

**SHIFTS IN SOCIAL SUPPORT: A PHENOMENOGRAPHIC STUDY OF NIGERIAN  
WOMEN WHO HAVE HAD A STILLBORN BABY**

**BY**

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## **Abstract**

Each year in Nigeria 314,000 mothers lose their babies to stillbirth. This study investigates the implications of these stillbirths for Nigeria's Yoruba women, especially in relation to their social networks. The study is theoretically framed within the theory of social capital and the research methodology is phenomenography, a qualitative approach that concerns itself with difference in relation to experience. Twenty mothers of stillborn babies were purposefully recruited from Saki, a Yoruba community in South-west Nigeria. Data were collected through semi-structured interviews, participants' drawings and a focus group discussion. The transcribed data were analysed according to the principles of phenomenography. This yielded four broad categories: (1) relationships change; (2) relationships matter; (3) material support makes a difference; and (4) health professionals neither help nor support. These findings indicated that stillbirth interfered with the social networks of the participants, leading to a decline in their social networks and an emergence of the family as the primary source of support. The participants gained encouragement and empathy through their relationships with others but received minimal material support, even though it was badly needed. The participants expressed distrust in health professionals due to a lack of compassionate care. This study contributes to the understanding of stillbirth bereavement in three different ways. First, culture really matters in how mothers of stillborn babies express their grief, how they are supported and how they would want to be supported. Second, there is still a deficit of kind, compassionate and skilled nursing care for mothers of stillborn babies. Third, support becomes smaller, but more intense for mothers after suffering a stillbirth. This study, therefore, adds to the ongoing global conversations about how better bereavement care can become more realistic for mothers of stillborn babies by extending the theory of social capital and the methodological approach of phenomenography to the issue of stillbirth bereavement. The study concludes with recommendations for nursing, for research and for policy.

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# Table of Contents

Abstract .....	ii
Acknowledgements .....	iii
List of figures .....	viii
List of tables .....	ix
List of abbreviations and acronyms used .....	x
Chapter 1: Introduction and background .....	1
1.1 Introduction .....	1
1.2 The research context.....	3
1.3 Healthcare system in Nigeria .....	5
1.4 Stillbirth in Yoruba society.....	7
1.4.1 Good birth versus bad birth among the Yoruba people.....	9
1.5 Aim of the study .....	13
1.6 Objectives of the study .....	13
1.7 Significance of the study .....	13
1.8 Operational terms.....	14
1.9 Outline of the thesis .....	14
Chapter 2: Literature review.....	16
2.1 Introduction .....	16
2.2 Search strategy.....	16
2.3 Factors associated with stillbirth in Nigeria .....	18
2.4 Cultural understandings of stillbirth: Yoruba perspective.....	21
2.4.1 Cultural understandings of stillbirth among other cultures in Nigeria .....	32
2.4.2 Cultural understandings of stillbirths in other contexts .....	33
2.5 Social consequences of stillbirth: Shame, guilt and isolation .....	36
2.6 The social networks of mothers of stillborn and the dominance of the family .....	39
2.7 Factors associated with poorer outcomes after stillbirth .....	43
2.8 Women's experience of health professionals' support after stillbirth.....	44
2.9 What helps women cope with stillbirth.....	49
2.10 Summary of the review .....	52
Chapter 3: Theoretical framework .....	54
3.1 Introduction .....	54
3.2 Social capital theory: A framework for studying the contribution of social relationships to stillbirth grief .....	56
3.3 Forms of social capital.....	62
3.4 Social capital in research.....	65
3.4.1 Bonding social capital in research among women .....	65
3.4.2 Bridging social capital in research among women.....	67

3.4.3 Social capital research among African populations and developing countries .....	69
3.5 Measuring social capital.....	70
3.6 Chapter summary .....	72
<b>Chapter 4: Research methodology .....</b>	<b>73</b>
4.1 Introduction .....	73
4.2 Selecting an appropriate methodology.....	74
4.3 Phenomenography as a methodology .....	77
4.4 Research methods .....	81
4.4.1 Study area.....	81
4.4.2 Participants .....	82
4.4.3 Recruiting the participants .....	83
4.4.4 Data collection.....	86
4.4.4.1 Interviews .....	88
4.4.4.2 Drawing activity.....	89
4.4.4.1 Focus group discussion .....	92
4.4.5 Data analysis .....	95
4.4.6 Methodologic issues with data collection with different methods.....	98
4.5 Rigour in phenomenographic studies.....	101
4.6 Ethical considerations .....	102
4.7 Positionality and subjectivity .....	105
4.8 Chapter summary .....	107
<b>Chapter 5: Findings.....</b>	<b>109</b>
5.1 Introduction .....	109
5.2 Relationships change .....	109
5.2.1 Social bonds decrease .....	110
5.2.2 Family is central.....	117
5.2.3 Experiences are diverse .....	120
5.3 Relationships matter.....	125
5.3.1 Encouragement and empathy help.....	127
5.3.2 Forgetting and moving on can be both helpful and harmful advice.....	130
5.3.3 Looking to religion for meaning .....	132
5.4 Material support makes a difference .....	136
5.4.1 People give less if a baby is stillborn .....	136
5.4.2 People still help in limited ways.....	140
5.5 Health professionals neither help nor support .....	142
5.5.1 Breaking the bad news .....	143
5.5.2 Losing faith in the health professionals' competencies.....	145

5.5.3 Opportunities for improvement in bereavement support .....	147
5.6 The outcome space: Seeking a positive pathway for stillbirth bereavement .....	150
5.7 Summary .....	151
Chapter 6: Discussion and conclusions .....	153
6.1 Introduction .....	153
6.2 Summary of the findings .....	153
6.3 Implications of the findings.....	155
6.3.1 Relationships and all the benefits that they bring get smaller but more intense .....	155
6.3.2 Culture really matters in terms of how grief is expressed and supported .....	157
6.3.3 There is a real deficit of kind, compassionate, and skilled nursing care .....	162
6.4 Contribution to phenomenography .....	164
6.5 Contribution to theory .....	168
6.6 Recommendations.....	170
6.6.1 Recommendation for nursing practice and education.....	170
6.6.2 Recommendations for future research.....	171
6.6.3 Recommendations for health policy .....	172
6.7 Conclusion of the study .....	172
References .....	174
Appendices .....	194
Appendix 1: University’s Ethics Committee Approval .....	194
Appendix 2: Local Ethics Approval .....	195
Appendix 3: Information sheet for interviews .....	196
Appendix 4: Consent form for interviews .....	198
Appendix 5: Interview consent in Yoruba.....	199
Appendix 6: Focus group consent form .....	200
Appendix 7: Focus group consent form in Yoruba.....	201
Appendix 8: Semi-structured interview guide .....	202
Appendix 9: Instructions for drawing exercises.....	203
Appendix 10: Focus group question .....	204

## List of figures

Figure 1: Burden of stillbirth in Nigeria .....	3
Figure 2: Location of Nigeria in Africa .....	5
Figure 3: Map of Nigeria showing the South-Western region.....	7
Figure 4: Tribal and religious distribution of Nigeria.....	19
Figure 5: Funeral of a ‘good death’ in Yoruba culture .....	23
Figure 6: Obituary notice for a ‘good death’ .....	24
Figure 7: Lying-in-state and paying respect in ‘good death’ .....	25
Figure 8: Lying-in-state for Yoruba Muslims in ‘good death’ .....	26
Figure 9: Example of a participant’s social networks generated through a name-generator.....	71
Figure 10: Outcome space of Swedish registered nurses’ conceptions of caring.....	80
Figure 11: Outcome space of how registered nurses in palliative care in Sweden see themselves .....	80
Figure 12: Map of Oyo state showing the study area (Saki).....	82
Figure 13: Social networks of SK15 .....	86
Figure 14: Social networks of SK15 before stillbirth .....	87
Figure 15: Participant (SK16) showed that her husband provided strong financial support by allotting him three lines .....	88
Figure 16: Participant (SK15) showed and labelled her social networks after stillbirth .....	90
Figure 17: Participant (SK12) showed that the father of the stillborn child did not provide any support during the crisis.....	91
Figure 18: Sample of researcher labelled drawing of a participant .....	92
Figure 19: Mementoes donated to the study participants by SANDS New Zealand.....	93
Figure 20: Diagram showing the social networks of a participants before and after stillbirth .....	98
Figure 21: Participant (SK12) illustrates the loss of relationship with an ex-boyfriend after stillbirth.....	110
Figure 22: Participant (SK17) illustrates the loss of some relationships after stillbirth .....	111
Figure 23: Participant (SK18) illustrates the loss of relationships after stillbirth.....	112
Figure 24: Participant (SK15) illustrates the decline in her social relationships after stillbirth .....	113
Figure 25: Participant (SK6) illustrates her social networks after stillbirth .....	114
Figure 26: Participant (SK12) illustrates the loss of relationship with the child’s father.....	115
Figure 27: Participant (SK16) illustrates how the entire support that she received was from the family .....	117
Figure 28: Participant (SK15) illustrates the dominance of the family after stillbirth .....	118
Figure 29: Participant (SK9) illustrates how she became closer with her family members after stillbirth.....	125
Figure 30: Participant (SK5) illustrates the value of relationships .....	127
Figure 31: Participant (SK11) illustrates the role of faith in her adjustment.....	133
Figure 32: Participant (SK8) illustrates the influence of support from religious sources .....	134
Figure 33: Participant (SK17) makes a distinction between stillbirth and livebirth.....	137
Figure 34: Participant (SK16) included her spouse because of the financial support provided .....	140
Figure 35: Participant illustrate the support she received from a health professional .....	142
Figure 36: The outcome space .....	151



