bereaved mother in her own home for a period of time following hospital discharge, offering emotional and physical support. This support ranged from providing physical help such as with activities of daily living, dressing surgical sites, comforting them emotionally using words of encouragement and being present.

> *.... my family also came from time to time to check on me and speak with me. They did not leave me. They would speak with me. If I'm alone too they would not let me be alone. They'll tell me to come play and watch TV, and all that."* [Koko].

Some mothers did note that their mothers' approach to supporting them was at times too stern which initially upset them. For instance, they threatened to leave the mother and return to their home if they remained sad or tearful despite their presence and support. Another mother explained that her mother asked for the nursery to be cleared to avoid the constant reminder of the baby's death, which was very upsetting for her. Although it was a difficult experience for them, they resigned themselves to understanding that their mothers' actions were an effort to support them through their grief.

"*when I got home and I entered my room, because the baby's room is opposite my room… my mum told my husband to dismantle everything and tidy it up, I just started crying*" [Kanyinsola].

Conversely, one mother chose to stay with her in-laws who allowed her to grieve in her own way which she regarded as very supportive. Nevertheless, she felt that she needed someone external to her family thus she chose a close friend to speak with about her experiences. Some mothers also found their older children as a source of emotional support and encouragement. For instance, Banky said;

"*…if he see [sic] me that I'm depressed, I used to see it in his face. It feels somehow. He will just be looking at me that mummy are you okay? What happened? I'll tell him I'm fine. Nothing is happening. Until I smile, the boy will not leave my front. If he did not cheer up, he will not go anywhere. He will just sit down and be saying my mummy is not talking to me. I'm just looking. I'm okay. So the boy too is there for me – I'm okay.*" [Banky]

5.4.1   Summary of Main Findings

Communication was an issue when perinatal death occurred, and mothers often experienced delays in being informed about the death of their baby. The presenting circumstances surrounding perinatal death, such as poor physical health, influenced how and when mothers were informed. Where antepartum stillbirth occurred, there were delays in informing them about the death of their baby and this was attributed to hospital processes. Deception was also adopted in delaying breaking the news of perinatal death where health care professionals had concerns about the health of mothers. This was particularly common in neonatal death and intrapartum stillbirth where the mother had a caesarean section. The majority of mothers would have preferred to have been made aware of their baby's death immediately. However, some

147

were grateful for the delay in sharing the news until they were recovered from the immediate effects of birth and surgery to prevent further deterioration to their health. Emotional support was of great importance to mothers, but this was not adequately given by health care professionals. Following discharge from hospital, there was an invitation to routine postnatal follow-up as offered to all mothers with or without living babies, but this was solely focused on physical health. Some nurses were reported to have voluntarily offered mothers follow-up outside of the hospital, but this was often dependent on the rapport between both parties. Family including partners were a source of support for mothers particularly after discharge.

5.5   Discussion

This study explored the lived experiences of women of care and support following perinatal death in South-Western Nigeria. Mothers described mixed experiences of care and support in South-Western Nigeria following the death of their baby. Mothers with existing children were able to compare their bereavement care and support experience with when they birthed a living baby. They explained that healthcare professionals were more involved and present when there was a living baby compared to when perinatal death occurs as also reflected in Actis Danna et al.'s (2022) study in Malawi, Tanzania and Zambia. However, asides this, the experience of care and support following perinatal death was similar for mothers with existing children and nulliparous women. Experiences of receiving news of their baby's death varied based on their circumstances, similar to responses from mothers who experienced perinatal death in other settings in sub-Saharan Africa (Mills et al., 2020). There were delays in informing mothers about the death of their baby due to hospital processes or concerns of potential deterioration in their own health if informed too soon. Mothers were dissatisfied and significantly concerned with the delay in gaining information about their baby and insufficient or a lack of communication from health care professionals following the death of their baby, an experience

148

shared in low and high income setting as highlighted by studies in Iran (Sereshti et al., 2016), Kenya and Uganda (Mills et al., 2020), Spain (Camacho-Avila et al. 2019) and the UK (Siassakos et al., 2018). Consequently, mothers expressed feelings of anxiety and uncertainty which further exacerbated their grief experience. Bakhbakhi et al. (2017) explained that the news of the death of a baby should be communicated in a timely manner and by a trained health care professional. This seems in line with the practice narrated by mothers except for the delay, which should be avoided due to the anxiety that it triggers (Bakhbakhi et al., 2017; Siassakos et al., 2018). Doctors were deemed to have lesser interactions with mothers in contrast to nurses. Nurses had a closer interaction with mothers and offered physical and emotional support such as condolences and words of encouragement. However, this was determined by the level of rapport between mothers and nurses and in some cases, this was dissatisfactory as nurses were non-empathetic, insensitive and rude.

Physical nursing interventions such as assistance with personal care needs, and medication administration were mostly satisfactory following perinatal death as expressed by mothers. However, non-physical care and support from health care professionals were dissatisfactory and concerning. The opportunity to see and hold their deceased babies was given to most mothers as a form of support. This is a practice which carries the potential of further psychological distress such as depression and anxiety, it can also bring benefits and in high-income countries is well-known and encouraged when a baby dies because it is deemed as valued and beneficial to bereaved mothers, but is not always provided or accepted in low- and middle-income countries (Atkins et al., 2022; Flenady et al., 2014; Hughes et al., 2002; Kuti and Ilesanmi, 2011). This study found that in some cases the rationale for providing the opportunity for mother to see and hold their babies was to uphold hospital policies rather than a supportive approach. Cultural beliefs around having contact with deceased babies causing

future fertility issues or further perinatal deaths and the fear of worsening their grief also hindered a few mothers from seeing and holding their deceased babies, as is in common with other low-income settings (Ayebare et al., 2021; Adebayo, Liu and Cheah, 2019).

Mothers' notion of health care professionals being insensitive was further reinforced when they were invited to a 6- to12 -week postnatal appointment at the same clinic with those with living babies. Health care professionals at these clinics were unaware that they had experienced perinatal death, which reveals poor communication between inpatient and outpatient departments of hospitals. Communication with mothers and between healthcare professionals following perinatal death has an impact on the grief experience of mothers. There was an expectation from mothers to receive follow-up, at least a phone call, from the hospital but this did not occur which reflects a total lack of post-discharge support. Ellis et al. (2016) identified in their study that follow-up support following discharge is appreciated by mothers following perinatal death. However, nurses recognised this gap, and contacted mothers after discharge on a personal basis to offer support as was acknowledged by some mothers. A few mothers independently sought individuals of a health care background to gain support and advice where they had no follow-up from the hospital. On discharge from hospital, family including fathers, siblings, mothers, and in-laws were the mother's main source of physical and emotional support. This is not limited to countries in sub-Saharan African countries. as found by Popoola, Skinner and Woods (2021) and Kuti and Ilesanmi, (2011), but is also highlighted by Fernandez-Sola et al. (2020) in their Spanish study. Partners were a key source of support, as also found by Kirui and Lister (2021) in their study in Kenya. This was not shared by all mothers, as a few partners were not supportive of mothers and chose to end their relationship due to the death of their baby, thereby worsening their grief experience (Adeyemi et al., 2008). A breakdown in relationships is widely known as an impact of perinatal death on some mothers and their

partners in both high and low- and -middle income countries (Heazell et al., 2016; Fernandez-Sola et al., 2020).

5.5.1   Strengths and Limitations

One of the strengths of this study is that it explored in-depth the experience of bereaved mothers affected by perinatal death, in a population that has not been studied, in South-Western Nigeria. This created an understanding of the feelings of mothers in relation to their treatment by health care professionals and the system as whole. In addition, data collection was conducted virtually via telephone interviews while mitigating all global restrictions due to the COVID-19 pandemic; this had a positive impact as it allowed participants to discuss their experiences freely and allowed a wider reach. However, a limitation of this study was the virtual recruitment of participants via support groups and the hospital. As the researcher was not physically present at the support group meetings and hospital, this meant that there was often a time gap between the contact person's informing the potential participant and then confirming their expression of interest to the researcher. Thus, there is a chance that some participants may have been lost during that time. Another limitation is the inability to observe and record non-verbal cues during the interviews due to the virtual nature of data collection. The global restrictions also prevented the researcher from developing an even closer rapport with the participant through their being physically present. However, the virtual nature of the study can be regarded as a strength, as it has shown that qualitative studies into lived experiences can be undertaken effectively with the assistance of technology.

5.6   Conclusion

Overall, this study is the first to explore the experience of care and support following perinatal death in South-Western Nigeria. It offers a unique insight into the areas where care and support

are lacking and the perception of mothers in relation to their experience of the provision. It is evident from this study that mothers do not feel adequately supported by the health care professionals and system. It is felt that they receive lesser attention and care from health care professionals because of the absence of a living baby. The recommendations from this study include that bereaved mothers should be treated as a priority, communication should always be maintained by health care professionals, emotional support should be considered beyond words of encouragement, and follow-up support post discharge should be developed. These would contribute to better experiences and outcomes for mothers. Nonetheless, further research is required to explore ways of improving the care and support provided to mothers following perinatal death in South-Western Nigeria. There is also a need for further research into the care and support experiences of partners and family members following perinatal death.

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6   Chapter 6: Paper 3

An exploration of health care professionals' lived experiences of care and support provision
following perinatal death in South-Western Nigeria: A phenomenological study.

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(In preparation for submission)

6.1 Abstract

Background

Health care professionals are vital in shaping the experience of bereaved mothers and their families following perinatal death. The approach of these individuals can improve or worsen the grief experience, thereby contributing positively or negatively to their short- and long-term outcomes.

Aim

This study aimed at exploring the experience of care and support following perinatal death as provided by health care professionals in South-Western Nigeria.

Methods

This was hermeneutic phenomenological qualitative study, using semi-structured telephone interviews in collecting the data. Van Manen's approach to hermeneutic phenomenology was used in analysing the data. Fifteen nurses who had cared for women who have experienced perinatal death in hospitals in Lagos, Nigeria were recruited.

Findings

Four main themes emerged *"madam sorry oh we cannot hear your baby's heartbeat"*, *"nurses' approach to supporting mothers after informing them of their baby's death"*, *"I take it up on myself personally to follow mothers up after discharge"*, and *"Impact of perinatal death on nurses"*. Nurses assessed the physical health status of mothers to determine their approach to breaking the news of their baby's death. On informing mothers of perinatal death, nurses perceived they provided adequate bereavement support, but this was sometimes hindered by a lack of resources. In addition, the bereavement care and support they provided was based on

160

their practice and knowledge, as opposed to a national or local organisational policy or guidance. There was identification by most nurses of the need for effective follow up support of mothers after discharge, thus as this was not provided by the health care services, they facilitated this outside of their role. Perinatal death also has an impact on nurses but they mostly "let go" of their feelings as there were no structured procedures to support them in such instances, rather they sought avenues to cope with their experience independently.

Conclusion

Overall, this is the first study to explore the care and support provided to mothers and their families following perinatal death from the perspective of health care professionals in South-Western Nigeria. Nurses strive to provide effective bereavement care to women particularly but were hindered in some instances by cultural beliefs and available resources within the healthcare settings. Nonetheless, they moved beyond their role to ensure that mothers felt supported beyond the hospital setting, even if this meant using their own leisure time.

Keywords

Perinatal death, nurses, bereavement care, health care professionals, sub-Saharan Africa

6.2 Introduction

Perinatal death is a challenging experience for mothers, partners and families globally, which is worsened by the absence of appropriate bereavement care. The impact of perinatal death can last for the short- and long-term and ultimately affect the quality of life of mothers and their families. Health care professionals play a key role when perinatal death occurs, in supporting mothers, and their families (Ellis et al., 2016; Camacho-Avila et al., 2020). Perinatal death is often not predictable but when it happens, adequate bereavement care is essential to managing its short- and long-term impact (Gandino et al., 2019). A compassionate approach in attitudes and communication from health care professionals is essential towards bereaved mothers and families in ensuring positive outcomes (Flenady et al., 2014; Camacho-Avila et al., 2020).

Studies have been conducted in high income countries over the years into the care and support from health care professionals towards mothers and families following perinatal death (Gold, Dalton and Schwenk, 2007; Koopmans et al., 2013). These have often contributed to the development of guidelines in promoting bereavement care in perinatal death, such as in the United Kingdom (UK) (NICE, 2014). It has been identified that the care from health care professionals has a lasting effect on the overall experience of perinatal death and coping (Ellis et al., 2016; Kalanlar, 2018; Gold, 2007). Health care professionals are of importance as they are often the first to interact with mothers when perinatal death occurs in a hospital setting or is diagnosed. Therefore, their interactions are of major significance as their behaviours, actions and care can impact their grief experience positively and/or negatively (Ellis et al., 2016). The lived experience of care and support of women following perinatal death in South-Western Nigeria (Paper 2) has been explored and found bereavement care to be inadequate. Thus, it is important to explore the experience of care and support from the perception of health care professionals to develop an understanding of their approach and provision which would help

determine the areas of recommendation. Therefore, this study explored health professionals' experience of care and support for mothers and their families following perinatal death in South-Western Nigeria.

6.3   Methodology and Methods

6.3.1   Study Design

This qualitative study was guided by Heideggerian (hermeneutic) phenomenology (Heidegger, 1962) and explored the lived experience of care and support as provided to mothers and their families by health care professionals following perinatal death in South-Western Nigeria. Hermeneutic phenomenology was used because it helps researchers focus on understanding and interpreting experiences as lived by individuals via in-depth study to reveal deep-rooted meanings enclosed within them (Matua and Van der Wal, 2015; Lopez and Willis, 2004; Laverty, 2003). Hermeneutic phenomenology rejects bracketing on the basis that understanding an individual's lived experience is an interpretative process augmented by preconceptions which cannot be bracketed; rather embracing it promotes deeper understanding and interpretation (Reiners, 2012; Gearing, 2004; McConnell-Henry, Chapman and Francis, 2009)**.**

6.3.2   Ethics

Ethical approval (ref: 2020-9052-16039, appendix 10) was gained from the University of Manchester (UK) and the Lagos State Government research ethics committee (ref: SUB/LIMH/78/VI/892, Appendix 11). Audio-recorded verbal consent was obtained from all participants whose identities were concealed using pseudonyms. Recognising the sensitivity of the research topic, a distress protocol was developed (Appendix 9). This policy highlighted steps to follow should a participant experience distress during the interview, for example, the

researcher could offer support due to their being a trained mental health nurse. If this was insufficient, a referral with the participant's consent would have been made to the appropriate services for adequate support. None of the health care professionals displayed distress in this study.

6.3.3   Participants, Study Setting and Recruitment

Health care professionals were eligible for inclusion in this study if they were nurses, midwives, doctors, psychologists or maternity ward attendants who provide care for women who have experienced perinatal death and work in a hospital with over a year's experience. They were recruited virtually due to the COVID-19 pandemic, via the contact person (Chief Nursing Officer/Apex Nurse) at the hospital who had been provided with information sessions and electronic participant information sheets by the researcher. The contact person presented the study information to health care professionals at staff meetings and provided them with the researcher's contact number to gain further information and/or express their interest in taking part. On receiving an expression of interest via text or phone call, the researcher made contact to provide further information about the study, and a participant information sheet and consent forms were sent electronically via WhatsApp for them to read. Participants were contacted after 24 hours to answer any questions, confirm their participation and arrange a time for the interview.