## **List of tables**

Table 1: Descriptive data of the participants .....	85
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## **List of abbreviations and acronyms used**

ANC: Antenatal Care

CIA: Central Intelligence Agency

CS: Caesarean Section

FGD: Focus Group Discussion

FMoH: Federal Ministry of Health

HREC: Human Research Ethics Committee

ISA: International Stillbirth Alliance

PTSD: Post-traumatic stress disorder

SANDS: Stillbirth and neonatal death society

SK: Saki

USAID: United States Agency for International Development

WHO: World Health Organisation

UN: United Nations

## **Chapter 1: Introduction and background**

### **1.1 Introduction**

By the time a woman gets close to giving birth she will have begun to identify as a mother (Murphy, 2012). Others in her social milieu will also have noticed this change in her. Women are anchored to both pregnancy and motherhood identities in many ways – for example, changes in their bodies, comments and well wishes from others, baby showers and naming ceremonies that may have been done and the intimate connection of spouses, grandparents, aunts and even siblings. Even if the child is born prematurely at this stage, and requires some forms of medical intervention, the expectation of the mother and everyone connected to her is that the child will come home with the mother. If the baby dies (stillbirth), there is a rapid deconstruction of the identities and the expectations that have been built over time. Thus, it can be said, that stillbirth is not a private event because just as the pregnant woman has built her pregnancy identity on her interactions with others in the community, she will need to confront the community about the loss of a child that will never be. For the woman, she may feel that she has failed and may feel enormous pressure to avoid social interactions with people she once dealt with regularly (Dickstein, 1996; de Montigny, Verdon & McGrath, 2015; Hsu, Tseng & Kuo, 2002). From this perspective, stillbirth is not only an individual experience. It is also a social issue requiring both a social understanding and a social response.

The phenomenon of stillbirth is a public health issue of international proportions because every year, it threatens the well-being and the motherhood identity of around 2.6 million women worldwide (Lawn et al., 2016). Stillbirth interrupts the flow of a woman's everyday life, and some studies have demonstrated that parents often feel abandoned by their family and friends after stillbirth events (Hazen, 2003; Malacrida, 1999; Nuzum, Meaney & O'Donoghue, 2018). The social support system of many mothers of stillborn babies falters because some people do not think a mother can have a relationship with her unborn child and as a result, stillbirth grief is traditionally susceptible to disenfranchisement (Murphy, 2012; Tseng, Hsu, Hsieh & Cheng, 2018; Walter, 2010). Stillbirth is often an isolating and marginalising experience for women, and there is substantial evidence in the literature that the social support networks of mothers of stillborn babies are small, disconnected and under-resourced (de Bernis et al., 2016; de Montigny, Beaudet &

Dumas, 1999; Gold, Treadwell, Mieras & Laventhal, 2017). Many mothers of stillborn babies have been forced to rely only on few family members (Heazell et al., 2016; Shaw, 2014; Tseng, Chen & Wang, 2014), despite that the need for adaptation extends beyond the intimate family circle to include extended family, friends and as well as community members (Brierley-Jones, Crawley, Lomax & Ayers, 2014; Golan & Leichtenritt, 2016; Hazen, 2003).

The impact of stillbirth on women's social networks have led some researchers to explore the social context of stillbirth loss and the findings from these studies have demonstrated that adjusting to stillbirth is dependent on the support provided by the social networks of the stillbirth-affected woman (Bownlee & Oikonen, 2004; Cacciatore, 2013; Rice, 2000; Kiguli, Namusoko, Kerber, Peterson & Waiswa, 2015; Raitio, Kaunonen & Aho, 2015; Sisay, Yirgu, Gobezeayehu & Sibley, 2017; Tseng et al., 2018). Through social network ties, resources such as information (Cacciatore, Schnebly & Froen, 2009), emotional comfort (Tseng et al., 2014), counselling (Allahdadian, Irajpour, Kazemi & Kheirabadi, 2015; Haws et al., 2010), sense of belonging (Cacciatore, 2007; Inati et al., 2018), listening (Gopichandran, Subramaniam, Kalsingh, 2018; Sutan & Miskam, 2012), and help with practical needs such as household chores (Kavanaugh, Trier & Korzec, 2004; Kiguli et al., 2015) have been made available to mothers of stillborn babies.

However, not all mothers of stillborn babies have been able to derive the necessary social resources necessary for them to cope with stillbirth grief from their social networks. For instance, women who are black, poor, unmarried, un-educated and non-religious have been reported to have limited support after stillbirth (Cacciatore et al., 2009; Gold et al., 2017; Paris, de Montigny & Pelloso, 2016). As an illustration, a recent study conducted in the US found that African-American women were significantly less likely than Caucasian women to have the support of family members at the time of delivery of a stillborn baby (Gold et al., 2017). Despite this evidence, insufficient empirical attention has been paid to the social networks of mothers of stillborn babies, especially from developing countries. This lack of information about how mothers deal with the tragedy of stillbirth creates problems for health professionals working with mothers of stillborn babies in developing contexts.

## 1.2 The research context

This thesis seeks to contribute to the growing literature on the social context of stillbirth bereavement by examining the social networks of mothers of stillborn babies and the support they provide from the experience of women in Nigeria. This research is vital in the context of Nigeria because, since 2000, Nigeria has been witnessing an annual increase in the number of stillbirths (Horton, 2016). Currently, Nigeria has the second highest rate of stillbirth (42.9 per 1000 births) in the world and this means nearly 314,000 women lost third-trimester pregnancies to stillbirth in 2015 alone (Blencowe et al., 2016) (figure 1). However, despite the magnitude of stillbirth in Nigeria, most research in Nigeria on stillbirth tends to be fixated on how to prevent the occurrence of stillbirth or how to identify the causal factors related to depression (Agbata, Eze, Ukaegbe & Odio, 2017; Kuti, Awowole & Okunola, 2017; Mbachu et al., 2018; Okochi, Isah, Agida & Adewole, 2018; Ugwa & Ashimi, 2015). Yet, how women deal with the tragedy of stillbirth and what health professionals can do to support these women is limited in the literature.

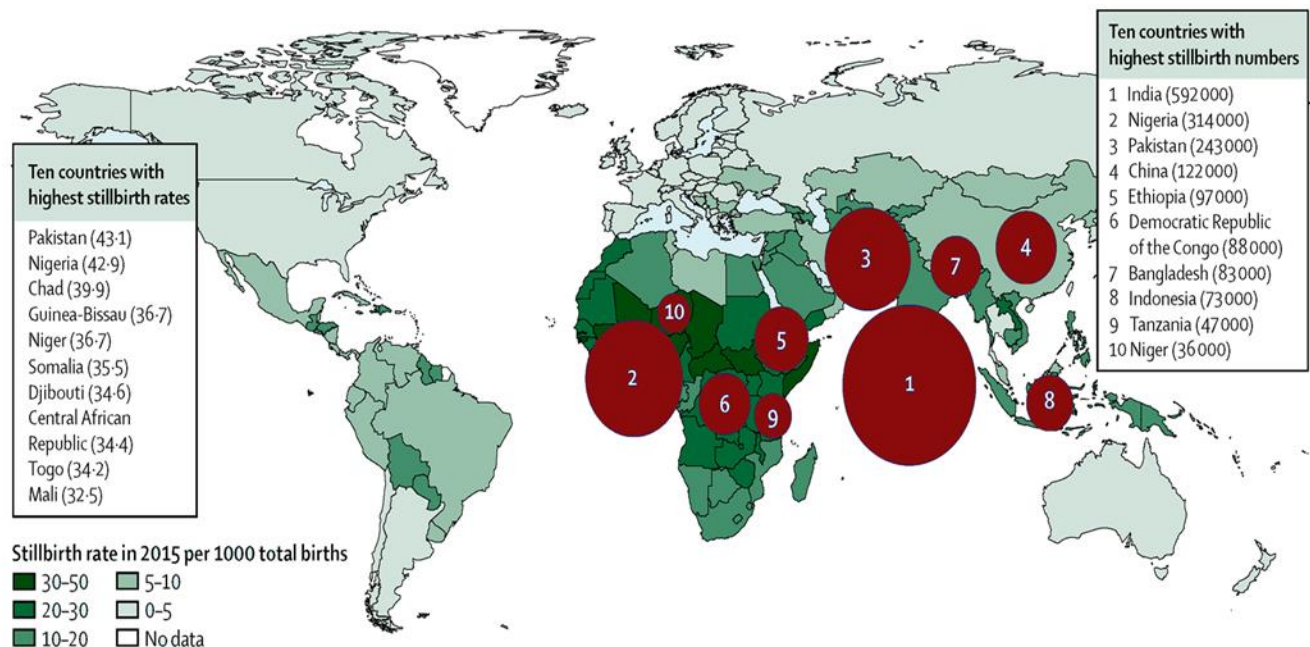


Figure 1: Burden of stillbirth in Nigeria. Source: Blencowe et al. (2016)

Understanding the social response to stillbirth in Nigeria is essential because many more women will continue to face the tragedy of stillbirth. Presently, the Federal Ministry of Health is aiming to reduce the current rate of stillbirth from 42.9 per 1000 births to 27 per 1000 births by 2030 (Federal Ministry of Health [FMoH], 2016). However, even if this was achieved, around 189, 000

women will still be at risk of stillbirth every year, and they have no choice but to deal with it (FMOH, 2016). To make matters worse, many of the factors accounting for stillbirth in Nigeria have been consistently linked with adverse socioeconomic determinants of health such as poverty, illiteracy and poor access to basic obstetric care (Mbachu et al., 2018; Okochi et al., 2018; Ugwa & Ashimi, 2015). A recent study in Nigeria found that 73.5% of women who experienced stillbirth were of low social class (Agbata et al., 2017). Unfortunately, the situation will only get worse because recent statistics suggest that six people go into poverty every minute in Nigeria (World Poverty Clock, 2018), and this means around 85 million Nigerians live below the poverty line (World Bank, 2018). The implication of this for mothers of stillborn babies in Nigeria is that their experience of grief may be magnified because the resources needed to mourn might not be available.

While there is compelling evidence that women in Nigeria face a higher risk of stillbirth (Blencowe et al., 2016; Horton, 2016; Lawn et al., 2016), context is necessary because of Nigeria's diversity. Nigeria is widely regarded as the "Giant of Africa" (USAID, 2017, p. 1) due to its estimated population size of 196 million, the largest of any African nation (Population Reference Bureau, 2018). With this population, it is hardly surprising that Nigeria is a diverse country. The Central Intelligence Agency (CIA, 2018) noted that there are 250 ethnic groups in Nigeria and even though English is the official language, there are over 500 indigenous languages that are spoken in Nigeria to date (Adebayo, Liu & Cheah, 2018). Individuals from various ethnic groups still maintain their respective ethnic and cultural norms, traditions and religious practices (Pate, Song, Abdullahi & Umar, 2014) and this means all ethnic groups in Nigeria cannot be assumed to be similar. However, despite the plurality and heterogeneity of ethnic groups in Nigeria, only three of the ethnic groups are politically influential. These three ethnic groups include Hausa and Fulani, Igbo (Ibo) and Yoruba, and together, these three ethnic groups make up 70% of Nigeria's population (Scott-Emuakpor, 2010).



*Figure 2: Location of Nigeria in Africa. Source: Sambo (2010)*

### **1.3 Healthcare system in Nigeria**

In order to properly contextualise some of the barriers that contribute to the high rate of stillbirth in Nigeria, it is important to briefly discuss the health system in Nigeria. The healthcare system is organized into primary, secondary and tertiary healthcare levels and this means that public health provision is a concurrent responsibility of the three tiers of Government (Home Office UK, 2018). The Local Government Areas (LGAs) are responsible for primary healthcare, the State Governments are responsible for providing secondary care while the Federal Government is responsible for policy development, regulation, overall stewardship and providing tertiary care at teaching and specialist hospitals (Pharm Access Foundation, 2015). The LGA level is the least funded and organized level of government and therefore has not been able to properly finance and organize primary healthcare, creating a very weak base for the healthcare system (Scott-Emuakpor,

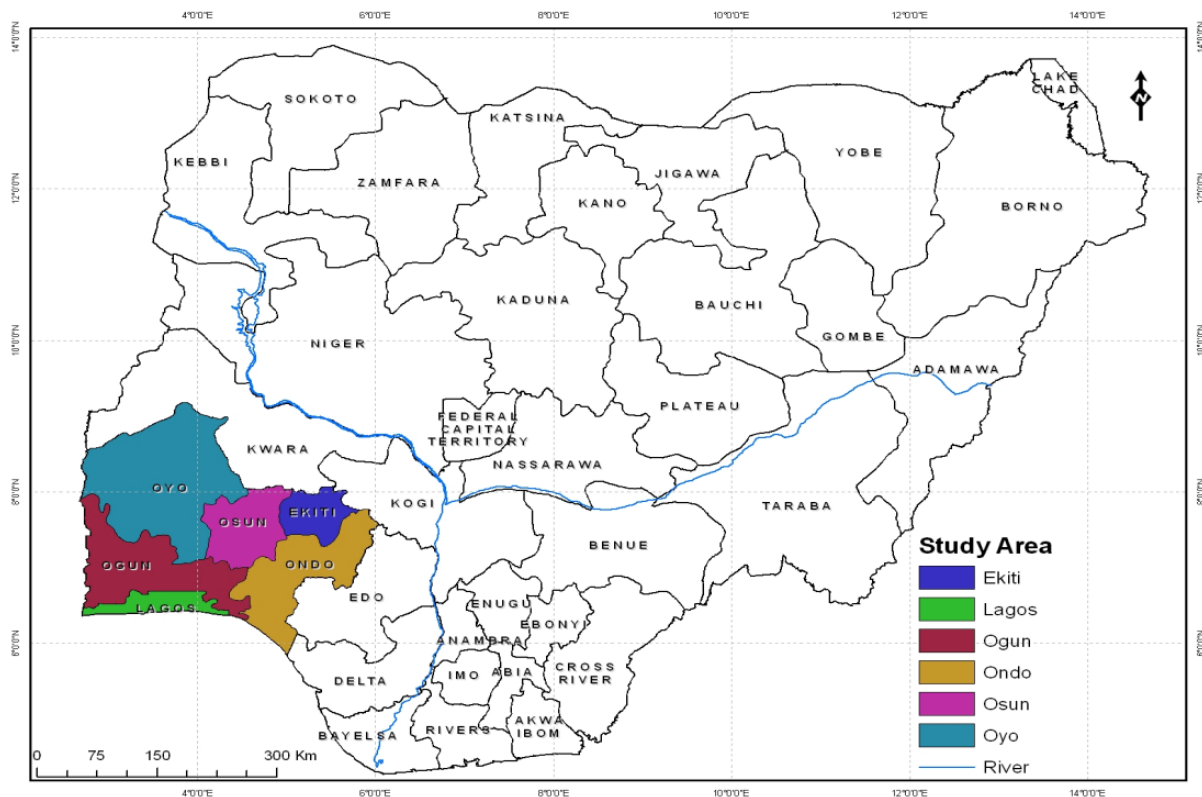
2010). While Primary Health Care (PHC) is supposed to be the community's entry point into the healthcare system, the disconnection between the three tiers of healthcare delivery has created a situation where the tertiary, secondary and primary healthcare are not accountable to one another. The referral system that is supposed to exist between the three levels of healthcare is not always respected and some studies (Aguwa et al., 2010; Okoli et al., 2017; Akande, 2004) have estimated that about 60-90% of patients bypass the PHC facilities to self-refer to the referral levels. This means that conditions that are supposed to be managed at the primary level are often managed at the tertiary level (Koce, Randhawa & Ochieng, 2019).

This indiscriminate use of the higher levels of care further diminishes the relevance of PHC facilities in Nigeria because they are not only underutilized, but also unrecognized by the community that are supposed to use them. The burden that the weak PHC has created means that the ability and role of referral facilities (secondary and tertiary facilities) to manage advanced medical conditions and as well as obstetric emergencies have been negatively impacted (Home Office UK, 2018). To put into context, there are 34,173 health facilities in the whole of Nigeria, out of which 30,098 (88 percent) are primary healthcare facilities, 3,992 (12 percent) are secondary facilities, and just 83 (< 1 percent) are tertiary facilities (FMoH, 2016). But with the majority of secondary and tertiary health facilities located in major cities, urban dwellers' access to healthcare has been reported to be four times that of rural and town dwellers (Home Office UK, 2018). Furthermore, the Nigerian government's health allocation is poor, estimated at only 6% of the national budget (Home Office UK, 2018) and this has created a situation where 71.7% of the total health expenditure are out-of-pocket (Pharm Access Foundation, 2015). This situation has pushed people of low socioeconomic status further away from healthcare access. The fragmented state of Nigerian healthcare system has direct implications for the government's ability to prevent the high rate of stillbirth in Nigeria. This is because the government has identified the "strengthening of community-based interventions" as one of the four intervention packages required to reduce the high rate of stillbirth (FMoH, 2016, p. 20). But with the weak readiness of primary healthcare facilities to provide quality newborn care to the women who need it the most, the rate of stillbirth in Nigeria is likely to remain high for a long time.