A purposive sample of 15 nurses was recruited from a federal government hospital in an urban area of South-Western Nigeria. These nurses are regularly posted across hospitals, so this was an added advantage for the study as it meant they would bring knowledge and experience from more than one single hospital. Nurses were recruited from November 2020 till July 2021. Only nurses were recruited into the study as there were difficulties recruiting other health care

professionals. There were two doctors and a social welfare staff member who expressed interest in the study but were lost, as they did not attend pre-arranged interviews for data collection and did not respond when the researcher contacted them afterwards on two occasions. The social welfare staff member who agreed to be contacted did not respond to telephone calls from the researcher. The use of only nurses in this study was not intentional as explained above. However, the recruitment of only nurses meant that only the views/experiences of this group of health care professionals are included in this study and does not accommodate that of others. Thus, this reflects the need to conduct further studies in the future to explore the experiences of other healthcare professionals. In addition, the nurses provided most of the care to bereaved mothers as also identified by mothers. Nonetheless, the nurses provided in-depth narratives that allowed insight into their care and support they provide to bereaved mothers following perinatal death.

6.3.4   Data Collection

Telephone interviews were conducted. Demographic data was collected during the phone call, using a questionnaire (Appendix 7) designed by the researcher. The interviews lasted between 40 and 60 minutes and were guided by a topic guide (Appendix 2) developed based on the metasynthesis conducted prior to this study and knowledge from existing studies focused on health care professionals. All interviews were conducted in English and audio recorded with participants' consent on a University of Manchester-owned encrypted data recorder.

6.3.5   Data Analysis

The data analysis in this study was guided by Van Manen's approach to hermeneutic phenomenology, as explained in Paper 2, which aided transformation of the lived experience as narrated by participants into textual expressions of meanings which were structured by the

165

themes (Van Manen, 1990; Abbasi et al., 2014). This analysis occurred in three stages; (1) "wholistic approach" examined the text as a whole by reading and re-reading transcripts to become immersed and familiar with the data; (2) selective approach – as the text was read, salient aspects were highlighted, underlined with explanatory notes attached; (3) detailed/line by line approach – texts were related with each other line by line and based on their similarities were grouped in clusters (Ritruechai et al., 2018; Abbasi et al., 2014, Van Manen, 1990). These steps were to uncover thematic aspects and isolate thematic statements to achieve linguistic transformations and thematic descriptions (Ritruechai et al., 2018; Abbasi et al., 2014; Van Manen, 1990). Heidegger advocated the importance of the hermeneutic circle in analysing the text (Gadamer, 1975, 1976; Longxi, 2018). Thus, the researcher followed the hermeneutic circle, moving repeatedly between the whole text and parts to ensure accuracy of the lived-experience and achieve an in-depth and subjective interpretation (Longxi, 2018). From the analysis, the researcher generated themes and subthemes, and achieved the final interpretation from regular discussion with and guidance of the supervisory team.

6.4   Findings

Interviews were conducted with 15 nurses who were all female and aged 26 years and above, had a bachelor's degree in nursing and were employed full time. 53% (8) nurses had been working at hospitals between 1 and 9 years and 47% (7) from 10 years and above (47%). These nurses were either single (13%) or married (87%), 80% had children, and 87% practised Christianity and 13% Islam. They were all from the Yoruba tribe. Table 1 (page 163-164) shows the characteristics of these nurses. Four main themes emerged (1) *"madam sorry oh we cannot hear your baby's heartbeat",* (2) *nurses' approach to supporting mothers after informing them of their baby's death,* (3) *"I take it up on myself personally to follow mothers up after discharge",* (4) *Impact of perinatal death on nurses.*

Table 1: Characteristics of Study Participants (Health care professionals)

Characteristics	Health care professionals - NURSES	Total (n=15)
Age	18-25	0
	26-30	3
	31-40	7
	41 and above	5
Marital Status	Single	2
	Married	13
	Civil Partnership	0
	Divorced/Separated	0
Gender	Male	0
	Female	15
Educational level	HND	0
	BSc	15
Religion	Christianity	13
	Islam	2
Employment status	Full time	15
	Part time	0

Have children	Yes	12
	No	3
Ethnicity	Yoruba	15
	Igbo	0
	Hausa	0
Years of hospital working experience	1 year – 4 years	4
	5-9 years	4
	10 years and above	7

Theme 1: "*Madam, sorry oh we cannot hear your baby's heartbeat*"

Nurses believed they were sensitive in their approach to informing mothers about the death of their baby. They took into consideration the mother's physical health status and were guided by this in determining when to break the news to them. Informing mothers about the death of their baby was regarded as the responsibility of nurses, doctors and the social welfare department.

> *"when nurses check and doctors confirm [perinatal death], we call the most senior nurse and the most senior doctor, maybe the most senior reg on ground to break the news to the mother or the husband, we have a social welfare department with the nurses to break the news"* [Dupe]

When perinatal death was confirmed, nurses informed either the mother, depending on her health being medically stable, or her husband/partner. In instances where mothers presented with pregnancy complaints or concerns were identified by nurses or doctors, questions were asked and scans were conducted by the health care professionals to determine the status of the baby. On confirmation of perinatal death, mothers were informed immediately. However, this is often in cases of antepartum stillbirth where the baby had died prior to the commencement of labour.

> *"what we do is when you don't hear the fetal heart rate, immediately you inform the patient. Madam, sorry oh we cannot hear your baby's heartbeat so let's take you for a scan to confirm that… [After confirming perinatal death] we give the patient prior notice to what is happening, before the baby comes out [is born] we would have told the patient [that the baby had died].* [Bisi]

In the majority of cases of neonatal death, and intrapartum stillbirth when nurses confirmed that there were no signs of life after the birth of the baby, the mother was informed immediately.

> *"…if it is a normal [vaginal] delivery,…they might tell the woman the condition of the baby immediately the baby is delivered so that they won't say my baby cried so what is now happening that they are now…telling me that my baby is no more. So immediately the normal delivery and the baby is not really responding, they will make the woman be aware of it there…"* [Lade]

There were instances when nurses delayed informing mothers about the death of their baby due to concerns about their health. For instance, where mothers presented with concerns such as pre-eclampsia, and antepartum stillbirth was detected via a scan, they were not informed. Some nurses explained that husbands/partners were informed immediately and shown the baby at birth instead of the mother to reduce the risk of further health deterioration. This was also to prevent legal actions against their practice and the hospital as nurses were concerned about the possibility of accusations from mothers and their families who may believe that their baby did not die but was swapped at birth.

> *"…if the mother does not look stable health wise, if she is a pre-eclamptic patient then we might not be able to break the news to her or else her case might become more serious [worse]. Or in the case that she has gestational diabetes, we might not tell her [but] just try to reassure her but the husband or the relative will be aware that they brought a case of in-utero fetal death, intrauterine fetal death. After delivery, we still examine the baby to check if actually the baby is dead then they show it to the husband."*
> [Dupe]

Delays in informing mothers of perinatal death also occurred when birth was via caesarean section where they were under general anaesthesia. Many nurses justified concealing information from mothers immediately after recovery from general anaesthesia to allow them sufficient time to recuperate. Deception was used in some cases to divert the attention of mothers whilst giving them time to recuperate to a medically stable state. However, a family member mostly the partner/husband was informed at this time.

> *"So sometimes we tell the mother that your baby needs emergency attention, and it's been taken to baby's ward for further evaluations…we try to use that to divert her mind at least she can recuperate well from the effect of the whether it is CS or normal delivery that she has had"* [Moria]

However, a nurse identified that they informed partners prior to telling mothers when perinatal death occurred. This is so partners were present when breaking the news as they were felt to know the mothers better and could support them too.

> *"once it [perinatal death] happens like that, the first contact is the husband. We try to do it like that because he knows her [the mother], he knows her weakness and some other thing. But telling the patient herself, we don't tell the patient direct, we would have told her husband. We have baby ward in the hospital so after delivery, we transfer the baby there and once anything happens [if the baby dies], they will send for the father and they will [inform him]. So [if] it happens, you look for the husband and try to encourage him, it has happened, so you have to be a man to at least inform the wife so that if he decides to break down now, it would affect her too."* [Odun]

171

Partners were viewed by nurses as another source of support for mothers as opposed to needing support themselves as they were often invited to console and encourage them after confirmation of the death of their baby.

> *"once we tell the wife [that the baby died], we bring the husband along [to support her]."* [Sanye]

Theme 2*: Nurses' approach to supporting mothers after informing them of their baby's death*

Time and space were given by nurses to mothers after informing them of the death of their baby, if there was no risks of harm to themselves to allow them the opportunity to mourn their loss and grieve effectively. Family members such as partners, and mothers were also invited to physically remain with the bereaved mothers to support them.

> *"we empathise with them, we don't start by telling them what to do and what they have done wrong. First we empathise with them and we give them time, time to cry, time to cling with their family, time for family to also speak to them before we start speaking about what causes. Because when you start with what caused and what should not be done, they won't get it next time."* [Sanye]

Nurses expressed that they built a close rapport, were patient with mothers and actively encouraged them to attend to their physical health needs whilst mourning the death of their baby.

> *"Most of the time you have to be very patient because if you are not patient, the patient [mother] will just tag you as a wicked nurse or the nurse that does not have emotions. And at the same time, we try to be firm [assertive]… of course, its normal to brood, to*

grieve over a loved one but at the same time, there are other things that needs to be

considered, things like her own health." [Moria]

Showing the mothers and fathers their deceased baby

Mothers and, particularly, their partners were given the opportunity to see and hold their baby by many nurses. A few nurses assessed the mothers' ability to cope with the news of perinatal death as this determined whether they would give them the opportunity to see and hold the baby. However, where mothers insisted despite the nurse's concerns, they were given their babies to see and hold.

> *"Some of them [mothers] want to see the baby while some of them [mothers] don't want*
> *to…It depends on how the mother is. If I look at the mother and I see through her mood*
> *and physical appearance that she would not be able to console herself [if she sees the*
> *baby]. She would not be able to put herself together, if she sees the baby, I'll talk to*
> *her. I'll still console her that 'woman you don't need this [to see the baby], your*
> *[other]children need you now, they need you more so that you would not just invite*
> *unnecessary disease [health complications to herself]'. But if the patient insists, there's*
> *nothing I can do. I'll just gladly allow her to see her baby."* [Karioran]

However, seeing and holding was not practised by a few nurses who explained that they did not routinely show the babies to mothers, only if they insisted.

> *"No it's not routine [for mothers to see their baby]... If the wife [woman] is bold*
> *enough, [and] the wife insisted [sic] that she wants to see the baby, of course we show*
> *the baby to her that the baby is dead but, in most cases, you know in Nigeria, the*
> *husband would not even allow the wife to see such thing. It is the husband that will see*
> *and confirm that truly this is my baby and its dead."* [Bimpe]

Many nurses explained that they discussed it with mothers and offered the opportunity to see and hold the baby. However, all nurses explained that they always showed the babies to partners or appropriate family regardless of the mother seeing and holding the baby or not. This was to prevent complaints or accusations as highlighted in Theme 1.

> *"...there was an incident that the baby was ermmm inevitable…So the baby is dead already in the utero so when the mother expelled [birthed] the baby we wanted to show the mother. Immediately we wanted to show her, she said 'no no I don't want to see it'. I said 'you will see it, if you don't see it now, later you will come back to me to tell me what came out of you, the nurse did not show you'. I called the husband, the husband said 'no I don't want to see', [I said] 'one of you must see'. You talk to them, let them know the reason you're doing that. If the mother cannot see, the husband must or one of the relatives must see."* [Ireti]

Nursing mothers in a supportive environment

Mothers were monitored closely for health deterioration, by having regular physical observations such as blood pressure monitoring. Most nurses expressed that an understanding that nursing them on the same ward environment as those with living babies had a detrimental impact on the psychological state and grief of bereaved mothers. Thus, they were moved to separate wards such as gynaecological wards where other women without babies including those who may have also experienced perinatal death were admitted. However, there was no specific ward identified for the bereaved mothers. These nurses explained the rationale for the move was to limit the psychological effect that seeing a woman with her living baby may have on these mothers.

174

"If they [the woman] lost the baby… we normally transfer them from AA ward to GG ward [a] gynae ward, there is no baby there… because some if they are left with mothers that have their baby… they cannot stand it. They just have to get out of [that] ward when they see other women carrying their own baby and they have lost their own." [Yemisi]

Bereaved mothers were moved where possible to the same ward where they could form a peer support for each other whilst at the hospital, prior to discharge. This was considered to be a supportive approach by nurses.

"…we create a kind of a very roomy environment [on the ward]. We encourage them [mothers] to make friends among themselves, because you find out that some women, in fact they are like regular customers. They've had previous experience of losing a child [baby]…most of the time the patient themselves will even make your work easier once you tell them to interact with themselves because you see that all of them are having the same issue [experienced perinatal death], as long as they are in the same ward. So there's no way they won't relate…" [Moria]

However, it was not always possible to nurse them away from environments where there were living babies due to a lack of bed space. Thus mothers were nursed on wards that were deemed by nurses to be inappropriate for their grief experience and psychological wellbeing.

"If they [mothers] need extra care [following perinatal death]…we move them to postnatal ward but there is no space, there is no place [ward]…allocated for mother who do not have babies, no". [Bisi]

Managing psychological distress in mothers following perinatal death

Nurses identified that some mothers experienced psychological distress such as psychosis after becoming aware of the death of their baby. Consequently, they monitored all mothers closely for signs or symptoms of psychological distress. In circumstances where bereaved mothers presented with symptoms, doctors were informed prior to administration of sedative or anxiolytic medication, and monitored for 24 hours.

> *"...for people [mothers] that are... tilting towards irrational behaviour that's when we'll now give them all our sleeping pill [sedatives]."* [Kunbi]

The mothers who remained psychologically distressed after 24 hours were referred to psychiatrists for an in-reach visit into the hospital for assessment and treatment or a transfer to the psychiatric units depending on the severity. However, some nurses immediately referred to the psychiatrist for assessment and treatment. This reflects that nurses had differing understanding of when to involve psychiatrists.

> *"the consultant or the doctors on duty would send a consult to the psychiatrist... So the psychiatrist would come clerk her, [and] will place her on the drugs [medication] to use so that she will become more OK. So we continue to monitor her and give her her due drugs until she becomes better. If it is a case we couldn't manage, [on psychiatrist advice, the mothers are moved to the mental health unit for monitoring and treatment] ..."* [Dupe]

Emotional support provided to mothers by nurses

Nurses used the terms psychological, emotional support and counselling interchangeably in explaining their approach to consoling, encouraging and reassuring mothers. All nurses

consoled mothers using words of encouragement to instil hope immediately and after they are informed of the death of their baby. The emotional support offered by nurses was mainly conversational in nature.