## 1.4 Stillbirth in Yoruba society

To understand how women in Nigeria emerge from stillbirth grief, I turned my attention to Yoruba women because motherhood confers the highest value and respect for Yoruba women (Aluko, 2015). Nearly 30 million people are of Yoruba ethnicity in Nigeria (CIA, 2018), making them the third largest of any ethnic group (Okolie et al., 2018). The Yoruba people have a definite geographical boundary (Adamolekun, 1999) and the south-western part of Nigeria, consisting of six states (figure 3), is the ancestral home of the Yoruba ethnic group (Odebode & Onadipe, 2011). The Yoruba people share a common language and similar culture, and as such, the word Yoruba itself refers to the culture, language and people of Yoruba ethnic group (Akanle & Adejare, 2016; Busari, Owojuyigbe, Okunola & Mekoa, 2017).



*Figure 3: Map of Nigeria showing the South-Western region. Source: Faleyimu and Agbeja (2012)*

The occurrence of stillbirth has a particular significance for Yoruba women for a number of reasons. First, continuity is a societal value in Yoruba society, and the cultural ideology of continuity remains the core of Yoruba life (Koster, 2003; Makinde, 2004). The role of women is therefore defined by fertility. Koster (2003) noted that having children in Yoruba culture is a

precondition to a successful life. It is therefore not surprising that a recent study in one Yoruba community found that 79% of women in the study were under intense social pressure to become pregnant (Fehintola et al., 2017). Second, although continuity is valued among Yoruba people, stillbirth is inconsistent with the characteristics of what the Yoruba people believe is a 'good death' (Olomola, 1988; Osanyinbi & Falana, 2016). Thus, immediately after a stillborn infant is delivered, the child is detached from the mother, and the mother will not see the child again because of the beliefs that the malevolent spirit of the child will harm subsequent pregnancies (Adebayo et al., 2018). Because of these beliefs, stillborn babies are either abandoned in the hospitals, thrown into the bush without burial or buried quickly without the mothers' knowledge in unmarked graves far away from home (Adeboye, 2016; Ebhomienlen, 2016; Olomola, 1988). These practices surrounding stillbirth are a direct opposite to mourning practices for 'good deaths' in Yoruba society, where it is essential for the bereaved and her relatives to see the body (Kuti & Ilesanmi, 2011; Ololajulo, 2017).

These beliefs surrounding stillbirth in Yoruba culture means mothers of stillborn babies have no access to public mourning or funerals for their stillborn children, and they are also prohibited from discussing the loss (Kuti & Ilesanmi, 2011). A recent study conducted to understand the sociocultural dynamics of perinatal loss among Yoruba women revealed that mothers of stillborn babies believed that the practice of detaching them from their stillborn babies immediately after birth is a deliberate and coordinated societal attempt to "completely wipe off the child's existence" (Adebayo et al., 2018, p. 10). This suggests that the social consequences of stillbirth may place Yoruba mothers of stillborn babies at higher risk of psychosocial problems. This is because these cultural beliefs amplify the discrepancy between the same culture that extols the value of motherhood and at the same time places restriction on grief resulting from stillbirth. However, regardless of the cultural restrictions placed on stillbirth grief, no Yoruba woman can forget that she had a baby who was stillborn, and they still have to live with the loss in the same context where their grief is discredited. Therefore, understanding the resources that help Yoruba women deal with stillbirth grief can be useful for those working in cross-cultural contexts, as well as in developing countries.

The full impact of the beliefs and taboos against stillbirth grief among Yoruba women is yet to be fully explored, but they definitely affect it. Although limited studies have reported on the rules and

norms that affect stillbirth grief in Yoruba culture, no study has examined how these cultural norms influence the support available for mothers of stillborn babies. I believe it is important to understand how beliefs about stillbirth influence the support available to Yoruba women after stillbirth because healthcare professionals working with mothers of stillborn babies have long sought to understand how they can offer culturally sensitive care to grieving patients (Kelley & Trinidad, 2012; Mills, Ricklesford, Heazell, Cooke & Lavender, 2016; Raitio et al., 2015; Siassakos et al., 2017). In Nigeria, limited, but recent studies have revealed that healthcare providers have yet to meet the social and emotional needs of mothers of stillborn babies (Adebayo et al., 2018; Kuti & Ilesanmi, 2011).

#### **1.4.1 Good birth versus bad birth among the Yoruba people**

In order to understand the contextual reality of women experiencing stillbirth in Yoruba society, it is important to understand the societal response to a pregnancy that results in a livebirth. If a baby is born alive in Yoruba society, the default congratulatory greeting for the mother of the child from others is expressed as ‘a ku ewu omo’, translated literally as ‘congratulations for surviving the danger inherent in the process of becoming a mother’. This greeting highlights the acknowledgement of those associated with the mother of the newborn baby that pregnancy and childbirth are events fraught with risks and dangers (Olaoye, 2013). The fear of pregnancy as an unsafe event which is reflected in how mothers with liveborn babies are congratulated makes sense when one considers that about 58,000 women die from childbirth every year in Nigeria (WHO, 2018). This realisation of the dangers inherent in the pregnancy journey have therefore made pregnancy a social event where the role of keeping the pregnancy safe is not only that of the pregnant woman, but also of those associated with her.

Specifically, there are some traditional practices that have been designed to offer protection for the mother and child. As an illustration, a recent study conducted among 250 Yoruba women found that during pregnancy, 54.0% of the participants avoided going out when the sun is high, 53.2% avoided going out at night, 61.2% avoided the consumption of snails, rodents, and kola nuts, while another 29% avoided sexual intercourse throughout pregnancy (Aworinde et al., 2019). Some of the reasons why these women modified their behaviours during pregnancy are to ward off evil spirits, avoid miscarriage/stillbirth, and avoid prolonged labour (Aworinde et al., 2019). It is believed that the consumption of certain food such as kolanuts stimulate premature contractions

and other local foods contribute to the development of an abnormally large fetus, which may complicate birth (Oni & Tukur, 2012). For a woman to successfully make necessary lifestyle modifications and observe the pregnancy taboos, she needs the cooperation of not only the family, but the wider community. For instance, the diet modifications may change the way food is prepared in the home and the woman's inability to go out at certain times means greater dependence on others. The safety of the pregnancy thus become a collective effort between the pregnant mother and her support networks.

With regards to this collective effort among the Yoruba people towards the positive outcome of pregnancy, Adetunji (1996, p. 1566) wrote that

the traditional support system recommends those who are not carrying the pot and water [pregnancy] – partners, parents-in-law, relatives and friends – should stand by and look after those carrying them. They are to watch out for, point out and remove possible sources of danger along the way, thereby contributing to the safety and enjoyment of the trip.

The traditional system of support represents the social capital of the pregnant woman because they help her negotiate the dangers inherent in pregnancy and they contribute to the woman's positive pregnancy experience (Dike, 2013). If the baby survives childbirth, the role of the traditional Yoruba support system extends beyond pregnancy. A child-naming ceremony called 'isomo loru'ko' is held when the baby is eight days old and this naming ceremony signifies the entrance of the baby into the community. These naming ceremonies, which are witnessed by friends, family and well-wishers are very symbolic not only because of their flamboyance and festivities, but because they also cement the mothers' own realities of pregnancy and motherhood. From the moment the child is given a name, the woman ceases to be known or called by her first name, but rather by the name of the child. For instance, if the child is named Steph, the mother will become 'mama Steph', meaning the mother of Steph.

In addition, the naming ceremony also represents an informal opportunity for the mother to show her appreciation to all those who have assisted and played a role in her achievement of a safe pregnancy. Those who have assisted the new mother during her pregnancy journey are honored with an opportunity to contribute the names that the child will bear. As an illustration, Fakuade, Fadahunsi, Rafiu and Adekeye (2015, p. 15) wrote that:

... the child is named, and other extended family members are given the honour to give their own names to the child. They do this with gifts of money and clothing. In many cases,

they would want to call the child by the name they give him or her. Due to this, a new baby may end up with more than a dozen names.

The birth of a child therefore leads to the binding together of the extended family, friends and well-wishers in a helping act of solidarity that is designed to provide social welfare for the new mom and her child (Olaore & Drolet, 2017). However, despite the immense involvement of the traditional system of support during pregnancy; women who suffer stillbirth are abandoned to their grief. MacLean (1971) wrote that the Yoruba customs do not regard stillborn children as possessing an existence independent of their mothers. And because of this, neither the community nor the stillborn mother's social capital take part in her mourning, but rather "she is abandoned to her weeping as she bewails the passing of her child" (MacLean, 1971, p. 151). This means that the loss of a baby to stillbirth not only robs a mother of a child, it also robs her of the change in status and identity that accompanies a livebirth and as well as the people that ought to show up for her in solidarity

In order to understand how social beliefs in Yoruba society influence social support after stillbirth, I turned my attention to the theory of social capital because stillbirth changes how others interact with women after stillbirth. An analysis of Yoruba women's social networks can help in understanding how problems of stillbirth bereavement are met. Adapting to stillbirth depends on the support from others, and this makes the concept of social capital suitable in this research because it can help capture the process through which support becomes available to mothers of stillborn babies (Adler & Kwon, 2002; Lin, 2005). A social capital analysis is valuable in this research because of the need to analyse the source of support for mothers of stillborn babies, the type of support received and how they perceived the support. This is important because in cultures where belief systems say, 'do not grieve because it will affect subsequent pregnancies' or 'do not grieve because if you do, you will appear ungrateful to others', it is difficult to accurately assess what seems to be muted grief (Rosenblatt, 1998). In such cultures, Rosenblatt (1988, p. 69) argued that it is pointless to "try to distinguish where the rules that mute grief leave off and real grief begins". Instead, how culture plays out in social relationships after stillbirth have been espoused as a significant part of the social context of stillbirth bereavement (Brownlee & Oikonen, 2004). In other words, when caring for mothers of stillborn babies in varied cultural contexts, one cannot assume that because a mother of a stillborn baby has a circle of friends and family, that support will be available for her. This is because perceived sociocultural expectations surrounding stillbirth

can hamstring friends and family from providing any meaningful support for the bereaved mother (Plagge & Antick, 2009).

Thus, apart from recognising the social networks of mothers of stillborn babies, it is much more important to identify the source and type of support received and determine whether the received support promoted or undermined the well-being of the woman. This is because there is conflicting evidence as to the kind of support that benefits women after stillbirth. As an illustration, some studies have found that support provided by spouses and immediate family was the only form of support that prevented depression or led to personal growth after stillbirth (Adeyemi et al., 2008; Cacciatore et al., 2009; Obi, Onah & Okafor, 2009; Raitio et al., 2015). However, others have found that support from friends was more important than that of family members to prevent depression (Chung & Reed, 2017; Sutan et al., 2010). This suggests that where women receive support from after stillbirth can determine the kind of support that is available to them, as well as the psychosocial outcomes of bereavement. Approaching this study from a social capital perspective, therefore, allows me to theoretically identify the source of social support for mothers of stillborn babies, the type of support received and how they perceive this support (Lin, 2005).

I developed an interest in Yoruba mothers of stillborn babies because I am aware of the existence of beliefs and taboos against stillbirth that make them grieve in silence. But having lived in other countries outside Nigeria, I returned to the same context of Yoruba society to understand how Yoruba women emerge from stillbirth loss despite that they are not supported to mourn their loss as in other contexts. Despite that Yoruba women share a cultural context, it would be a gross oversimplification to assume that their experience of stillbirth is also shared. Bereaved people do not grieve their losses the same way (Hall 2011). Rather, people grieve in qualitatively distinct ways. For example, due to the value placed on motherhood in Yoruba society, a woman who has already proved her fertility through previous successful pregnancies is unlikely to experience stillbirth loss in the same manner as a woman expecting her first baby. As a result, one important methodologic decision in this study was to select a research design that not only aligns with the sociological ideas of social capital theory, but that also embraces the idea that the experience of stillbirth is not only embedded in a cultural context but that it is also highly individualised.

Phenomenography was selected as a methodological base for this research because it concerns itself with the qualitatively different ways in which people experience a phenomenon by focusing on the relationship between the phenomenon and the person experiencing it, in order to tease out the diversity of experiences. Phenomenography, therefore, is able to support the consideration of how social factors, such as age, parity, marital status, and presence or absence of social support diversify mothers experience of stillbirth. This is also reflective of healthcare professionals' increasing recognition that differences exist in how women experience stillbirth, and this means the provision of effective and compassionate care rest on the ability to acknowledge these differences in experiences (Heazell et al., 2013; Horton & Samarasekera, 2016).

### **1.5 Aim of the study**

This study aimed to understand the role of social capital in how Yoruba women experience stillbirth loss, in order to contribute to a more realistic bereavement care as well as to contribute to the theoretical debate on the value of social capital analysis.

### **1.6 Objectives of the study**

The objectives of this study were to:

1. identify and describe the social networks of Yoruba women who have experienced stillbirth loss.
2. examine Yoruba women's description of the ways in which their social networks supported them after suffering a stillbirth.
3. understand the bereavement needs of Yoruba women after stillbirth.
4. bring attention to social capital analysis as a tool for the provision of realistic stillbirth bereavement care.

### **1.7 Significance of the study**

The international research on stillbirth bereavement is ongoing, and currently, there is a global effort to achieve a consensus on a package of care for stillbirth bereavement by 2020 (de Bernis et al., 2016; Shakespeare et al., 2019). The findings of this thesis made three contributions to the cross-cultural understandings of stillbirth bereavement, and this will be useful to the ongoing international debate on how mothers of stillborn babies can be better supported. First, this study

contributes that culture really matters in how mothers of stillborn babies express their grief, how they are supported and how they would want to be supported. Second, there is still a deficit of kind, compassionate and skilled nursing care for mothers of stillborn babies. Third, mothers of stillborn babies in contexts where social and cultural norms target stillbirth grief may only have the support of their family after stillbirth. But family-only support may be inadequate without community support for stillbirth grief. Together, these contributions provide support for the need for bereavement care that is culturally safe and competent, as well as recommendations that can result into nursing care and policy initiatives that seek to reduce harm for mothers of stillborn babies.

## 1.8 Operational terms

**Bereavement:** refers to the period after a loss (Hall, 201, p. 8)

**Grief:** refers to the physical, emotional, cognitive, spiritual and social experience of a loss (Hall, 2011, p. 8)

**Perinatal loss:** refers to the death of a baby during pregnancy or in the newborn period (Kavanaugh, Trier & Kozec, 2004, p. 70)

**Mourning:** refers to the social expressions of grief which are shaped by the practices of a given society or cultural group (Stroebe & Schut, 1998, p. 7)

**Social capital:** refers to a range of resources available to individuals thanks to their participation in social networks (Herrerros, 2004, p.6)

**Social network:** refers to the web of social relationships surrounding an individual, in particular, structural features such as the type and strength on each social relationship (Umberson & Montez, 2010, p. 1).

**Social support:** refers to a social network's provision of psychological and material resources intended to benefit an individual's ability to cope with stress (Cohen, 2004, p. 676).

**Stillbirth:** refers to a baby born with no signs of life at or after 28 weeks' gestation (WHO, 2016, p.1).

## 1.9 Outline of the thesis

This thesis is made up of six chapters. Chapter 1 presented the background to the study, the research aim, the research objectives, the significance of the study, the operational definition of



terms and the thesis outline. Chapter 2 presents the summary of the major findings in the literature review as it relates to this study. The findings are arranged into seven broad categories and these are: factors associated with stillbirth in Nigeria, cultural understandings of stillbirth, social consequences of stillbirth, social networks of mothers of stillborn babies, factors associated with poorer outcomes after stillbirth, women's experience of health professionals support and what helps women cope with stillbirth. The chapter concludes with the summary of the reviewed studies. Chapter 3 presents the theoretical framework in relation to the research problem. The chapter has sections on the theoretical ideas of the social capital theorists, the forms of social capital, the findings from social capital research among women, and the measurement of social capital in research. Chapter 4 presents the research methodology of phenomenography that was used in this study, as well as the research design. The design feature included the study area, the participants that were selected, data collection approaches which included drawings, interviews and a focus group discussion. This chapter also included the phenomenographic data analysis technique that was used and issues surrounding integration of the three datasets. Methodologic rigour and ethical considerations are addressed. Chapter 5 presents the research findings from the three datasets in four broad categories which are: relationships change, relationships matter, material support makes a difference and health professionals neither help nor support. Except for the third category (material support makes a difference), which has two sub-categories, all the other themes had three sub-categories each and this means the findings are presented in four major themes and 11 sub-categories. Finally, an outcome space, which is a diagrammatic representation of all the categories related to one another is presented. Finally, the last chapter presents a summary of the findings, implications of the findings, the contributions of the study to phenomenography and social capital theory and the recommendations for nursing practice, future research and health policy.

## **Chapter 2: Literature review**

### **2.1 Introduction**

Many women suffer stillbirth at near or full term, and this means they have experienced months of preparation and eager anticipation for the arrival of their baby. The phenomenon of stillbirth is, therefore, a life-changing experience for women who have experienced the horror and it is not surprising that stillbirth changes how women view themselves as well as others after the event (Cacciatore & Bushfield, 2007). Stillbirth opens up women to both psychological and social needs that require re-adjustment to a changed and unfamiliar body, social interactions, as well as feelings of fear and worry (Murphy, 2012). Without adequate social support, a stillbirth can exert a devastating impact on the well-being of women. However, the abilities of women to obtain necessary support that can boost their chances of better outcomes after stillbirth is often challenged because of the complex interaction of societal factors such as beliefs, shame, and guilt that may lead to withdrawal from social relationships (Allahdadian et al., 2016; Flenady et al., 2014; Horton & Samarasekera, 2016). This chapter, therefore, discusses the relevant conceptual and empirical literature in order to identify the theoretical and philosophical basis on which the link between social capital and stillbirth bereavement rests, particularly within a defined cultural context. I conducted an extensive literature review on the phenomenon of stillbirth generally, but I focused mainly on the social and cultural aspects of stillbirth experience.