> *"So basically, the psychological assurance is just the words of mouth, basically that we do. That's all. That's just it."* [Kunbi]

This involved encouraging bereaved mothers to move on from the death of their baby, to channel their thoughts differently and positively, and empathising with them. Some nurses encouraged mothers to be thankful that they were alive and did not have a baby with lifelong complications.

> *"We have to tell her that you have [she has] to be thankful because some people don't even come out of it alive.* [Moria]

Nurses had a sense of responsibility to console mothers, as opposed to doctors who seemed to have a distant role in the care of bereaved mothers.

> *"It's my role because I am the one on the ward with the patient, it is my ward…The doctors, they come and go. So, I am the one that sees like see the patient often. So it is my work, my role as a nurse to console the patient. The patient, the doctor will just come and leave, I stay there. For example, I do 8 hours duty, I do 24 hours. I stay with the patient so I know more about the patient even than the doctor. So its my role as a nurse to console the patient."* [Karioran]

The understanding of counselling differed amongst nurses. Some referred to this as emotional support whilst others explained this as health education to prevent a reoccurrence of perinatal

death. In relation to health education, the counselling offered was informed by the number of children that the woman already had.

> *"if the person [woman] already has like 4 children, we counsel her and tell her to go for family planning"* [Bimpe]

Nurses who had personal experiences of perinatal death or the loss of a loved one used this in consoling bereaved mothers, and it also influenced their approach to empathising and caring for them.

> *"…it has happened to me once, even though my own, it was due to prolonged second stage or labour and due to cord around the neck that is tightening the baby. It has happened to me; you will take it. God give, God take. It has happened to me once, that was 2005. Yes [her experience influences her caring for bereaved mothers]."* [Lobito]

The nurses without a lived experience of perinatal death attempted to put themselves in the shoes of mothers in order to support them effectively. One participant explained that their approach to supporting mothers was determined by the number of perinatal deaths the mother had experienced or the length of time they had been trying to conceive. Nurses identified another type of health care professional they could involve in providing support to bereaved mothers, known as social welfare staff who are trained social workers. The role of these individuals was identified by nurses as supporting bereaved mothers emotionally, and with social issues such as financial difficulties by seeking funding from different sources to pay or reduce their care bills when perinatal death occurred, but their input was limited to the hospital setting only.

> *"…we inform the social welfare department. The social welfare workers, whenever a woman lose [loses] her baby in the hospital, it is the work of a nurse, the nurse in [on]*

that ward to inform social welfare, in order to come and meet them [mothers] and speak

to them again, and console them about what happened" [Karioran]

Partners seemed to be isolated as there was limited emotional support given to partners by nurses, rather the entire focus was placed on caring and supporting mothers as highlighted by a majority of the nurses. A few nurses offered words of encouragement to them but on a superficial level in contrast to that given to mothers.

"Basically, we don't do anything to support the men, I won't lie. We just reassure them

together. We don't have any special package for the men because it's really the woman

that really feels most of this burden. We don't have much to say to the men because in

this part of the world, we just believe that men are stronger, so we don't really do much

much much like that. We don't do much, we don't." [Kunbi]

Theme 3: "*I take it on myself personally to follow mothers up after discharge*"

There was no routine follow-up offered by the hospital besides postnatal appointment for bereaved mothers after discharge. At discharge, mothers were invited to a 6-week routine postnatal appointment but this is not specific to those who experienced perinatal death and is also for those with living babies. This appointment solely focused on their physical health assessment and there was no specific record to indicate to attending staff that they experienced perinatal death.

"They call it postnatal check-up so after 6 weeks of delivery, they [mothers] will come

back. They [health care professionals] will check the position of the uterus, the Loki

and all that. So when they come like that [attend the appointment] we ask them some

questions since they've been discharged till when they came back, what has been

happening [with their health]. That will give you clue if there is any cause for alarm to

raise or they're okay. Its [the postnatal clinic] not specifically for those that lost their babies oh. There's no clinic for those that lost their baby. It's just general for those that delivered then…" [Ireti]

The majority of the nurses took up the responsibility on a personal level to provide follow-up in the community to mothers who experienced perinatal death, outside of their role. This involved nurses making telephone calls and/or visiting mothers at home in their own leisure time. This is because of their recognition of a need for continued support of mothers after discharge which is not offered by the hospital.

"No, it's [follow-up after discharge] not routine in Nigeria. But personally, I…take it upon myself to do that, yes." [Bimpe]

However, follow-up was provided to those with whom nurses had a good rapport, thus not all mothers received this support. This is because some mothers were identified by nurses as believing that they had ulterior motives when they offered follow-up support in the community to them, personally.

"There are some patients that you feel, it depends on their condition, you want to follow up with phone… There are sometimes you would want to get the contact of the patients then there will be another thing…. especially in this our Nigeria, they will think there is more to it so we tend to leave it as a nurse-patient relationship, you don't want to go more into details because of the social aspect of it. People will tend to believe that there is something you want to gain out of it or there is maybe or something, so you just want to leave it at that nurse-patient relationship." [Latifa]

Theme 4: **Impact of perinatal death on nurses and support available to them**

The effect of perinatal death was not limited to mothers but also extended to nurses. Nurses managed their own emotions and sought encouragement themselves when perinatal death occurred as there was no system in place within the hospital or management team to support staff.

> *"if you yourself know that you are feeling somehow [after perinatal death occurs] and you need someone to talk to. It is you that would find time and the person that you think you can discuss with."* [Ireti]

Nurses identified that they were only taught on providing bereavement care and coping with emotions when perinatal death occurs whilst undertaking their nursing training. They did not receive further training on this from their organisation.

> *"not like anyone would try to tell you how to handle the [emotions that comes with the] case. They believe you've studied in school and you already know the theoretical part [of providing bereavement care and managing own emotions]. They are just waiting for you to practicalize it so the hospital does not really have anything special [any specific training]. So we just have to practicalize what we have been taught in [nursing] school."* [Kunbi]

Most nurses who were emotionally affected by perinatal death mainly resorted to "letting it go" as a way of coping with the emotions. There was a feeling of sadness, and failure expressed by nurses whenever a baby died but they hid their feelings from mothers as they felt they had to remain "strong" to support them.

"I entered into the nurses' room, I was just crying like a baby. When I cried till I was satisfied, I used water to clean my face and I put on my smile again because I don't want the patient or client to know that I cried. It [the death of a baby] is highly demoralising, but you must not show it, you still have to wear your smiling face so that the patient will not see you crying because if you as a nurse are crying for such a thing, what do you want the client to do [how do you want them to cope?]" [Bimpe]

Some nurses spoke with their colleagues at work or their husbands after their shift for those who were married, or prayed, sang praises and read their bible.

"I console myself then I talk to my husband about it and…we just pray for the patient so that God can just console her and she can take that issue out of her mind. So, I talk to someone… especially my husband or my colleague when I'm at work so that…they will console me, talk to me so that at the end of the day, I will take it off my mind."
[Karioran]

A nurse expressed that they were able to move past the emotions immediately as they had many other patients to look after.

"I do feel bad [but] I behave normally. There's nothing.. If I see a mother going through such [perinatal death] no, that would not affect me, it. I feel bad but that doesn't affect what I do. I do everything normally. I attend to her, and others. I do everything I'm supposed to do normally." [Ireti]

6.5 Discussion

This study explored the experience of health care professionals in providing care and support to mothers and families in South-Western Nigeria following perinatal death. Nurses believed

they were pivotal in supporting mothers following perinatal death, therefore offered words of encouragement, physical presence, used personal experience of loss in consoling them, and involving external staff such as social welfare for additional support. However, this support given was based on the experience and practice of nurses as opposed to national or hospital guidelines or specific training as there was none available as explained by the nurses. Nurses felt that the only education that prepared them to provide bereavement care was their nursing training. This is similar to Mills et al.'s (2022) finding in their study in Kenya and Uganda on the experience of health workers caring for parents after stillbirth, who identified that nurses felt ill-prepared to provide bereavement support to mothers. It is important to consider the development of a bereavement care guideline and trainings within hospitals in South-Western Nigeria to adequately educate nurses which will contribute to robust and consistent support for all mothers. This is also in line with the RESPECT principle 8 for consensus on global bereavement care after stillbirth which suggests that healthcare teams are provided with comprehensive and ongoing training and support to contribute to high quality bereavement care (Shakespeare et al., 2020; Table 2).

Nurses believed they were sensitive in their approach to informing mothers about the death of their babies, driven by an aim to prevent health deterioration. This reflects that focus was placed on the physical as opposed to psychological health of mothers, as also found in studies in Iran (Allahdadian et al., 2016), South Africa (Modiba and Nolte, 2007), and Malawi (Simwaka, de Kok and Chilemba, 2014). However, partners were kept informed of concerns and diagnosis of perinatal death and shown the baby for confirmation of identity and death, to prevent legal actions against their practice and hospitals. Similar to our findings, Mills et al.'s (2022) study found that health care professionals had fears of litigation and complaints from families who falsely accused them of selling or exchanging their baby for another who had died. Thus, this

reflects that nurses practised seeing and holding the baby with partners and where possible mothers, as a protective measure against such issues. In addition, this is also because nurses regarded partners as "stronger" in contrast to mothers. This is a social and cultural belief in high and low- and middle-income settings that men have a "masculine" characteristic which is the ability to manage and cope effectively with grief in contrast to women (Bonnette and Broom, 2011; Mills et al., 2020; Roberts et al., 2017; Avelin et al., 2013; Kelley and Trinidad, 2012). Thus, similar to Shakespeare et al. (2018), Matsikwa's (2019) study found that nurses focussed solely on mothers, thus there is a lack of bereavement care for partners. This demonstrates a need for further research into partners' experiences to influence the development of appropriate strategies to support them. In relation to the RESPECT principle (2) which suggests that respectful maternity care to bereaved mothers, their families and babies should be provided (Shakespeare et al., 2020; Table 2). Our findings reflects that some effort was made by nurses in promoting this principle but there is still significant work to improve the bereavement care and support provided to bereaved mothers and their families.

The findings of this study also highlighted that many nurses were at times apprehensive of mothers seeing and holding their baby due to concerns that this intervention may worsen their grief experience but were led by mothers' preference. This apprehension may have been influenced by cultural beliefs which does not support this practice, as identified by Mills et al. (2020), Ayebare et al. (2021) in Uganda and Kenya and Kuti and Ilesanmi (2011) in Nigeria. Thus, seeing and holding their deceased baby is not embraced in some sub-Saharan African countries, in contrast to high income settings such as the UK where the practice is encouraged for both parents, on the basis of its benefit of improved outcomes but harm of higher levels of psychological distress has also been associated with this (Mills et al., 2020; Flenady et al., 2014; Redshaw, Hennegan and Henderson, 2016). However, the RESPECT principles also

highlight the need for staff to have an acknowledgment of the depth and variety of normal grief responses following the death of a baby and provide appropriate emotional support in a supportive environment which may include seeing and holding their deceased babies (Principle 5; Shakespeare et al., 2020; Table 2). Thus, there is a need to review this practice within the Nigerian setting.

Another finding from this study linked to the RESPECT principle 5 is that nurses had consideration of the ward environment where mothers were cared for, following perinatal death (Table 2). This is an approach appreciated by many bereaved mothers, as identified by Ellis et al. (2016) in their systematic review of studies on care following stillbirth from high income countries, who preferred to be nursed away from living babies and their mothers. Nursing mothers on a more appropriate ward was hindered in some cases by a lack of space, as also highlighted in Mills et al.'s (2020) findings. This could be addressed by having a designated ward for mothers who experienced perinatal death however due to the financial constraints of the healthcare system, this may prove difficult in sub-Saharan African countries such as Nigeria.

Recognised follow up support in the community specifically for bereaved mothers and their families following discharge from hospital, besides routine postnatal appointment, was non-existent but regarded to be important by nurses. This was also found by Matsikwa's (2019) study on management of perinatal death in Zimbabwe and Shakespeare et al.'s (2018) systematic review of studies in low- and middle-income countries. Gandino et al's (2019) study and Lisy et al.'s (2016) metasynthesis of studies in high income countries such as the UK, Sweden, Canada, United States of America (USA) on the provision of care following perinatal death identified that support should continue after hospital discharge and in the community. The need for adequate postnatal care and ongoing support has also been proposed by the

RESPECT principles (Table 2). Principles 6 and 7 state respectively that staff should "o*ffer appropriate information and postnatal care to address physical, practical, and psychologic needs, including a point of contact for ongoing support*" and "*provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow- up*" (Shakespeare et al., 2020, p.146; Table 2). The majority of the nurses in this study recognised this need and took personal responsibility to provide follow-up outside of their role and the hospital. This support was led by the rapport between nurses and mothers, and their reception of the follow-up. Therefore, this reflects that not all mothers are in receipt of follow up from nurses. There is a need for a recognised and consistent approach within the health care system in South-Western Nigeria to relieve the onus on nurses to provide follow-up outside their role but also widen the scope where more mothers are supported by health care professionals after discharge. However, it is recognised that this may be difficult to achieve due to poor resources within the health care system to provide support outside of the hospital setting.

Nurses also felt emotionally affected whenever a baby died which reminded some of them of their own personal experience of perinatal death which they then used in supporting mothers. Perinatal death evokes feelings of pain and sadness in nurses who felt compelled to hide their emotions from mothers to effectively care for them. There were also limited to no measures or organisational policies in place within the hospital to support nurses when perinatal death occurred, and they demonstrated resilience and sought other avenues to address their own feelings such as family or colleagues. Mills et al.'s (2022) study, and studies by Petrites et al., (2016) and Modiba (2008) in Ghana and South Africa respectively also highlighted this finding and identified a need for effective support measures including training, policies and guidelines to help nurses cope with perinatal death when it occurs.

186

Table 2: FINAL PRINCIPLES FOR CONSENSUS ON GLOBAL BEREAVEMENT CARE AFTER STILLBIRTH

1	Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities
2	Provide respectful maternity care to bereaved women, their families, and their babies
3	Support women and families to make shared, informed, and supported decisions about birth options
4	Make every effort to investigate and identify contributory factors to provide an acceptable explanation to women and families for the death of their baby
5	Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment
6	Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment
7	Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow- up
8	Enable the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the healthcare team

(Shakespeare et al., 2020)

6.5.1 Strengths and Limitations

Only nurses were included in this study because of the difficulties in recruiting other professionals such as doctors and social welfare staff which could be deemed as a limitation. Recruitment of other professionals was hindered, despite efforts by the researcher, by the virtual nature of the study thereby making it difficult to have a wider reach of participants. Nonetheless, having solely nurses as participants in this study is a strength as it allowed a greater focus on their experience. In addition, nurses worked on a rotational basis within federal government hospitals in Lagos, and some had previous experience of working in private facilities. Thus, they brought their diverse and rich experience to the study. The researcher being a nurse also helped create a better rapport with participants, as there was a shared characteristic. Another limitation in this study was the loss of some participants who did not keep to interview dates or experienced network difficulties that hindered telephone interview from taking place. The researcher addressed this limitation by sending text messages to rearrange the scheduled interviews and placing a call through at a later time. However, some participants did not respond, even after two attempts. Due to the COVID-19 pandemic, some interviews had to also be rescheduled because of the demands on nurses during the time. Thus, these elements contributed to lost time during the recruitment of nurses.