### **2.2 Search strategy**

The literature was searched extensively for relevant information on social and cultural factors influencing the experience of stillbirth and the support available for mothers of stillborn babies. A limited search of PubMed, PsycINFO and Web of Science – core collection was undertaken initially by means of keywords in the title to identify subject headings and further potential keywords relating to stillbirth and social capital. A solo search of 'stillbirth' in PubMed and PsycINFO databases revealed synonyms that other researchers have used to characterise the phenomenon of stillbirth, and these were: involuntary pregnancy loss, perinatal death, perinatal mortality, perinatal loss, stillborn and foetal death. A similar process was conducted on Web of Science for 'social capital' and synonyms identified were: networks, personal networks, relationships, relationship quality, social networks, social relations, social asset, social resources, social connections, social support and social bonds. The search for this literature review was then

undertaken in CINAHL, Medline, PubMed, PsycINFO, Web of Science, Cochrane, as well as Google Scholar by combining the keywords with Boolean operators. A record sheet was kept detailing essential information for each article retrieved, including the aims and objectives of the study, study design, key results, country of origin, outcome measures and sample description.

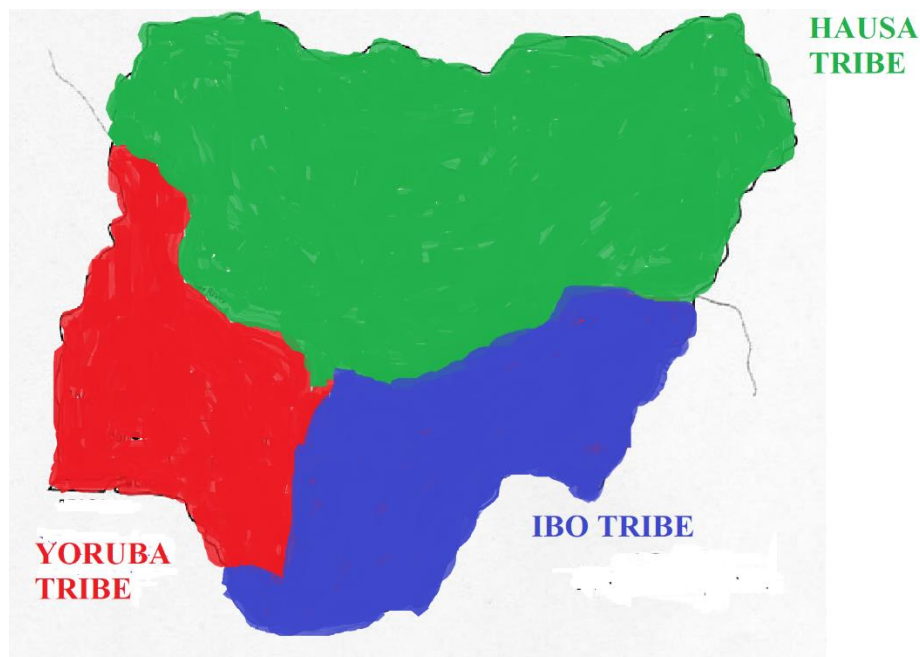
There was particular attention paid to the sample description of each recruited article because of the overlap between definitions of stillbirth that different countries and authors adopt. Although for international comparison, the World Health Organisation (WHO, 2016) has recommended that only pregnancies that have reached at least 28 weeks of gestation before foetal demise should be counted as stillbirth, not all countries adopt the WHO's definition of stillbirth. Most developed countries adopt a lower threshold in their definitions of stillbirth, and as an example, in Australia, New Zealand and the US, stillbirth is defined as the death of a foetus after 20 weeks of pregnancy. Because most researchers tend to adopt the legal definition of stillbirth of the country where a study is carried out, the implication is that a loss regarded as stillbirth in a US study, for instance, may be regarded as miscarriage in some contexts like Nigeria. These differences in the definition of stillbirth across different contexts mean much of the literature to date has grouped all forms of pregnancy or perinatal loss such as miscarriages, stillbirths and neonatal death into one. When I tried to limit my inclusion criteria to only studies that adopted WHO's definition of stillbirth, which is also the official definition of stillbirth in Nigeria, I ended up with limited articles.

However, in order to establish the goals for the present research, I had to rely on the same research studies that conflated all perinatal losses (miscarriage, stillbirth and early neonatal loss) into one experience. However, it is important to point out that while all forms of pregnancy loss are devastating for women and their families, evidence suggests that the further a pregnancy has progressed, the greater the attachment the mother has to the baby. As an illustration, the risk of relationship dissolution after a miscarriage lasted for three years, whereas it persisted for up to 10 years for mothers of stillborn babies (Gold, Sen & Hayward, 2010). Thus, some authors (Brownlee & Oikonen, 2004; Campbell-Jackson & Horsch, 2014) have argued that conflating all pregnancy loss into one experience of perinatal loss will only serve to further confuse the understanding of the grief process.

Also, there is increasing acknowledgement from researchers that stillbirth events come with devastating effects for men as well. As such, an increasing number of studies are striving to include men in their sample and treating parents of stillborn babies as dyads. In this study, the focus was on mothers because of the unique relationship between them and their stillborn babies due to the psychological, physiological and social processes of pregnancy and also because it is the mothers in Yoruba communities that are targeted by the harsh traditional value judgements after stillbirth. Therefore, I reviewed papers that only reported on mothers or that separated the results for mothers from other family members or spouses. The findings from the literature which are presented below are organised into seven categories which are: factors associated with stillbirth in Nigeria, cultural understandings of stillbirth, social consequences of stillbirth, social networks of stillborn mothers, factors associated with poor outcomes after stillbirth, women's experience of health professionals support and what helps women cope with stillbirth. It is also noteworthy to highlight that none of the reviewed studies approached stillbirth bereavement from social capital perspectives. Even though social support was a salient theme in the stillbirth literature, social support is only just a dimension in the concept of social capital and as such, how stillbirth and sociocultural factors interact together to influence the support available for women after stillbirth has not been covered in the literature.

### **2.3 Factors associated with stillbirth in Nigeria**

Apart from the ethnic diversity that characterises the population of Nigeria, one dominant theme in the lives of Nigerians is the issue of religion. Religion plays a significant role in the lives of Nigerians to the extent that some authors have argued that no issue in Nigeria can be fully understood without considering the role of religion (Adebayo et al., 2018; Koster, 2003; Olajubu, 2008). The Central Intelligence Agency (2018) estimated that 50% of Nigerians practice Islam, 40% are Christians and the remaining 10% adheres to their indigenous beliefs. Interestingly, Nigeria is geographically divided according to the religions that people practice (figure 4). For instance, persons who believe and uphold the teachings of Islam (Muslims) represent most of the population in the Northern part of Nigeria, while Christians are the majority in the South (Library of Congress, 2008; Scott-Emuakpor, 2010). This means that most people in the northern part of Nigeria (Hausa tribe) are Muslims, while those in the southern part (Igbo and Yoruba) are mostly Christians and this is reflected in the diagram below.



*Figure 4: Tribal and religious distribution of Nigeria. Source: Lewis (2011)*

However, despite that majority of Nigerians identifies with either Christianity or Islam, there is evidence in the literature that people still adhere to their traditional beliefs (Adebileje, 2012; Lawuyi & Olupona, 1988; Osanyinbi & Falana, 2016). This means that most Nigerians adhere to the beliefs and practices of more than one religion and this has made coping with grief very complicated (Eyetsemitan, 2002). The coexistence of traditional religious beliefs with that of modern religious beliefs has been described as a double-edged sword because on the one hand; they provide guidance, comfort and hope during challenging times; while on the other hand, they can be disempowering (Adebayo et al., 2018). The plurality of beliefs that exist side by side in people's mind have created a mental-psyche kind of framework in the minds of Nigerians (Ebhomienlen, 2016), and this continues to influence the adoption of preventative measures against stillbirth, as well as health-seeking behaviours. This is well reflected in the factors that have been empirically identified as causing stillbirth in Nigeria.

Findings from studies that have investigated the factors responsible for the high rates of stillbirth in Nigeria seem to confirm that social factors such as ignorance, religion, low literacy level and out-of-health facility deliveries contribute the most to the high rate of last trimester stillbirths in Nigeria. Fourteen studies, mostly recent studies that investigated factors causing stillbirth from all geopolitical zones in Nigeria were identified in the review. Twelve of the studies collected

retrospective data on incidences of stillbirths from hospital records over specific periods of time (Agbata *et al.*, 2017; Audu, Alhaji, Takai & Bukar, 2009; Awoleke & Adanikin, 2016; Dahiru & Aliyu, 2016; Ezugwu, Onah, Ezegwui & Nnaji, 2011; Kuti, Awowole & Okunola, 2017; Mbachu *et al.*, 2018; Okeudo *et al.*, 2012; Omo-Aghoja, Onohwakpor, Adeyinka & Omene, 2014; Ugboma & Onyearugha, 2012; Ugwa & Ashimi, 2015; Suleiman, Ibrahim & Abdulkarim, 2015), while two studies collected data prospectively (Alkali, Jalo, El-Nafaty & Bode-Thomas, 2014; Mutihir & Eka, 2011).