6.6 Conclusion

Nurses play a significant role in caring and supporting women who experience perinatal death. Nurses carry a dual burden of caring for mothers at hospital and providing follow-up outside of their role to mothers in the community. Consideration should be made by the healthcare system into the provision of follow up care after hospital discharge thereby improving outcomes. In addition, nurses aim to support mothers effectively, both emotionally and

physically, but this was often based on their experience and knowledge as opposed to recognised guidelines. National guidelines need to be developed to promote consistency of care and support following perinatal death within the hospital and in the community setting. Furthermore, bereavement care needs of partners require some recognition in this region thus research should be undertaken to understand their experience and develop approaches to improving the grief experience following perinatal death. This will support nurses in providing care and support rooted in evidence-based literature, thereby ensuring a consistent approach to all mothers, and effective follow-up following discharge. Further research is also required into the perspectives of other health care professionals for wider understanding.

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7 Chapter 7: Discussion and Conclusion

7.1 Aim and Phases of the Thesis

This thesis aimed at exploring the lived experience of care and support following perinatal death in South-Western Nigeria. In achieving this, there were two phases; (i) a metasynthesis to synthesise existing literature on the care and support of women following perinatal death in countries with high rates of neonatal death and stillbirth (high burden settings) to reveal new understanding and interpretation; (ii) a hermeneutic phenomenological study, using semi-structured interviews to explore the lived experiences of women, families and health care professionals of care and support following perinatal death in South-Western Nigeria. This thesis is presented in the alternative format, and contains chapters on the introduction, background, methodology, and three (3) papers, one of which has been published and two which are prepared for submission for publication. This chapter gives a discussion of the findings, strengths and limitations of the study, and recommendations.

7.2 Paper 1 – Women's experiences of care and support following perinatal death in high burden countries: A metasynthesis.

This paper (1) presents a metaethnographic metasynthesis of women's' experiences of care and support following perinatal death in high burden settings. This was essential in developing an understanding of the knowledge of existing studies and revealing new reinterpretation from their findings. This contributed to the foundational basis on which Papers 2 and 3 studies were developed and undertaken. This paper utilised a systematic search in identifying 8 studies that explored the topic of interest, and Noblit and Hare's (1988) approach was used in synthesising and critically reinterpreting the findings. This metasynthesis revealed that women in high burden settings have a mostly negative experience of care and support following the death of

their baby. This negative experience is mostly as a result of women and their families' cultural beliefs, lack of societal understanding and knowledge of medical reasons for perinatal death. Thus, women were "isolated in their loss" which has the potential to significantly impact their psychological wellbeing.

7.3   Paper 2 - An exploration of women's' lived experiences of care and support following perinatal death in South-Western Nigeria: A phenomenological study.

Paper 2 (Chapter 5) explored the lived experience of women, and families of care and support following perinatal death in South-Western, Nigeria. In this study, 14 women who had experienced perinatal death were recruited from a support group and a federal government hospital in Lagos, Nigeria. Hermeneutic phenomenology informed this study and steps as highlighted by Van Manen (1990) were used in analysing the data. This study found that communication was not satisfactory for mothers as they experienced delays in being informed of the death of their baby. Most mothers preferred to be made aware of concerns and status of their baby immediately. Deception was used in instances where there were health concerns, which caused upset to mothers. Nurses, however, deemed this necessary to prevent further health deterioration as they viewed it as their role to prevent harm to the mothers. Some mothers were appreciative of the use of deception as they felt being informed immediately may have had significant impact on their physical health. On the other hand, nurses identified that in the absence of health concerns, they informed mothers immediately. Therefore, deception seemed to be an approach used by nurses in supporting mothers till they attained stable health to bear the news of the death of their baby. Mothers were not satisfied with the care they received from health care professionals. Not all mothers wanted to see or hold their baby, but this was found to be imposed on majority of them by health care professionals to uphold the hospital policy as opposed to being a supportive measure. Conversely, nurses explained that

196

they discouraged mothers from seeing and holding their deceased babies due to concerns that such intervention may trigger further psychological difficulties. However, majority of the nurses also explained that either the mother or a family member had to see the baby to confirm identity and prevent allegations of exchanging or selling their babies. Bereaved mothers also felt that health care professionals were distant from them, in contrast to mothers who had living babies. Nurses were perceived to have closer interactions in contrast to doctors, but bereaved mothers felt this was superficial. Nurses agreed that they have closer interactions with bereaved mothers, but most believed that they spent sufficient time with to console them and provide emotional support following perinatal death. This reflects that nurses perhaps do not have a good understanding of the level of interactions that mothers deem sufficient and supportive. Nonetheless, physical care was satisfactory for majority of the mothers, but emotional support was not sufficient. Following discharge from hospital, mothers felt abandoned by health care professionals as they did not provide follow-up contact in the community. However, some mothers received follow-up support from nurses with whom they had developed a personal relationship whilst they were at the hospital. Nurses identify that this is a gap that needs to be filled but is not due to lack of resources. Therefore, where possible, outside of their role, nurses provided follow-up support on a personal level outside of the hospital. Family including partners, mothers and mothers-in-law were regarded as a consistent source of support by mothers following perinatal death and on discharge. Mothers felt that partners were often compelled to be a source of support for mothers despite also being affected by the death of their baby, but this meant that they had to supress their feelings and experience of grief. However, not all mothers were supported by their partners, rather they experienced a breakdown in their relationship.

Overall, women's experience suggested a lack of understanding of their needs by health care professionals. This shows that it is imperative that health care professionals receive adequate training in providing bereavement care to mothers. This will help create a better understanding of ways to support mothers who experience perinatal death. In addition, follow up support in the community after discharge requires more attention as this can be key to limiting the short- and long-term impact of their baby's death on them. It was also important to undertake a study to understand from the perspective of health care professionals, the care and support they provide to mothers and families following perinatal death as addressed in paper 3. This will be vital in making recommendations to improving the bereavement care and experience of mothers and families following perinatal death.

7.4 Paper 3 - An exploration of health care professionals' lived experiences of care and support provision following perinatal death in South-Western Nigeria: A phenomenological study.

Paper 3 (Chapter 6) explored the experience of care and support following perinatal death from the perspective of health care professionals who provided this to bereaved mothers and their families in South-Western Nigeria. Fifteen nurses were recruited from a federal government hospital in South-Western Nigeria. The data from the semi-structured interviews were analysed using the same approach as in Paper 2 (Chapter 5). This study found that nurses felt they were sensitive in their approach towards informing and supporting mothers following confirmation of their baby's death. They perceived that they were considerate of the physical health of mothers when considering the time and approach to inform mothers of the death of their baby to prevent a deterioration in health after breaking the news. Most mothers did not agree with this notion but felt that health care professionals could have taken a better approach at informing them of the death of their baby. However, partners were informed immediately and

shown the babies, but this was to prevent complaints and legal actions against their practice and the hospital. Partners were isolated as nurses did not feel they had to provide them with any emotional support based on their belief that they are "strong" and can cope with the grief of perinatal death. Nurses perceived that they were very supportive of mothers in grieving effectively, by giving them sufficient time and space, but also consoling and encouraging them. This is a differing view from that expressed by mothers who felt that health care professionals particularly nurses were distant due to the absence of a living baby. In addition, mothers felt that the support offered by nurses was superficial. However, many nurses expressed that the knowledge that they used in supporting bereaved mothers was gained during their nursing training and from their years of practice. This reflects that nurses provided bereavement care using knowledge that may be outdated, and there was a lack of training provision on this aspect from the hospital organisation. Those who had personal experience of perinatal death used this to shape their approach towards consoling and encouraging mothers. Nurses were often not supportive in showing mothers their deceased babies, which was often driven by their cultural beliefs. This is an aspect in which mothers expressed dissatisfaction as they preferred to have been given the opportunity to see and hold their babies. However, where mothers insisted and to confirm the identity and death particularly in the absence of partners, mothers were given their babies to see and hold. Social welfare staff were also involved in providing emotional and social support whilst mothers were still in the hospital. There was also consideration made for the environment within which bereaved mothers were nursed to reduce the psychological distress that may be caused by the presence of mothers with living babies on the same ward. This was often hindered by a lack of space as there were no designated wards for mothers who had experienced perinatal death. This highlights the difficulties that a lack of resources in health care provisions poses to mothers, and nurses.

Perinatal death in some cases led to some mothers experiencing significant psychological distress requiring psychiatric care. Thus, based on their knowledge of this, nurses assessed mothers closely for symptoms of psychological distress in order to provide immediate care such as involving psychiatrists earlier. Nurses carried a dual burden of providing care and support at the hospital and follow-up support on discharge in the community outside of their role. Mothers were often very receptive and appreciative of the follow-up support offered by nurses outside of their role and on a personal level. Thus, the need for follow-up support on discharge is a gap in the literature that needs to be addressed and may contribute to the outcomes of bereaved mothers. This study also found that nurses were affected by perinatal death but managed their feelings via other avenues such as support from colleagues and family, as there were no provisions within the organisation to support them. Therefore, this reflects the need for further attention to be paid to support for nurses in managing their feelings when perinatal death occurs.

7.5   Conclusion

There were some contrasting and shared perceptions and understanding between all studies (Papers 1, 2 and 3) in this thesis. The study with women (Paper 2) was reflective of the findings of the metasynthesis where mothers felt dissatisfied with the care and support, they received from health care professionals. Dissatisfaction was a common theme amongst mothers which is reflective of their notion that the bereavement care from the communication to the interaction from health care professionals was inadequate. Mothers had an understanding that they were of lesser priority in contrast to those with living babies as identified in the metasynthesis and study with women (Paper 2). However, nurses in Paper 3 perceived that they provided adequate attention, were cautious and sensitive in their approach to support mothers following perinatal death. This led to them employing strategies such as deception and delays in information

sharing to prevent physical health deterioration as a result of informing mothers that their babies had died. However, most mothers interpreted their strategies as insensitive. Mothers expressed a lack of opportunity to discuss their baby's death in depth particularly from doctors, which is not reflective of nurses' understanding that they provide sufficient time to have this discussion and give health education to prevent a reoccurrence. Seeing and holding the baby was not embraced in these studies, despite evidence from HIC advocating this practice based on it benefits, and mothers were often dissuaded by family and health care professionals from having contact with their deceased babies. This was often based on the cultural beliefs of mothers, their families and nurses which did not support the practice. However, seeing and holding was practiced by nurses as a precautionary measure against complaints. This highlights that these nurses in contrast to those in HICs had limited understanding of the benefits of promoting the seeing and holding of their babies for mothers, but mainly believed that it carried more risks of psychological harm to them. Nurses perceived that their approach was effective and adequate. Thus, this presents that the approach of health care professionals did not match the support needs and preferences of mothers. Furthermore, it shows that the level of emotional connection from nurses with mothers was not in depth, thereby hindering their ability to identify their care and support needs. Partners were acknowledged by mothers and nurses as being unrecognised in the provision of support based on the assumption that they are "strong". It has been identified in the literature that this is a false assumption which places partners at a disadvantage. Therefore, this shows that the needs of mothers and their partners were not understood by nurses in managing their grief. Furthermore, the dissatisfaction of mothers is reflective of health care professionals' approach being outdated which is in line with nurses' explanation that they received no training on bereavement care from the hospital other than in their nursing training. This need for appropriate training of health care professionals in all care

settings on respectful bereavement care following perinatal death has been emphasised on a global scale by the Lancet Ending Preventable Stillbirth Series (Flenady et al., 2016; Heazell et al., 2016). This unavailability of trainings for nurses as shown in these studies may be indicative of the lack of resources within the health care system which does not make allowance for appropriate training of nurses in bereavement care following perinatal death. The lack of resources is also acknowledged by nurses as impacting on care provision such as follow up support following discharge, which was also highlighted and desired by mothers. However, nurses maintained that they provided adequate support within the limited resources available to them. In relation to nurses, they felt unsupported by the hospital as there were no recognised avenues of support for when they encounter mothers following perinatal death. There is a need for further resources within the health care system to enable appropriate development and implementation of interventions to promote adequate bereavement care support in South-Western Nigeria.

7.6   Strengths, Weaknesses and Limitations

These studies aimed at understanding bereavement care following perinatal death as provided in healthcare facilities and after discharge from hospital in one of the countries in sub-Saharan Africa that carries the highest global burden of neonatal death and stillbirth. The metasynthesis in this thesis was conducted in a rigorous and systematic manner using meta ethnography in synthesising and critically reinterpreting the findings, whilst ensuring that the voice of participants in the included studies remained evident. This is a strength as the metasynthesis did not aggregate findings but delved deeper into the existing understanding to reveal new meanings. It is the first metasynthesis exploring the experience of care and support following perinatal death in high burden settings. As there were only eight (8) studies identified and included, this shows that this is an area that is under-researched in settings with high rates of

perinatal death. Therefore, this metasynthesis is a first step into this area. The metasynthesis informed the qualitative hermeneutic studies (Papers 2 and 3) in exploring the lived experience of care and support following perinatal death from the perspectives of women and health care professionals. The qualitative studies utilised hermeneutic phenomenological methodology which aided the researchers' exploration and interpretation of the experiences of women and healthcare professionals whilst remaining within the context of the participants' narrative. The purposive sample of women was drawn from two sources, one hospital and a support group. The use of these two sources supported the rigour (transferability) of the study to other populations where possible. The health care professionals (nurses) were from a single source, the largest maternity hospital in South-Western Nigeria. This may be viewed as a limitation, but it is also a strength as nurses work on a rotational basis. A majority of the nurses had worked at other federal government hospitals and some previously at private hospitals, therefore they brought their vast knowledge and experience to the study. Nonetheless, if the researcher had been able to access other hospitals, this would have created a wider base of knowledge and experience. The ability to conduct the research virtually via telephone semi-structure interviews while taking advantage of technological advancement during a pandemic is a strength of these studies. This also meant that participants were interviewed in their own chosen environment, which would have been the case if the interviews were conducted in person. The interviews were conducted in English and Yoruba which the researcher is fluent in, depending on the preference of the participant. This meant that the participants were able to comfortably converse and narrate their experience to the researcher, ensuring that the true context is preserved, and rich in-depth data is gained.

There were some limitations in these studies, many of which were due to the COVID-19 pandemic. In Paper 2 (Chapter 5) the researcher aimed to recruit partners and family members

who were closest/offered most support to the mothers following perinatal death. For many of the mothers, this was their partner, but this group of individuals were difficult to recruit virtually. The researcher attempted to recruit via mothers (snowballing sampling) but (1) they did not wish to let their family know they were taking part in the study, and (2) partners who were approached refused to take part (Archarya et al., 2013; Emerson, 2015). These partners declined participation on the basis that they did not wish to speak about their experience. Attempts were made to also recruit family members via Postpartum Network support groups and the hospital, but they were unable to reach family members without the women. Thus, snowballing approach to recruitment was considered but did not prove effective. This was particularly difficult as some mothers did not want family members to know that they were taking part in the study. This seemed to be associated with the feeling of shame that is associated with perinatal death in Sub Saharan Africa where stigma remains in relation to the loss (Adebayo, Liu and Cheah, 2018). It is not felt that other alternative strategy could have enabled the recruitment of these groups of individual because this was significantly impacted by the virtual nature of the research due to COVID-19 restrictions. If the research was conducted in person, other recruitment strategies may have been considered to increase chances of recruiting these individuals.