The data collection period varied from nine months (Alkali *et al.*, 2014) to six years (Ugboma & Onyearugha, 2012). Collectively, these studies reported data on 117, 136 births that were recorded between 2005 and 2015 in various tertiary level hospitals across the country. Out of the 117, 136 total births, 4,111 pregnancies resulted in stillbirths after 28 weeks of gestation. This means the stillbirth rate in these studies was 35.1 per 1000, which is lower than the current national stillbirth rate of 42.9 per 1000 births. However, except for Alkali *et al.* (2014) who included community women in their study, all the other thirteen studies collected data from teaching hospitals (tertiary-level health facilities) and this suggests that the rate of stillbirth could be an under-representation since not all pregnant women make it to tertiary level of care for childbirth. Two of the studies (Dahiru & Aliyu, 2016; Omo-Aghoja *et al.*, 2014) did not distinguish whether the stillbirths recorded in their studies were fresh (death of a foetus during labour or delivery) or macerated (death of a foetus sometime before the onset of labour). When these two studies were excluded, a total of 1508 (42.4%) stillborn babies were categorised as fresh stillbirths, meaning that these babies were alive when labour started (Mbachu *et al.*, 2018; Suleiman *et al.*, 2015). However, despite that some of the fresh stillbirths occurred at full-term to mothers who had healthy pregnancies, none of the mothers of the stillborn babies requested post-mortem or autopsy to determine the cause of stillbirth in all the studies.

There is agreement among all the studies regarding the cause of stillbirth in Nigeria. Many of the studies identified the following causes: (a) unplanned transfers from lower levels of care, churches or traditional homes due to labour complications (Akali *et al.*, 2014; Awoleke & Adanikin, 2016; Ezugwu *et al.*, 2011; Mbachu *et al.*, 2018; Ugboma & Onyearugha, 2012); (b) lack of antenatal care during pregnancy or not being registered for pregnancy care (Kuti *et al.*, 2017; Okeudo *et al.*, 2012; Omo-Aghoja; Suleiman *et al.*, 2015; Ugboma & Onyearugba, 2012; Ugwa & Ashimi,

2014;); (c) hypertensive disorders of pregnancy (*Kuti et al., 2017; Mutihir & Eka, 2011*); (d) injudicious use of oxytocin and inadequate intrapartum monitoring despite use of partograph (*Ezugwu, 2011*); (e) personal and socioeconomic factors such as low social class, being unmarried; low literacy/educational status; being unemployed and being a primigravida (*Agbata et al., 2017; Audu et al., 2009; Dahiru & Aliyu, 2016; Okeudo et al., 2012; Omo-Aghoja et al., 2014*); (f) and delay in seeking care for pregnancy and labour complications such as prolonged labour, obstructed labour, abruption placentae (*Mutihir & Eka, 2011; Ugboma & Onyearugha, 2012; Ugwa & Ashimi, 2014*).

In addition to the above, other authors (*Agbata et al., 2017; Kuti et al., 2017; Mutihir & Eka, 2011; Ugboma & Onyearugba, 2012*) reported that the risk of stillbirth was highest among women whose sociocultural and religious beliefs made them prefer childbirth at religious birthing centres. As such, religion, traditional and superstitious beliefs prevented some women from using conventional care. However, one would have expected the issue of stillbirth to have become a health scandal of national proportion considering that some of the over 40% of fresh stillbirths in the reviewed studies occurred in the hands of healthcare professionals. But this was not the case. Most of the women who were hardest hit by the tragedy of stillbirth in the reviewed studies were of a low social class, and this means poverty is another barrier preventing many women from having access to a skilled healthcare provider during childbirth (*NPC, 2014*). Less than 5% of Nigeria's population is covered by some form of health insurance, which means an individual will pay over 70% out of pocket to receive healthcare at any given time (*Pharm Access Foundation, 2015*). As a result, there is a considerable gap in healthcare access and outcomes among Nigerians based on their geographical location and socioeconomic status (*Okeudo, Ezem & Ojiyi, 2012; Fawole et al., 2011*). For instance, 86% of women in urban areas receive antenatal care (ANC) from skilled providers, compared to 48% of mothers in rural areas. Likewise, only 11% of births to uneducated mothers occur in health facilities, whereas 91% of women whose educational level is above secondary education gave birth in health facilities (*FMoH, 2016*).

## **2.4 Cultural understandings of stillbirth: Yoruba perspective**

Since this study sought to understand social capital from the perspectives of Yoruba women who have experienced stillbirth, I reviewed the literature relating to the cultural understandings of stillbirth. Most of these studies reviewed here are conceptual and anthropological. It was important

to first examine how Yoruba culture treats stillbirth events because even though stillbirth affects women of every culture and in any location, the experience of stillbirth and how societies deal with it differs across cultures (Oyebode & Owens, 2013; Rosenblatt, 2001). Much has been written about the variability of grief across different cultures (Layne, 1990; Lovell, 1983; Neimeyer, Klass & Dennis, 2014; Rosenblatt, 2008), but Lofland (1985) points out two reasons that reverberate with the current study. First, Lofland argued that if culture is the framework of beliefs and values that determine how individuals define their world and express their feelings, it is expected that the beliefs and values associated with death will share in the cultural diversity that defines every culture. Second, Lofland also maintained that what death looks like demographically- its frequency, size and shape is not always the same everywhere. Both of Lofland's arguments are reflected in the cultural practices of Yoruba people with regards to death and bereavement.

Like any other culture, the Yoruba culture provides answers to questions such as what should be done with the dead, who should be mourned, what mourners should do with their emotions, and how mourners should behave (Oyebode & Owens, 2013), and as such, all deaths are not treated the same. There is a consensus in the literature that there is a distinction between 'good' and 'bad' deaths among the Yoruba people (Adamolekun, 2001; Adeboye, 2016; Awolalu, 1979; Izunwa, 2016; Ogbuagu, 1989; Olasunkanmi, 2015; Osanyinbi & Falana, 2016). A person who reached old age and attained a life of accomplishment before dying is believed to have died a 'good death'. A 'bad death', on the other hand, refers to any form of premature death such as suicide or stillbirth. The distinction between bad and good death is reflected in the funeral and burial rites accorded to the deceased (Gire, 2014; Olasunkanmi, 2015). Those whose deaths are considered 'good deaths' (figure 5) are buried in the family compound in an elaborate and lavish ceremony (Adamolekun, 2001; Olasunkanmi, 2015), but deaths categorized as bad do not receive proper burial rites and are not buried anywhere near the family home (Adeboye, 2016; Olomola, 1988; Osanyinbi & Falana, 2016).





*Figure 5: Funeral of a 'good death' in Yoruba culture. Source: Nairaland Forum (2016)*

The distinction between good and bad deaths in Yoruba ontology is important in this study because it offers a revealing window through which one can appreciate the impact of stillbirth on women. As such, it is important to start first by discussing the features of a good death as it is practised among the Yoruba people and weave its sociocultural relevance to the understanding of stillbirth. The Yoruba culture believes in reincarnation, generally described as the soul of a dead person taking a new body (Akinola, 2011). From this perspective, the traditional attitude to death is that it is a transition from one phase of life to another (Ogbuagu, 1989). The belief that death on earth is not the end and that men live posthumous lives constitutes the main reasons for elaborate funeral rites performed by the living for the dead (Osanyinbi & Falana, 2016). The proper performance of burial rituals is considered very important to enable the dead person to peacefully move into the next world (Olomola, 1988). Those who are not buried properly cannot enter the society of their dead ancestors (Ogbuagu, 1989).

There is also a consensus in the literature about the process that follows the deaths that are distinguished as good. First, there is the spreading of the message concerning the death, through diverse platforms, including word of mouth, print and social media (Izunwa, 2016; Ukeh, 2013). As an illustration, Ogbuagu (1989) examined nine different national newspapers in Nigeria for death notices placed by people in 1983. The analysis showed that 55.4% of the obituaries were placed by people of Yoruba ethnicity, 30% by Igbos and 11.4% by the Hausa/Fulani. The descriptive analysis also revealed that people of Yoruba ethnicity spent more money on obituaries than all other ethnic groups combined by spending a total of \$532,336.76 Nigerian Naira on newspapers adverts in 1983 alone. The value of that money today is well over 2 million US dollars (Bureau of Labour Statistics, 2019). However, Ogbuagu (1989) also notes that 84.5% of the obituaries are for people who are more than 40 years of age when they died, suggesting that deaths of relatively old people are more acceptable than that of children (figure 6).