In Paper 3, only nurses were recruited for the study. The researcher attempted to address this limitation by liaising with the contact person to widen the reach to other healthcare professionals. Two doctors had given consent to take part in the study but did not keep the appointment for the interview, and no other doctor expressed interest. Social welfare staff were also difficult to recruit as they were hard to reach virtually. This limitation may have been mitigated had the researcher been present in Nigeria during the recruitment and data collection phase. There were some participants who were lost following arrangement of interviews, as

they did not keep to the time or were unreachable at the agreed date and time, and on subsequent days. This may have been influenced by the researcher conducting the interviews virtually, and a lack of a physical presence to develop a better rapport.

7.7 Implication for Policy and Practice

The metasynthesis revealed that women are "isolated in their loss" following perinatal death due to the inadequate bereavement care and support. Perinatal death is recognised as psychologically and emotionally challenging but there is little acknowledgement of the grief experienced by mothers, and their families in high burden settings. In this thesis, it was identified in Paper 2 that women did not feel appropriately supported by health care professionals when their babies died. They often felt that they were less of a priority in contrast to mothers with living babies. In addition, greater focus was placed on physical health than psychological needs. Psychological support following perinatal death has been found to improve the health and wellbeing of mothers (Shaohua and Shorey, 2021; Fernandez-Ferez et al., 2021). Therefore, this calls for attention as it is imperative that the psychological impact of perinatal death on mothers is recognised and given priority within the care and management policies in health care systems in Nigeria. There has been some consideration of this in high income countries such as the UK (NICE, 2014). Paper 3 identified that nurses did not provide care based on a recognised guidelines when supporting mothers who experienced perinatal death as such guidelines do not exist. Nurses bore the notion that it was their responsibility to be physically and emotionally present for mothers, but not for the families. These studies reflect that nurses' perception that they support mothers as much as possible within the health care facility but recognise a lack of continuation of bereavement care and support in the community. There is a need for relevant and specific bereavement care training jointly developed by mothers and health care professionals, to be provided but not limited to nurses within the health

care system in South-Western Nigeria. This will help to adequately equip nurses when perinatal death occurs and promote consistency of care for all mothers. There is also a need for families including partners to be considered when providing support as they also experience the impact of perinatal death. Follow-up care on discharge from hospital also needs to be explored to ensure that mothers and their families receive ongoing bereavement support beyond their hospital admission. The findings of these studies identified that the input from healthcare professionals does not go beyond discharge from hospital. Thus, there is a need for better awareness within health care systems and facilities of the risks posed to mothers and their families in the absence of robust bereavement care and support both before and after discharge. This can be achieved by way of participatory action research for example, through establishing current knowledge and re-educating health care staff on the risks and developing specific educational programmes or training to equip them in providing tailored bereavement care and support to mothers, partners and families following perinatal death. This will also inform the community and society where the professionals can educate women and family members who have a poor understanding of perinatal death, thereby introducing a cultural shift from stigmatising to supporting mothers. This may be facilitated via postnatal clinics, and community outreaches.

Health care professionals, particularly nurses have recognised a gap in the support for mothers on discharge and believe it essential for this to be provided. Although numerous nurses undertake this on a personal basis, this is not offered to every woman as it is not routine, or hospital led. Thus, tailored follow-up care and support following discharge from hospital should be developed and incorporated as a routine for those who experience perinatal death. However, it has been identified in Nigeria that the expenditure on health care is significantly low which means that the insufficient resources maybe a major contributory factor regarding

the availability of resources and development and implementation of bereavement care interventions.

7.8   Implications for Research

This study creates a foundation for further research as it is the first qualitative hermeneutic study to explore the lived experience of care and support following perinatal death in South-Western Nigeria from the perspective of mothers and health care professionals. It revealed a dearth in the literature on this topic area particularly in areas of high burden such as sub-Saharan African countries. There is a need for further studies into the perspective of other health care professionals such as doctors and social welfare staff who may also provide care and support when a baby dies. The experiences of partners and other family members of receiving care and support, and their perceptions should also be studied. These will create a further insight into the care provisions at present and inform strategies for improvement. This knowledge would contribute to identification of areas where focus should be placed in the development of trainings and interventions in bereavement care. This will ensure health care professionals are well trained to identify the preferences and meet the bereavement care and support needs of mothers, partners and their families following perinatal death. This will also equip staff to provide person-centred bereavement care using updated and evidence-based approaches and promoting collaboration in care and support. In addition, further research will influence the development of appropriate support structures within hospital organisations for health care professionals in managing their emotions following perinatal death. This will also inform the facilitation of coproduction sessions between health care professionals and women to identify and address concerns regarding care and support following perinatal death within health care systems. The outcomes of these sessions will also contribute valuable knowledge to improving the care provided to bereaved mothers and their families. Thus, there should be

207

an increased involvement of women, partners and their families in research, development of and improvement of interventions within the hospital and health care system.

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Appendix 1: Quality Assessment Grading Key.

Quality Assessment Grading Key.	
Grade A	Article has few or no flaws thus concluding that the credibility, transferability, dependability and confirmability are high.
Grade B	Article has some flaws but they are unlikely to affect its credibility, transferability, dependability and confirmability.
Grade C	Articles have some flaws that can affect its credibility, transferability, dependability and confirmability
Grade D	Articles have significant flaws that will likely compromise credibility and transferability of the study.

(Walsh and Devane, 2012).

Appendix 2: Topic Guide (Health care professionals)

Topic Guide (Healthcare Professionals)

Exploring the view of women and their families and health care professionals on the lived-experience of care and support following perinatal death in Nigeria.

The researcher will commence with an introduction by giving another explanation of the study including its aims, objectives and processes to the participant. The participants will also be given an explanation of their rights within the study. The participants will also be reminded that their participation is confidential to ensure that they are fully informed and comfortable with taking part in the study. Before the interview commences, participant will be asked to sign the consent form, complete a short demographic form with the participant and choose a pseudonym of their choice. The researcher will introduce herself to the participant and provide an explanation of how the interview is going to run.

Participants will be offered a drink of water.

The audio recorder will be checked at this point and recording will commence.

Icebreaker

- What is your role?

- What does a typical day in your role involve?

- How are you involved in caring for the babies and mothers?

1. **Can you tell me about the care that you provide to women and families who experience the death of their baby?**

    a. *How do you inform women and their families about the death of her baby and how are they nursed after the death whilst still in hospital?*

    b. *What physical care and emotional support provided to the women?*

    c. *How long are they cared for in hospital?*

    d. *What steps are taken to help the women and their families cope with the death of their baby? (researcher's note -seeing or holding, offer for an autopsy)*

    e. *How do you involve the women and family members in the decision making around the death of their baby?*

    f. *What specialist services do you offer to help them cope with the death of their baby?*

    g. *How are women and families advised regarding the death of their baby and possible future pregnancies?*

    h. *How do you follow-up with the women (and their families) after discharge and what does this involve?*

2. **Can you tell me about how you feel when a baby dies?**

    a. *How does the death of a baby including the circumstances of the death (before, during or after birth) affect you personally and professionally? What are your feelings/experiences when this occurs?*

    b. *How does this affect your approach to care?*

c. *How does cultural beliefs influence the care you provide? How does your personal belief and experience influence your response towards the woman and her family? e.g. being a parent yourself or experiencing death of a loved one?*

d. *How does this affect your life outside of work?*

3. **How do you cope with your experience/feelings when a baby dies and you care for the woman/her family?**

   a. *How do you manage or express your feelings about the death?*

4. **Can you tell me how the women and families feel about the care they are given when their baby dies?**

   a. *What feedback do they give about the care?*

5. **Can you tell me about how your organisation/hospital helps you manage the death of babies?**

   a. *How does your organisation/hospital help you through these feelings e.g. supervision, counselling, debrief from colleagues or senior colleagues?*

6. **Can you please tell me how the hospital prepares you for the role of caring for women whose babies die?**

   a. *What are the policies and guidance in place for managing the death of a baby and caring for the women and their families?*

   b. *What trainings are you given in responding to the needs and providing care, particularly emotionally, to women and families who experience the death of their baby?*

In conclusion;

- Is there anything else you would like to talk about that I have not asked you?

Researcher will summarise the interview to the participant.

Debrief/Check-in

How are you feeling at present?

Are you feeling OK?

Thank you very much for taking part in this study.

Appendix 3: Topic Guide (Women)

Topic Guide (Woemn)

Exploring the view of women and their families and health care professionals on the lived-experience of care and support following perinatal death in Nigeria.

The researcher will commence with an introduction by giving another explanation of the study including its aims, objectives and processes to the participant. The participants will also be given an explanation of their rights within the study. The participants will also be reminded that their participation is confidential to ensure that they are fully informed and comfortable with taking part in the study. Before the interview commences, participant will be asked to sign the consent form, complete a short demographic form with the participant and choose a pseudonym of their choice. The researcher will introduce herself to the participant and provide an explanation of how the interview is going to run.

Participants will be offered a drink of water.

The audio recorder will be checked at this point and recording will commence.

Icebreaker

- How are you today?

- How did you find the journey here today? (If they travelled to a different location from their home)

7. **Can you please tell me about the pregnancy and birth of your baby?**

a. *How did you find out you were pregnant and was it expected/planned?*

b. *What was your experience of the pregnancy?*

c. *What was your birth experience like?*

8. **Can you tell me about the circumstance around the death of your baby?**

a. *How did you find out about the death of your baby?*

b. *Did you feel that you could mourn your baby?*

9. **How did you feel about the death of your baby?**

a. *Can you explain the emotions or feelings that you had/have now?*

b. *How did you express and cope with these feelings?*

(researcher's note - Religion, faith, family, self-medication, pursuance of another pregnancy, keepsake from your baby)

c. *How did you feel that your cultural and religious beliefs helped with your feelings or do you feel it did not?*

d. *How did you feel that the health care professionals recognise and understand your feelings and experiences?*

2. **How did your family/friends respond to the death of your baby?**

a. *How did you feel about their response?*

b. *How did you feel about speaking about the death of the baby with them?*

3. **Can you explain how your family/friends helped you cope with the death of your baby?**

a. *How did they help you cope with not having your baby physically with you at home?*

b. *How did they help you cope with the feelings you had about the death of your baby?*

c. *How did any cultural beliefs help or worsen your experience of the death of your baby?*

d. *How did their help contribute (or not) to managing your experience of the death of your baby?*

10. **What was your experience of the healthcare professional's care after and response to the death of your baby?**

a. *How were you informed about the death of your baby?*

b. *How did you know the roles of the health care professionals involved in you and your baby's care when the baby died?*

c. *What information were you given about the death of your baby and what was the language like?*

d. *What were you told about what led to your baby's death?*

e. *What explanation were you given about the processes or actions to be taken after your baby died and how involved were you in making decisions about your baby?*

11. **Can you tell me if and how health care professionals helped you cope with the death of your baby?**

a. *What steps were taken to help you manage the death of your baby? (researchers note - opportunity to see and hold your baby?) Can you talk me through the care and support that you received at the hospital?*

b. *What care and support did you receive after you were discharged from the hospital?*

c. *What did you think about the level of knowledge of the healthcare who helped you through the difficult time?*

d. *What else could they have done better or less of?*

In conclusion;

- Is there anything else you would like to talk about that I have not asked you?

Researcher will summarise the interview to the participant.

Debrief/Check-in

How are you feeling at present?

Are you feeling OK?

Thank you very much for taking part in this study.

Appendix 4: Participant Information Sheet (Women)

Participant Information Sheets (Women)

Exploring the view of women and their families and health care professionals on the lived-experience of care and support following perinatal death in Nigeria.

Participant Information Sheet (PIS)

You are being invited to take part in a research study which aims at exploring the view of women and their families and health care professionals on the experience of care and support following the death of a baby either during, before or shortly after birth in Nigeria, a research project for the fulfilment of a doctorate degree. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others or the researcher if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➢ **Who will conduct the research?**

Omotewa Kuforiji, a researcher at the Division of Nursing, Midwifery and Social Work, The University of Manchester, United Kingdom.

➢ **What is the purpose of the research?**

The death of a baby before, during or shortly after childbirth is a prevalent occurrence all over the world, particularly in sub-Saharan African countries such as Nigeria. Experiencing the death of a baby is a very traumatic and saddening occurrence with profound effects on women and also family members. Therefore, this research aims at understanding the experience of care and support that women and their families receive from health care professionals after the death of a baby before, during or shortly after birth in Nigeria. This study is being undertaken in order to fill the gap in the literature on the experiences of women and their families of care and support received (if any) following the death of their baby in Nigeria. Furthermore, this study aims to inform the health care professionals of the perspectives of women like you (and their families) on the current provisions of care and support being offered following the death of a baby.

You are being asked to take part in the study because you have experienced the death of a baby before, during or shortly after childbirth and have been cared for in one of the hospitals in Lagos, Nigeria. I would like to speak with about 15 women who have experienced care and support following perinatal death; I would also like to speak with your family member who you believe was most supportive during the time of the death of your baby.

➢ **Will the outcomes of the research be published?**

The findings of the research will form part of the researcher's thesis. They may also be published in applicable journals. Please note that your identity will be completely protected in the reporting of the findings. You will be informed of the findings if you express an interest in this.

➢ **Who has reviewed the research project?**

The project will be reviewed by The University of Manchester Research Ethics Committee.

What would my involvement be?

➢ **What would I be asked to do if I took part?**

You have been given this information sheet to keep and go through again in your own time. If you have given consent for the researcher to contact you, they will contact you to give you further information about the study and an opportunity to answer any questions you may have. After 24 hours of receiving the explanation, the researcher will contact you again to ask if you have chosen to take part in the study or not. If you choose to take part in this study, the researcher will arrange a suitable date, time and location for an interview. You will also be asked for the permission to speak with your family member. If you do not give consent to speak with your family member, this would not affect you or your participation in this study.

Due to the COVID-19 situation, the interview will be held over the phone. Prior to starting the interview, you will be given another explanation of the study and an opportunity to ask further questions. At the start of the interview, you will be asked to give consent to take part in the study and will be given a verbal explanation of the points on the consent form. You will be asked to say verbally that you agree to take part voluntarily in the study and this will be audio-recorded using an encrypted audio-recorder. Your interview will not be recorded on any other device or apps. During the interview, you will be asked to discuss your experience of care and support following perinatal death.

The interview can be up to an hour and a half long and will be audio-recorded by the researcher. It is essential for the researcher to audio-record all interviews to capture your experience exactly as it has been given by you. It is important that you are comfortable with the recording

process at all times. If at any point you are distressed during the interview, you can ask to stop the recording or take a break.

You will only be required to do only one interview.

As this study is about a sensitive topic area, the death of your baby, there is a chance that you may become distressed during the interview when remembering your experiences. If this happens, the researcher as a mental health professional will offer you immediate support and following the interview if appropriate will be supported by your family or friends. A courtesy follow-up phone call will be put through by the researcher to you, to offer extra support. If you are felt to require further professional support, you will be referred to the Postpartum Support Network with your consent. This will be discussed with you.

➢ **Will I be compensated for taking part?**

If you had to use more internet data for the interview than you normally would, you may be given some compensation towards this.

➢ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you decide not to take part, then you can inform the researcher of this decision when they contact you. If you change your mind after agreeing, please contact the researcher on this phone number **08098490111 (Whatsapp)**. If you decide to take part you are still free to withdraw at any time during the data collection period up to the 28th February 2021, without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been

anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

Data Protection and Confidentiality

➤ **What information will you collect about me?**

In order to participate in this research project, we will need to collect information that could identify you, called "personal identifiable information". Specifically, we will need to collect:

- Name

- Age

- Profession/employment status

- Telephone number.

- Marital status.

- Ethnicity.

- Highest educational qualification.

- Details about the birth and death of your baby.

When you are recruited into the study, you will be assigned a unique study identification number to be used on all study documents and electronic records that apply to you.

The audio-recording will consist of voice only of your experience and this will be taken during the interviews. The interviews will be recorded on an encrypted digital audio recorder and the audio-recordings will be transferred from the audio recorder on to a password-protected computer and will be written out word for word (transcripts) by the researcher to allow the analysis of the information. All your identifiable information such as your name and age will be removed to maintain your confidentiality. The researcher may use some word for word

quotations from your interview in publications but false names also known as pseudonyms will be used to protect your identity. The audio recordings will be destroyed after the completion of the research study. The research study documents such as consent and demographic forms will be stored securely in a locked cabinet at the University of Manchester. Anonymised documents such as transcripts will be stored on a password-protected and an encrypted data storage system at the University of Manchester. Only the researcher and research supervisors will have access to these documents.

Your contact details will be retained till the end of the study, and will be used to provide you with the study findings only if you choose to have this. The consent forms, and transcripts will be stored securely for 5 years after the completion of the study. Audio recordings will be deleted in the presence of the research supervisors following completion of the study.

> **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

> **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](http://documents.manchester.ac.uk/display.aspx?DocID=37095) which is available at http://documents.manchester.ac.uk/display.aspx?DocID=37095.

➢ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- You will be assigned an identification number; this will replace your identifiable information. Only the researcher will have access to the key that links this ID number to your personal information.

- Your identifiable information will be stored separately to the audio recordings and transcripts in a secure location at the University of Manchester. Only the researcher will have access to your identifiable information.

- Your data will be fully anonymised during transcription and use in the research findings.

- Your data will be transcribed by the researcher to uphold confidentiality and all identifiable information will be removed from the transcript.

- Your data will be held on the secure storage system at the University of Manchester, accessible only by the researcher and the research supervisors. The data will be transferred securely from the audio recorder to the university computer system.

- Your identifiable (including consent form) and anonymised data will be stored for 5 years, according to the University of Manchester's Data Management Policy, on the University of Manchester Secure Data Storage System.

- Audio recordings will be deleted from the audio recorder immediately after transfer to the University of Manchester's computer system. The audio recordings will be deleted from the computer system after transcription in the presence of the supervisory team.

Potential disclosures:

- o If, during the study, we have concerns about your safety or the safety of others, we will inform your family member.

- o If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities.

- o Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

➢ **Contact details for complaints**

If you have a complaint that you wish to direct to members of the research team, please contact: **me directly on the phone number 08098490111 or by email at** omotewa.kuforiji@postgrad.manchester.ac.uk **or my supervisors Dr Tracey Mills (**tracey.mills@manchester.ac.uk**) and Prof. Karina Lovell (**Karina.lovell@manchester.ac.uk**). Minor complaints should be reported to the researcher, Omotewa. If you have a major complaint, this can be reported to the research supervisors, Dr Mills and Prof. Lovell.**

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information (https://ico.org.uk/make-a-complaint/) Tel 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researcher on **phone number 08098490111 or by email at** omotewa.kuforiji@postgrad.manchester.ac.uk

Appendix 5: Participant Information Sheet (Healthcare Professional)

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Participant Information Sheets (Women)

</div>

Exploring the view of women and their families and health care professionals on the experience of care and support following perinatal death in Nigeria.

Participant Information Sheet (PIS)

You are being invited to take part in a research study which aims at exploring the view of women and their families and health care professionals on the experience of care and support following perinatal death in Nigeria, a research project for the fulfilment of a doctorate degree. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➢ **Who will conduct the research?**

Omotewa Kuforiji, a researcher at the Division of Nursing, Midwifery and Social Work, The University of Manchester, United Kingdom.

➢ **What is the purpose of the research?**

The death of a baby before, during or shortly after childbirth is a prevalent occurrence all over the world, particularly in sub-Saharan African countries such as Nigeria. Experiencing the death of a baby is a very traumatic and saddening occurrence with profound effects on women and also family members. Therefore, this research aims at understanding the experience of care and support that women and their families receive from health care professionals after the death of a baby before, during or shortly after birth in Nigeria. This study is being undertaken

269

in order to fill the gap in the literature on the experiences of women and their families of care and support received (if any) following the death of their baby in Nigeria. Furthermore, this study aims to inform the health care professionals of the perspectives of women like you (and their families) on the current provisions of care and support being offered following the death of a baby.

You are being asked to take part in the study because you are a healthcare professional who has cared and cares for individuals who have experienced the death of a baby before, during or shortly after childbirth at one of the hospitals in Lagos, Nigeria. A total of 15 health care professionals will be recruited to take part in this study.

➤ **Will the outcomes of the research be published?**

The findings of the research will form part of the researcher's thesis. They may also be published in applicable journals. The participants will be informed of the outcomes if they express an interest in this.

➤ **Who has reviewed the research project?**

The project will be reviewed by The University of Manchester Research Ethics Committee.

What would my involvement be?

➤ **What would I be asked to do if I took part?**

You have been given this information sheet to keep and go through again in your own time. If you have given consent for the researcher to contact you, they will contact you to give you further information about the study and an opportunity to answer any questions you may have. After 24 hours of receiving the explanation, the researcher will contact you again to ask if you have chosen to take part in the study or not. If you choose to take part in this study, the researcher will arrange a suitable date, time and location for an interview.

Due to the COVID-19 situation, the interview will be held over the phone. Prior to starting the interview, you will be given another explanation of the study and an opportunity to ask further questions. At the start of the interview, you will be asked to give consent to take part in the

study and will be given a verbal explanation of the points on the consent form. You will be asked to say verbally that you agree to take part voluntarily in the study and this will be audio-recorded using an encrypted audio-recorder. Your interview will not be recorded on any other device or apps. During the interview, you will be asked to discuss your experience of care and support following perinatal death.

The interview can be up to an hour and a half long, and will be audio-recorded by the researcher. It is essential for the researcher to audio-record all interviews to capture your experience exactly as it has been given by you. It is important that you are comfortable with the recording process at all times. If at any point you are distressed during the interview, you can ask to stop the recording or take a break.

You will only be required to do only one interview.

As this study is about a sensitive topic area, the death of a baby, there is a chance that you may become distressed during the interview when recalling your experiences of caring for women and families. If this occurs, the researcher as a mental health professional will offer you immediate support and following the interview if appropriate you will be supported by your family or friends. A courtesy follow-up phone call will be put through by the researcher to you, to offer extra support If you are felt to require further professional support, you will be referred to the Apex Nurse with your consent, who are also able to offer support to you or you may be referred to BTH Therapy or Synapse services, with you consent. This will be discussed with you.

Will I be compensated for taking part?

If you had to use more internet data for the interview than you normally would, you may be given some compensation towards this.

➢ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you decide not to take part, then you can inform the researcher of this decision when they contact you. If you change your mind after agreeing, please contact the researcher on this phone number XXXXX. If you decide to take

part you are still free to withdraw at any time during the data collection period up to the 28th February 2021, without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

Data Protection and Confidentiality

➢ **What information will you collect about me?**

In order to participate in this research project, we will need to collect information that could identify you, called "personal identifiable information". Specifically, we will need to collect:

- Name
- Age
- Profession/employment status
- Telephone number
- Marital status
- Ethnicity
- Highest educational qualification
- Length of time you've been employed at the hospital

When you are recruited into the study, you will be assigned a unique study identification number to be used on all study documents and electronic records that apply to you.

The audio recording will consist of voice only of your experience and this will be taken during the interviews. The interviews will be recorded on an encrypted digital audio recorder and the audio-recordings will be transferred from the audio recorder on to a password-protected computer and will be written out word for word (transcripts) by the researcher to allow the analysis of the information. All your identifiable information such as your name and age will be removed to maintain your confidentiality. The researcher may use some word for word quotations from your interview in publications but false names also known as pseudonyms will be used to protect your identity. The audio recordings will be destroyed after the completion of the research study. The research study documents such as consent form will be stored securely in a locked cabinet at the University of Manchester prior to being stored electronically.

Anonymised documents such as transcripts will be password-protected and saved on an encrypted data storage system at the University of Manchester. Only the researcher and research supervisors will have access to these documents.

Your contact details will be retained till the end of the study, and will be used to provide you with the study findings if you choose to have this. The consent forms, and transcripts will be stored securely for 5 years after the completion of the study. Audio recordings will be deleted in the presence of the research supervisors following completion of the study.

➢ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

➢ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research which is available at http://documents.manchester.ac.uk/display.aspx?DocID=37095.

➢ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- You will be assigned an identification number, this will replace your identifiable information. Only the researcher will have access to the key that links this ID number to your personal information.
- Your identifiable information will be stored separately to the audio recordings and transcripts in a secure location at the University of Manchester. Only the researcher will have access to your identifiable information.
- Your data will be fully anonymised during transcription and use in the research findings.
- Your data will be transcribed by the researcher to uphold confidentiality.
- Your data will be held on the secure storage system at the University of Manchester, accessible only by the researcher. The data will be transferred securely from the audio recorder to the university computer system.
- Your identifiable (including consent form and contact details) and anonymised data will be stored for 5 years, according to the University of Manchester's Data Management Policy, on the University of Manchester Secure Data Storage System.
- Audio recordings will be deleted from the audio recorder immediately after transfer to the University of Manchester's computer system. The audio recordings will be deleted from the computer system after transcription in the presence of the supervisory team.
- The audio recording will be transcribed by the researcher and all identifiable information will be removed from the transcript.

Potential disclosures:

o If, during the study, we have concerns about your safety or the safety of others, we will inform your family member.

o If, during the study, you disclose information about misconduct/poor practice, we have a professional obligation to report this and will therefore need to inform your employer/professional body.

o If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities.

- o Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

> **Contact details for complaints**

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<u>Contact Details</u>

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Appendix 6: Participant Information Sheet (Yoruba)

Ika Alaye Alabase (Yoruba)

Sise awari lori ero awon obirin ati idile won ati osise ilera lori iriri won ni ti itoju ati atileyin lehin iku omo inu oyun tabi omo-owo ni Nigeria.

Ika Alaye Alabaṣe

A n pe yin lati kopa ninu iwadi eyiti o ni ero lati ṣawari iwoye ti awọn obinrin ati awọn idile wọn ati awọn alamọdaju ilera lori iriri ti abijuto ati atileyin ti o tọ lẹhin iku omo inu oyun tabi omo-owo ni Nigeria, ise akanṣe iwadii fun imuse iwọn-oye ti dokita ti imoye.

Ṣaaju ki o to pinnu boya o yẹ ki e kopa, o ṣe Pataki fun yin lati ni oye idid ti mo fi n ṣe iwadii naa ati ohun ti yoo kopa. E jọwọ e lo akoko lati ka alaye wọnyi ni pẹlẹ ki e to pinnu boya e ma kopa ati lati jiroro rẹ pẹlu awọn miiran ti e ba ẹ fe. E jọwọ e beere ti o ba je pe ohunkohun o ye yin tabi ti e ba fẹ alaye diẹ sii. E ṣeun fun lilo akoko lati ka ika alaye alabaṣe yii.

<u>Nipa Iwadi Naa</u>

➢ **Tani yoo ṣe iwadii naa?**

Omotewa Kuforiji, oniwadi ni ile-eko ti Nọọsi, Agbẹbi, ati awujo iṣẹ. Ile-ẹkọ giga ti ilu Manchester, Apapọ ijọba Gẹẹsi.

➢ **Kini idi ti iwadii naa?**

Ipadanu omo oyun inu tabi iku ibẹrẹ ọmọde jẹ iṣẹlẹ ti o gbilẹ ni kariaye, ni pataki ni awọn orilẹ-ede Afirika ti o wani iha isale Sahara bii Nigeria. Iriri ipadanu omo oyun inu tabi iku omo tuntun jẹ iṣẹlẹ ti o ni ipọnju ati ibanujẹ pupọ pẹlu awọn ipa ti o jinlẹ lori awọn obirin at paapaa awọn ẹbi.

Nitorinaa, ero iwadii yii ni agbọye iriri ti itọju ati atileyin ti awọn obirin ati awọn idile wọn gba lati ọdọ awọn oṣiṣẹ ilera lehin ipadanu omo oyun inu tabi iku omo tuntun. Ni afikun, iwadii

277

yii ni ero lati tun ni oye itọju ati atilẹyin ti awọn oṣiṣẹ ilẹra fun si awọn obinrin ati awọn idile wọn.

Mo n beere lowo yin lati kopa ninu iwadi naa nitori pe e ti ni iriri ipadanu ọmọ inu oyun ti o ju ọsẹ mejidinlogbon tabi ẹgbẹrun giramu ṣaaju ibimọ tabi iku iẹrẹ ọmọde laarin awọn ọjọ meje akọkọ, ati pe e ti ni itọju ni ọkan ninu awọn ile-iwosan ni ilu Eko, Nigeria.

Emi yoo fẹ lati ba yin ati ọmọ ẹgbẹ ẹbi yin ti e gbagbo pe won se atilẹyin julọ lakoko ipadanu sọrọ ni pa iriri yin.

➢ **Njẹ awọn abajade ti iwadii yoo wa ni atẹjade?**

Awọn awari ti iwadii naa yoo di apakan ti iwe iwadii naa. Wọn tun le ṣe atẹjade ni awon iwe iroyin to wulo. A yoo sọ fun eyin ti e je olukopa ninu iwadii naa nipa iyọrisi ti e ba ṣafihan ohun pe e o nifẹ ninu eyi.

➢ **Tani o ṣe atunyẹwo iṣẹ iwadi yii?**

A ṣe atunyẹwo iṣẹ naa nipasẹ igbimọ ti iwa ni ile-ẹkọ giga ti manchester.

Kini ikopa mi yoo jẹ?

➢ **Kini yoo beere lọwọ mi lati ṣe ti mo ba gba lati kopa ?**

Ti e ba gba lati kopa ninu iwadi naa, ao beere lọwọ yin lati fowosi iwe-aṣẹ kan ti o fun ni aṣẹ lati kopa ninu iwadi naa. Eyin yoo kopa ninu ijomitoro ni akoko ati ipo ti o rọrun fun yin.

Gẹgẹbi obinrin, ao beere lọwọ yin lati jiroro iriri yin ti abojuto ati atilẹyin ti o tẹle Ipadanu omo oyun inu tabi iku iẹrẹ ọmọde. Emi yoo tun beere fun aṣẹ lati sọrọ pẹlu ẹgbẹ ẹbi yin. Ti e ko ba fun mi laṣẹ lati sọrọ pẹlu ẹgbẹ ẹbi yin, eyi ko ni kan iwọ tabi ikopa rẹ ninu iwadi yii.

A o se iforowanilenuwo ni ori foonu nitori isele ti o n sele lowo tii COVID-19, eyi ti wo n pe ni Corona. A o fun yin ni alaye iwadii naa. A o tun beere pe se e fun w ani ase pe e fe kopa ninu iwadii naa. E o ni lati fi ohun sile lori ero igbasile ohun pe e gba lati kopa ninu iwadii naa.

Iforowanilenuwo le to wakati kan ati idaji pipe, ati pe emi (oluwadi) yoo gbasile ohun nipase oluwadi naa. O se pataki fun oluwadi lati se igbasile gbogbo awon ibere ijomitoro lati mu itan kikun ti a so nipa re. O se pataki pe e ni itunu pelu ilana gbigbasile ni gbogbo igba. Ti o ba je pe nigbakugba ti e ko ni irorun, e le da gbigbasile sile fun awon atunse deede lati se fun itunu yin.

E yoo nilo lati wa ijomitoro kan nikan.

Geege bi iwadi yii se je nipa agbegbe koko-oro ti o ni imolara anfani wa ti o le se ibanuje lakoko ijomitoro nigbati e ba tin ranti awon iriri yin. Ti eyi ba waye, oniwadi naa gegebi osise ilera ilera yoo fun yin ni atileyin lesekese ati atele ijomitoro ti o ba ye e yoo ni atileyin nipase awon ebi re tabi awon ore.

Oniwadi yoo fun yin ni ipe foonu ti o lawo lati fun yin ni atileyin afikun. Ti oluwadi ba ro pe e nilo atileyin ojogbon siwaju, oniwadi yoo toka yin si Postpartum Network Support pelu ase yin. Eyi ni yoo jiroro pelu yin.

➢ **Se o yoo san isanpada fun mi lati kopa?**

A o fun yin ni isanpada die lori owo credit ti foonu , ti e ba ni lati lo ju iti e ma n lo lo.

➢ **Kini yoo sele ti mi o ba fe lati kopa tabi ti mo ba yi okan mi pada?**

Iyan re ni lati pinnu boya lati kopa tabi lati ma kopa. Ti e ba pinnu lati kopa ninu iwadii naa, jowo kan si oluwadi lori nomba ero ibanisoro yii 08098490111. Ao fun yin ni iwe alaye yii lati toju ati pe a yoo beere lowo yi lati fowo si iwe-ase ati ki e pese ifohunsi enu. Ti e ba pinnu lati kopa e si ni ominira lati yo ara yin kuro nigbakugba lati iwadii naa laisi fifun idi kan ati laisi iparun fun yin. Ojo ti o gebyin to e ba fey o ara yin ni ojo 28 no osu keji ni odun 2021. Sibesibe, kii yoo see se lati yo itan yin kuro ninu ise naa ni kete ti a ba ti so di alailoruko nitori pe a kii yoo ni anfani lati da itan yi mo yato si ti awon imiran. Eyi ko kan awon eto asiri alaye yin. Ti e ba pinnu lati ma kopa ninu iwadii yii, eyin ko nilo lati se ohunkohun siwaju sii.

Idaabobo itan ati Asiri

➢ **Alaye wo ni iwo yoo gba nipa mi?**

Lati le kopa ninu iṣe iwadi yii a yoo nilo lati gba alaye ti o le ṣe idanimọ yin, ti a pe ni "alaye idanimọ ti ara ẹni". Ni pataki a yoo nilo lati gba:

- Orukọ
- Ọjọ ori
- Oojọ / ipo oojọ
- Adiṛesi (ti o ba je pe oniwadi yoo ṣe iforọwanilẹnuwo ni ile yin)
- Nọmba tẹlifoonu
- Ipo igbeyawo yin, ti e ba ni iyawo tabi oko

Gbigbasilẹ ohun yoo ni ohun nikan ni ti iriri yin, ao si gba eyi nigba awọn ibere ijomitoro..

> **Labẹ ipilẹ ofin wo ni o gba alaye yii?**

A n gba, a sin toju alaye idanimọ ti ara ẹni yii ni ibamu pẹlu ofin aabo itan eyiti o daabobo awọn ẹtọ yin. Awọn wọnyi ṣalaye pe a gbọdọ ni ipilẹ labẹ ofin (idi kan pato) fun gbigba itan rẹ. Fun iwadii yii, idi pataki ni pe o jẹ "iṣẹ-ṣiṣe inifẹ gbogbogbo" ati "ilana ti o yẹ fun awọn idi iwadi".

> **Kini awọn ẹtọ mi ni ibatan si alaye ti iwọ yoo gba nipa mi?**

E ni awọn ẹtọ labẹ ofin aabo itan nipa alaye ti ara ẹni yin. Fun apẹẹrẹ e le beere ẹda ti alaye ti a dimu nipa yin, pẹlu awọn gbigbasilẹ ohun. Ti e ba fẹ lati mọ diẹ sii nipa awọn ẹtọ oriṣiriṣi yin tabi ọna ti a lo alaye ti ara ẹni yin lati rii daju pe a tẹle ofin, e jọwọ e kan si wa tabi ki e ka [akyesi asiri fun iwadi](http://documents.manchester.ac.uk/display.aspx?DocID=37095) ti o wa ni http://documents.manchester.ac.uk/display.aspx?DocID=37095.

> **Njẹ ikopa mi ninu iwadii yoo jẹ ikọkọ ati alaye idanimọ ti ara ẹni mi ni aabo?**

Ni ibamu pẹlu ofin aabo itan, ile-eko giga ti Ilu Manchester ni oluṣakoso itan fun iṣẹ yii. Eyi tumọ si pe a ni iṣeduro lati rii daju pe a tọju alaye ti ara ẹni yin ni aabo ati asiri, asi ni lati lo nikan ni ọna ti a ti sọ fun yin pe yoo ṣee lo. Gbogbo awọn oniwadi ni ikẹkọ pẹlu eyi ni lokan, ati pe yoo ṣe abojuto itan yin ni ọna atẹle:

- A yoo fun yin ni nọmba idanimọ kan, eyi yoo rọpo alaye idanimọ yin. Oniwadi nikan yoo ni iwọle si kọkọrọ ti o sopọ nọmba idanimọ yii si alaye ti ara ẹni yin.

- Alaye idanimọ yin yoo wa ni ifipamọ lọtọ si awọn gbigbasilẹ ohun ati awọn iwe afọwọkọ ni ipo idaniloju ni Ile-ẹkọ giga ti Ilu Manchester. Oniwadi nikan ni yoo ni iwọle si alaye idanimọ yin.

- - Awọn itan yin yoo ni ailoruko ti a ba ti n tumọ re jade lati gbigbasilẹ ohun ati ti a ba tin lo ninu awọn iwadii.

- Oniwadii ni yoo tumọ itan yin lati inu gbigbasilẹ ohun lati le ṣe atilẹyin igbekele.

- Ao fi itan yin pamọ si ibi ipamọ to ni aabo ni ile-ẹkọ giga ti ilu-Mancgester, oniwadi nikan ni yoo ni wiwole sii. A yoo gbe itan naa ni aabo lati inu agbohunsilẹ ohun si ori kọmputa.

- Idanimọ rẹ (pẹlu iwe-aṣẹ ati awọn alaye ikansi) ati awọn itan ailoruko yoo wa ni ifipamọ fun ọdun marun, ni ibamu si afihan isakoso alaye lori Ile-ẹkọ giga ti Ile-ipamọ ibi ipamọ ti Ilu Manchester.

- Ao paare awọn gbigbasilẹ ohun lati olugbasilẹ ohun lẹsẹkẹsẹ lẹhin gbigbe si ori kọmputa ti Ile-ẹkọ giga ilu Manchester. Awọn gbigbasilẹ ohun yoo paarẹ kuro ninu kọmputa lẹhin ti a ba ti koo jade ni iwaju ẹgbẹ ti abojuto iwadii.

- Ao ko jade gbigbasilẹ ohun nipasẹ oluwadi ati gbogbo alaye idanimọ ni yoo yọ kuro lati inu iwe-kikọ naa.

Awọn ifihan gbangba:

o Nigba iwadii, ti a ba ni awọn ifyesi nipaaabo yin tabi aabo awon miiran, a yoo sọ fun ẹbu yin.

o Nigba iwadii, ti e ba ṣafihan alaye nipa aisedeede/iṣe ti ko dra, a ni ọran ọjọgbọn lati sọ fun agbanisiẹ rẹ/ẹgbẹ ọjọgbọn.

o Nigba iwadii yii, ti e ba ṣafihan alaye nipa eyikeyi awọn iṣe arufin ti isiyin tabi ti ọjọ iwaju, a ni iṣeduro ofin lati so eyi, nitorinaa a nilo lati sọfun awọn alaṣẹ ti o yẹ.

o Awọn ẹni-kọọkan lati Ile-ẹkọ giga, aaye ti iwadi wa ti n ṣẹlẹ ati awọn alaṣẹ ilana le nilo lati ṣe atunyẹwo alaye iwadii fun awọn iṣeduro ati ṣayẹwo awọn idi tabi ni iṣẹlẹ ti iṣẹlẹ kan..

E jọwọ e tun ṣe akiyesi pe awọn eniyan lati Ile-ẹkọ giga ti Ilu Manchester tabi awọn alaṣẹ iṣakoso le nilo lati wo alaye ti a gba fun iwadi yii lati rii daju pe a ṣe agbekalẹ iṣe naa bi a ti pinnu. Eyi le pẹlu wiwa ni alaye idanimọ. Gbogbo awọn ẹni-kọọkan ti o ṣe alabapin ninu iṣatunyẹwo ati abojuto iwadi naa yoo ni ojuṣe ti o muna ti asiri si ọ bi olukopa iwadi.

Tim o b ani ẹdun ọkan nko?

➢ **Awọn alaye ikansi fun ẹdun ọkan**

Ti e b ani ẹdun okan to e fẹ to si awọn ẹgbẹ iwadii, e jọwọ e kan si mi: taara lori nomba ero ibanisọrọ yii: 08098490111 tani nipasẹ ero ayelujara ni: omotewa.kuforiji@postgrad.manchester.ac.uk **tabi awọn alabojuto mi Dokita Tracey Mills (tracey.mills@manchester.ac.uk) ati alamọdaju obinrin Karina Lovell (Karina.lovell@manchester.ac.uk). Tio ba je pe e ni edun okan kekere, e le so fun oniwadii, eyi ti o je Omotewa. Ti o ba si je edun okan nla, e so fun awon alabojuto ise iwadi naa, eyi ti o je Dokita Mills ati Alamodaju obirin Lovell.**

Ti e ba fẹ lati ṣe ẹdun ọkan si ẹnikan ti o ni ominira lati ẹgbẹ iwadi naa tabi ti e ko ba ni inu didun pẹlu esi ti e ba gba lati ọdọ awọn oniwadi ni apẹẹrẹ akọkọ lẹhinna, e jọwọ e kan si adirẹsi ti o w ani isalẹ;

Oluṣakoso Ẹgbẹ Iwadi, Research Office Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, tabi nipa ti ero ayelujara: research.complaints@manchester.ac.uk tabi nipa pipe 0161 275 2674.

Ti e ba fẹ lati kan si wa nipa awọn ẹtọ aabo alaye yin, e jọwọ e kan si dataprotection@manchester.ac.uk tabi ki e kọ lẹta si The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL a yoo tọ yin nipasẹ ilana ti lilo awọn ẹtọ yin.

E tun ni ẹtọ lati ṣaroye si [ofisi asoku alaye nipa awọn edun okan ti o jomo alaye idanimo ti ara eni re (https://ico.org.uk/make-a-complaint/)](https://ico.org.uk/make-a-complaint/) nooma ero ibanisọrọ: 0303 123 1113

Alaye Awon Olubasọrọ

Ti o ba ni awọn ibeere eyikeyi nipa iwadi naa tabi ti o ba nifẹ lati kopa lẹhinna jọwọ kan si oluwadi lori nọmba ero ibanisọrọ 08098490111 tabi nipasẹ **ero ayelujara** ni omotewa.kuforiji@postgrad.manchester.ac.uk

Appendix 7: Demographic Form (Health care professionals)

Participant Code:
Date:

MANCHESTER 1824
The University of Manchester

<div style="background:purple;color:orange">

Demographic Form (Health Care Professionals)

</div>

Exploring the views of women and their families and health care professionals on the lived-experience of care and support following perinatal death in Nigeria.

Age: 18-21 ☐ 22-26 ☐ 27-31 ☐ 32-36 ☐ 37 -41 ☐ 42-46 ☐ 46-50 ☐

50 and above ☐

Gender: Male ☐ Female ☐

Marital Status:

Single ☐   Married ☐   Civil Partnership ☐   Divorced/Separated ☐

Do you have children: Yes ☐   No ☐   How many:_____

Religion: Christianity ☐ Islam ☐ Other ☐   If other, please state: _____

Prefer not to say ☐

Ethnicity: Yoruba ☐ Igbo ☐ Hausa ☐ Other:_____

Employment status: Employed full time ☐   Employed Part Time ☐

Occupation: _____

What is your highest level of education: WAEC/GCE ☐   NECO ☐ HND ☐ OND ☐
BSc ☐ MSc ☐   PhD ☐ Other:_____

Length of time employed at the hospital:

1 year ☐   5-10 years ☐ 10 years and above ☐

Appendix 8: Demographic Form (Women)

MANCHESTER
1824
The University of Manchester

Demographic Form (Women)

Exploring the views of women and their families and health care professionals on the lived- experience of care and support following perinatal death in Nigeria.

Age: 18-21 ☐ 22-26 ☐ 27-31 ☐ 32-36 ☐ 37 -41 ☐ 42-46 ☐ 46-50 ☐

Religion: Christianity ☐ Islam ☐ Other ☐   If other, please state: _____

Prefer not to say ☐

Ethnicity: Yoruba ☐ Igbo ☐ Hausa ☐ Other:_____

Marital Status:

Single ☐ Married ☐ Civil Partnership ☐ Divorced/Separated ☐

Do you live: Alone ☐ With your immediate family ☐ With your extended family such as in-laws/parents ☐

Residential area:_____

Employment status: Employed full time ☐ Employed Part Time ☐ Homemaker ☐
Unemployed ☐

Occupation: _____

What is your highest level of education: WAEC/GCE ☐ NECO ☐ HND ☐ OND
BSc ☐ MSc ☐ PhD ☐ Other:_____

Do you have (other) living children: Yes ☐ No ☐ How many:_____

What number was the baby that died? _____

Gender of baby: Male ☐ Female ☐ Unknown ☐

When did your baby die: before birth ☐ during labour ☐ after birth ☐

At how many weeks did your baby die? _____

What caused the death of your baby? _____

Did your baby have any medical condition/health problem before and/or after birth?
_____

Did you have any medical condition/health problem before and/or after the pregnancy?
_____

Appendix 9: Distress Protocol

Distress Protocol

Prior to study

Prior to commencement of the study, the participants will be given a participant information sheet with details of who to contact if they experience distress such as crying or reluctance to speak and these details will be reiterated again with the participant at the conclusion of the interview.

During the study

Should a participant report or show signs of distress and feeling uncomfortable such as crying, during the interview, the following actions will be taken by the researcher:

Step 1

Interview should be paused

Suggest that the participant takes a break and have a drink of water.

Ask the participant how they are feeling, listen with empathy and offer support.

What thoughts are you having at present?

How are you feeling at present?

Do you feel able to continue with the interview?

Do you feel safe and able to manage the rest of the day?

Step 2

If the participant would like to continue, the researcher will offer support and reassurance, and reiterate that they can stop the interview at any point if they would like to take a break.

If the participant would like to stop or appears highly distressed such as difficulty expressing their words, follow the actions in **Step 3**

Step 3

Stop the interview.

Mild distress: Encourage the participant to speak to **Dr Wale Aminu, Clinical Psychologist ((+2348113546313) at Postpartum Support Network (Women and families) and The Apex Nurse or BTH Therapy** (+234909 040 9229, +2349098587959) for support OR offer to do so for the participant.

Moderate distress: Immediately inform the family member whose contact details they have given**,** ask them to come and collect the participant and stay with the participant until they arrive.

High distress: Researcher will phone **an ambulance and their family members** for assistance but remain with the participant until they arrive.

In all instances the researcher will seek support from their supervisor.

Participants can also visit the following websites for support:

Mentally Aware https://www.mentallyaware.org/ (+2348051493163),

Postpartum Support Network https://postpartumafrica.org/contact/ (+2348113546313),

Synapse Service http://www.synapseservices.org/contacts.html (+2349085695593),

She Writes Woman http://shewriteswoman.org/our-solution/#helpline (+2348174913329).

BTH Therapy https://bththerapy.com/counselling-psychotherapy/ (+234909 040 9229, +2349098587959).

Follow-up actions

Offer to follow participant up with a phone call the following day.

Recommend the participant contacts **Dr Wale Aminu, Clinical Psychologist.** if they continue to feel distressed.

Appendix 10: Ethical Approval from the University of Manchester

MANCHESTER 1824
The University of Manchester

Ref: 2020-9052-16039

21/07/2020

Dear Miss Omotewa Kuforiji, Dr Tracey Mills, Prof Karina Lovell

Study Title: Exploring the views of women, their families and healthcare professionals on the lived-experience of care and support following perinatal death in Nigeria.

University Research Ethics Committee 3

I write to thank you for submitting the final version of your documents for your project to the Committee on 08/07/2020 17:21 . I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation as submitted and approved by the Committee.

COVID-19 Important Note

If you are conducting research with a data collection methodology that involves face-to-face contact (i.e. interviews, focus groups, psychological experiments, tissue sampling, and any other research procedure requiring face-to-face contact) you must switch to data collection via Skype, telephone or an alternative digital platform.

Please note, you do not need to seek a formal amendment to your existing ethical approval to make these changes provided your consent procedures remain the same (i.e. if you are still obtaining written consent but the form is returned by post or email). If you are choosing an alternative consenting procedure, please submit a formal amendment to your ethical approval via the usual process.

If switching your data collection to digital or electronic means is not possible (i.e. human tissue studies) then you must suspend all research activity until further notice unless doing so will have critical impacts on research participants (i.e. affect their wellbeing or care).

Please also consider whether you need to submit an amendment to extend your dates of data collection, due to postponed fieldwork or other research activities. If you need to seek an extension, you must do so before the end date as listed on your approved ethics application/last approved amendment or within 3 months of this date.

Researchers who wish to continue with face-to-face data collection during this period will require specific approval from the Research Governance, Ethics and Integrity Team. Such approval will only be given if 1) the researcher is a member of staff or PGR, 2) the research is specifically related to the Covid-19 situation and data collection has to take place at the present time, or 2) there are exceptional reasons for the continuation of face-to-face data collection (i.e. critical impacts on the wellbeing or care of research participants).

Please see https://www.staffnet.manchester.ac.uk/rbe/ethics-integrity/ethics/ for further details

Please see below for a table of the title, version numbers and dates of all the final approved documents for your project:

Document Type	File Name	Date	Version
Participant Information Sheet	PIS	04/03/2020	1
Participant Information Sheet	PIS Yoruba	05/03/2020	1
Consent Form	Consent to contact form OK	18/03/2020	1
Consent Form	Consent form OK	19/03/2020	1
Consent Form	Consent form OK Pidgin	22/03/2020	1
Consent Form	Consent form OK Yoruba	22/03/2020	1
Lone Worker Policy/Procedure	Lone working procedure OK	23/03/2020	1
Distress Protocol/Debrief Sheet	General Distress Protocol OK	25/03/2020	1
Default	Demographic form Families OK	01/04/2020	1
Default	Demographic form Healthcare Professionals	01/04/2020	1
Default	Demographic form Women	01/04/2020	1
Default	Topic guide Partner	10/04/2020	1
Default	Topic guide Healthcare Professional	11/04/2020	1
Default	Topic guide Family	13/04/2020	1
Default	Topic guide women	13/04/2020	1

Participant Information Sheet	PIS Pidgin	18/04/2020	I
Participant Information Sheet	PIS Family Pidgin	18/04/2020	I
Additional docs	NMSW Risk Assessment OK	18/04/2020	I
Advertisement	Advert OK	21/04/2020	I
Additional docs	Updates re signatory comments	22/04/2020	I
Participant Information Sheet	PIS Yoruba COVID-19	22/04/2020	I
Participant Information Sheet	PIS Pidgin COVID-19	22/04/2020	I
Participant Information Sheet	PIS COVID-19	22/04/2020	I
Participant Information Sheet	PIS HPs	09/06/2020	I
Participant Information Sheet	PIS HPs COVID-19	09/06/2020	I
Participant Information Sheet	PIS Family COVID-19	09/06/2020	I
Participant Information Sheet	PIS Family A	09/06/2020	I
Additional docs	Ethics amendments	09/06/2020	1
Consent Form	Verbal Consent Script	17/06/2020	I
Additional docs	Debrief sheet Family	17/06/2020	I
Additional docs	Debrief sheet HCP	17/06/2020	I
Additional docs	Debrief sheet Women	17/06/2020	I
Data Management Plan	DMP OK E	17/06/2020	I
Additional docs	Verficiation of translated documents B	07/07/2020	I

This approval is effective for a period of five years however please note that it is only valid for the specifications of the research project as outlined in the approved documentation set. If the project continues beyond the 5 year period or if you wish to propose any changes to the methodology or any other specifics within the project, an application to seek an amendment must be submitted for review. Failure to do so could invalidate the insurance and constitute research misconduct.

You are reminded that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a secure university computer or kept securely as a hard copy in a location which is accessible only to those involved with the research.

Reporting Requirements:
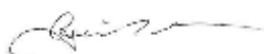
You are required to report to us the following:

1. Amendments: Guidance on what constitutes an amendment
2. Amendments: How to submit an amendment in the ERM system
3. Ethics Breaches and adverse events
4. Data breaches
5. Notification of progress/end of the study

Feedback

It is our aim to provide a timely and efficient service that ensures transparent, professional and proportionate ethical review of research with consistent outcomes, which is supported by clear, accessible guidance and training for applicants and committees. In order to assist us with our aim, we would be grateful if you would give your view of the service that you have received from us by completing a UREC Feedback Form. Instructions for completing this can be found in your approval email.

We wish you every success with the research.

Yours sincerely,

Mrs Genevieve Pridham

Secretary to University Research Ethics Committee 3

Appendix 11: Ethical Approval from Lagos State Government

LAGOS STATE GOVERNMENT

SUB/LIMH/78/VI/892   17 September, 2020

Omotewa Kuforiji,
Postgraduate Researcher
Division of Nursing, Midwifery and Social Work,
The University of Manchester,
Jean McFarlane Building,
Oxford Road Manchester M13 9PL,
tel +44(0)161 306 0260 fax +44(0)161 306 7707,
email omotewa.kuforiji@postgrad.manchester.ac.uk
www.nursing.manchester.ac.uk

RE: APPLICATION FOR ETHICAL APPROVAL

Having considered your application for the conduct of your study on care of women who experienced perinatal mortality in our facility, I hereby convey the Ethical Committee's approval for you to commence the research.

This is wishing you the best in your career endeavour, am hoping we get a look at your findings for the overall benfit of our patients.

Best regards,

Dr. S. O. Bazuaye
Head of Dept of O & G and
Chairman, Ethics Commttee – LIMH

LAGOS ISLAND MATERNITY HOSPITAL
Campbell Street, Lagos Island, Lagos.
Tel:......................... e-mail: oslandmaternity@yahoo.com Website: www.islandmaternity.com

291

Appendix 12: Consent to contact form

MANCHESTER
1824
The University of Manchester

Participant Consent to Contact Form

Exploring the views of women and their families and healthcare professionals on the lived-experience of care and support following perinatal death in Nigeria.

Consent to Contact Form

If you are happy for the researcher to contact you, please complete and sign the consent form below;

	Activities	Initials
1	I confirm that I have been given the information sheet (**Version I, Date 04/03/2020**) for the above study. I agree for the researcher to contact me to give me further details about the study.	

Name: _____

Phone number: _____

Preferred time of the day for researcher to contact: Morning ▭   Afternoon ▭   Evening ▭
(Please tick the applicable box)

Please note that your personal details provided on this form will only be used for sole purpose of contacting you about the research study. You will only be contacted by the researcher, Omotewa Kuforiji, and this form will be destroyed securely after the study is completed.

Your data will not be shared with any third party without your written permission.

If you decide to change your mind about being contacted about the study or would like your details to be destroyed you can contact the researcher Omotewa Kuforiji *(insert phone number XXXXX).*

_____   _____   _____

Name of Participant   Signature/ Thumbprint   Date

_____   _____   _____

Name of the person taking consent   Signature   Date

Appendix 13: Consent form

Participant Consent Forms

Exploring the views of women and their families and healthcare professionals on the lived- experience of care and support following perinatal death in Nigeria.

Consent Form

If you are happy to participate please complete and sign (or put a thumbprint) the consent form below;

	Activities	Initials
1	I confirm that I have read the attached information sheet (**Version I, Date 04/03/2020**) for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time during the data collection period up to the 28th February 2021 without giving a reason and without detriment to myself. I understand that it will not be possible to remove my data from the project once it has been anonymised and forms part of the data set. I agree to take part on this basis.	
3	I agree to the interviews being audio recorded.	
4	I agree that any data collected including word for word quotations from the interview may be published in anonymous form in academic books, reports or journals.	
5	I understand that data collected during the study may be looked at by individuals from The University of Manchester or regulatory authorities, where it is relevant	

	to my taking part in this research. I give permission for these individuals to have access to my data.	
6	I understand that there may be instances where during the course of the interview, information is revealed which means that the researchers will be obliged to break confidentiality and this has been explained in more detail in the information sheet.	
7	I agree to take part in this study.	
8	I agree that the researchers may retain my contact details in order to provide me with a summary of the findings for this study. This is optional, please tick this box only if you want to receive a summary of the study findings.	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants**.**

_____   _____   _____

Name of Participant   Signature (or Thumbprint)   Date

_____   _____   _____

Name of the person taking consent   Signature   Date

A copy of this consent form can be given to you if you wish. The original copy will be kept by the research team.

Appendix 14: Verbal Consent Script

The University of Manchester

<u>Verbal Consent Script (interviews)</u>

I am a student at the University of Manchester, in the United Kingdom. I am conducting a study exploring the **view of women and their families and healthcare professionals on the lived-experience of care and support following perinatal death in Nigeria.**

If you agree to participate in this study, I will ask you to take part in an interview to discuss your experience of [care and support following perinatal death (women)] or of [providing care and support following perinatal death (health professionals and family)]. By taking part in this interview, you are confirming that you have read the participant information sheet provided to you and have had sufficient time read through it, ask questions and have received satisfactorily.

This interview may cause you some distress due to recalling your experience, and if this is the case, I will provide support at the time. You will also be given information about services that can provide psychological support to you, should you feel the need.

Anything you tell me will be kept confidential, unless there are concerns or risks to yourself or others. If there are, the information cannot be kept confidential but will be escalated to the appropriate individuals to ensure that the concerns or risks are adequately addressed. You will be informed of this, if this is the case. I will not use your name or any details that might identify you when I write and publish my work. Any written notes that I take will be stored securely.

You will not be paid for taking part in this study as your participation is voluntary. You are free to withdraw from the study at any point during the data collection period, up on till the 28th February 2021 without giving any reason. Following this time, your data cannot be removed from the study once it has been anonymised.

Any data collected including word for word quotations from the interview may be published in anonymous form in academic books, reports or journals. This data may also be looked at by individuals at University of Manchester or regulatory authorities. You are in agreement with these statements.

You are agreeing for the interviews to be audio recorded.

Do you give your consent to take part in this study and for this interview to go ahead?

Do you have any questions about me, the study, or the interview before we begin?

My supervisors are Prof. Karina Lovell and Dr. Tracey Mills. If you have any concerns about this study or my behaviour, you can contact them. If you need help sending him/her an email, I will help you.

You can contact me at omotewa.kuforiji@postgrad.manchester.ac.uk, [+234XXXX] while I am in Nigeria, or via the same number on Whatsapp while I am in the UK.

Appendix 15: Debrief Sheet - Women

Study: **Exploring the view of women and their families and healthcare professionals on the lived-experience of care and support following perinatal death in Nigeria.**

Participant Debrief Sheet (Women)

Thank you for participating in the interview for this study. We hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to the researcher, please contact: *Omotewa Kuforiji, Phone number XXXX or you can send an email; omotewa.kuforiji@postgrad.manchester.ac.uk.*

There are also a number of organisations listed below that you can contact.

Organisations	
She Writes Woman http://shewriteswoman.org/our-solution/#helpline (+2348174913329).	BTH Therapy https://bththerapy.com/counselling-psychotherapy/ (+234909 040 9229, +2349098587959).
Mentally Aware https://www.mentallyaware.org/ (+2348051493163)	Postpartum Support Network https://postpartumafrica.org/contact/ (+2348113546313)

Appendix 16: Debrief Sheet – Healthcare Professionals

The University of Manchester

Study: **Exploring the view of women and their families and healthcare professionals on the lived experience of care and support following perinatal death in Nigeria.**

Participant Debrief Sheet (Health Professionals)

Thank you for participating in the interview for this study. We hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to the researcher, please contact: ***Omotewa Kuforiji, Phone number XXXX or you can send an email; omotewa.kuforiji@postgrad.manchester.ac.uk.***

There are also a number of organisations listed below that you can contact.

Organisations	
Synapse Service http://www.synapseservices.org/contacts.html (+2349085695593),	BTH Therapy https://bththerapy.com/counselling-psychotherapy/ (+234909 040 9229, +2349098587959).
Mentally Aware https://www.mentallyaware.org/ (+2348051493163)	