*Celebration of Life*

The entire family of ONIFADE announce the passing away  
in to the Glory of our beloved brother, father, grandfather

**LATE MR.  
EMMANUEL ADEREMI  
ONIFADE**

Who slept in the Lord on Sunday, January 20, 2019

**AGED: 70 YEARS**

**BURIAL ARRANGEMENTS AS FOLLOWS:**

**FRIDAY 22ND MARCH, 2019 - CHRISTIAN WAKE KEEP**  
At First African Baptist Church Isale Taba, Saki, Oyo State. Time: 4:00pm

**SATURDAY 23RD MARCH, 2019**

**LYING-IN-STATE**  
At His Residence, Onifade House, Surulere Area, Koomi Road, Saki, Oyo State. Time: 7:00am - 9:00am

**FUNERAL AND OUTING SERVICE**  
At First African Baptist Church, Isale Taba Saki Oyo State | Time: 10:00am

**INTERMENT** follows immediately after the Church Service at his residence

**ENTERTAINMENT OF GUESTS FOLLOWS IMMEDIATELY**  
@ OYSADEP Sports Complex, Koomi Road Saki, Oyo State, Nigeria

*May His Resourceful Soul Rest In Peace*

**ANNOUNCER: THE FAMILY**

Figure 6: Obituary notice for a 'good death'

After the spreading of the news, and before people start visiting the bereaved family, the corpse will be washed and dressed up in the best available apparel (Adamolekun, 2001; Olomola, 1988;

Izunwa, 2016). Enormous importance is attached to the washing ritual, which is usually done by the children of the deceased or at least the family members. The corpse is then laid in state for a period lasting for at least two days (if the deceased is a Christian) and during this time, people troupe in to pay their last respects (Izunwa, 2016; Olomola, 1988).



*Figure 7: Lying-in-state and paying respect in 'good death'. Source: Olarewaju (2018)*

Usually, guests come from everywhere, and the burial takes place on Friday or Saturday afternoon accompanied by an array of foods and a variety of drinks (Adamolekun, 2001). There are many activities at this time. Some people just come to eat, others to express their appreciation, yet others just come to sit and observe what is going on (Adamolekun, 2001). These activities allow guests, friends and relations to participate in the funeral ceremony, which has been found to be of value to the survivors (Adamolekun, 2001). A mixed-methods study examining the reasons why 100 participants who are indigenes of a Yoruba town (Kisi) attended funeral ceremonies revealed that 69% of study participants attended funerals to reunite with old friends, 52% see funerals as avenues for social get-together and another 49% attended funerals because they are viable outlets for making new contacts (Lawal, Lawal & Adeyinka, 2013). The activities involved in Yoruba funerals are lavish, creative and elaborate and some researchers have observed that funerals provide avenues for social networking, social bonding and building social and cultural capital (Adamolekun, 2001; Lawal et al., 2013; Nwoye, 2005). Friends, family and the whole community



are an essential part of funeral events because they make available the resources needed by the bereaved to cope with the loss and to organise a burial (Lawal et al., 2013). It is not uncommon for friends, relatives and neighbours to offer to sleep at the house of the bereaved for some days and close friends and relatives may even live with the bereaved for months (Nwoye, 2005). This scenario is the same for Yoruba Muslims because they also organise an elaborate funeral service for the late individual 40 days after burial which must have been done according to Islamic rites (Ogbuagu, 1989; Smith, 2004).



*Figure 8: Lying-in-state for Yoruba Muslims in 'good death'. Source: Olasupo (2018)*

The ability of a bereaved person to give the deceased a dignified burial is a significant cultural expectation. But central to this is the significance of home burial, which many believed is essential for a smooth transition to the afterlife and which also guarantees proximity of the bereaved with the spirit of the deceased (Adeboye, 2016; Lawuyi & Olupona, 1988; Ololajulo, 2017). In the mixed-methods study conducted by Lawal et al. (2013), 81% of participants believed that home funerals are a means to show respect and appreciation for the life of the deceased. The mutual contact between the living and the dead is acceptable and having the grave in the house is aimed at achieving this much-desired contact with the deceased (Adeboye, 2016). As such, having the physical grave of the deceased person in the home is a conscious effort by the mourner to let the public know that the deceased lived a good life and died a good death (Gire, 2014). Sixty-five per cent of participants in the study conducted by Lawal et al. (2013) believed that this is necessary for the departed soul to have eternal rest. The significance of burying the dead within the home was also confirmed in a study that sampled and collected data from 250 individuals across five

Yoruba cities using questionnaires, direct observation and interviews (Olajide, Alabi & Akinlabi, 2013). This study examined issues relating to housing of the dead and the findings from the descriptive statistics revealed that 77.1% of the respondents had more than 3 graves in their family compounds, and another 75.2% of the participants wished to be buried within the residential neighbourhood of their family house when they die (Olajide et al., 2013).

Closely linked with the importance of home burial is the selection of the appropriate time and setting for breaking bad news. This dimension of Yoruba grief work has significance for the understanding of stillbirth bereavement. The home of the bereaved is considered the most appropriate setting because the presence of family, friends, relatives and neighbours are an important component of grief resolution (Nwoye, 2005). A recent study that explored the views of 109 patients of Yoruba ethnicity in one teaching hospital in southwest Nigeria regarding their views about the breaking of bad news revealed that 88% of the participants wanted their relations around during the process (Adeleye & Fatiregun, 2012). This is because the bereaved needs the emotional support of familiar people and this means settings like the farm, market place or the hospital are considered inappropriate settings (Adamolekun, 2001). The role of familiar people when the bad news is broken is to allow others to cry with the bereaved in a joint protest against the loss, and this validates that the wailing and crying of the bereaved is an appropriate response to the loss and not a sign of weakness or immaturity (Nwoye, 2005). The same study conducted by Adeleye and Fatiregun (2012) found that 91% of participants expressed that they would not be happy if they are excluded from the process of breaking the bad news.

Considering these factors, Ebhomienlen (2015) argued that Yoruba grief work does not look at the bereaved individuals as a unit of analysis, but also considers the sociocultural environment. This means that the response to bad news such as the death of a child is a social construction because both the bereaved and those associated with her jointly co-construct a response that is appropriate to the type of loss (Adamolekun, 1999; Nwoye, 2005). However, this can create a dilemma for health professionals because unlike before where most births occur at home, more births in Nigeria are now taking place in health facilities. For instance, the Nigerian National Population Commission (NPC, 2014) reported that in 2013, 36% of all births in Nigeria took place in health facilities and this represented a 3% increase from 2003 estimates. Although, a 3% increase over ten years is marginal, when this is considered in the context of Nigeria's population, the picture

becomes clearer. In 2015 alone, the UN estimated that 7.1 million babies were born in Nigeria (United Nations [UN], 2016) and this means that every year, over 2.5 million women in Nigeria deliver their babies outside the comfort of their homes, many of whom may not be with their families. Thus, health professionals in Nigeria increasingly face the likelihood of encountering women with stillbirth during their practice, and they need to be able to negotiate how to break the news of the loss in a hospital setting which is culturally incompatible and unsupportive for such sad news.

Another important aspect of grief among the Yoruba that has relevance for stillbirth bereavement refers to the aspect of human memory that seeks answers and clarity regarding the facts surrounding the death. Adamolekun (2001) and Ololajulo (2017) wrote that Yoruba grief work is about seeking clarity about such things like whether the death really took place, how and why it took place and when and who might be responsible. Thus, rituals like viewing the body, the gathering of family and friends, the eulogy and lowering of the body into the grave help the bereaved person to assimilate the loss (Ololajulo, 2017). Findings from informal interviews and content analysis of social media illustrations of roadside corpses in two Yoruba states in Nigeria revealed that the inability to find answers to the cause of death or to know what happens to the body of the dead simply means "the body does not have people" (Ololajulo, 2017, p. 253).

Knowing the cause of death is important because it influences the kinds of support that will be provided and most importantly, the salutations that will be used in greeting the bereaved. As an illustration, a parent whose child died during infancy is greeted and supported differently from one whose child died at the age of 40 years. The appropriate expressions directed at the bereaved from others form part of the mourning rituals which help the bereaved feel supported (Adamolekun, 1999). However, in situations where bereaved persons are unable to find answers relating to their loss, there is delayed grief and distress (Adebayo et al., 2018; Nwoye, 2005). Thus, several factors such as the age of the deceased, the cause of death (real or imagined), and the circumstances surrounding the death are all taken into consideration when death occurs in Yoruba culture (Adamolekun, 2001; Eyetsemitan, 2002).

When a bereaved individual observes the necessary rituals matching the status of the dead as described above, there is a sense of fulfilment, contentment and approval from the community

through the giving of gifts, money and other resources needed to readjust to the loss (Adamolekun, 2001; Ogbuagu, 1988; Ololajulo, 2017). Some authors (Adeboye, 2016; Ogbuagu, 1989; Ukeh, 2013) have noted that the Yoruba people will go to any length and spend the last of their resources to celebrate the life of the deceased. Thus, it is not unusual for Yoruba Christians to keep the bodies of their dead in the morgue for several months in order to accumulate the resources necessary for a befitting burial ceremony for the dead (Ogbuagu, 1988; Ololajulo, 2017). It has also been observed that the society looks down on those who do not bury their dead in a befitting way and there is often societal pressure accompanying how well a funeral ceremony is performed (Adeboye, 2016; Ogbuagu, 1989; Ukeh, 2013). As such, the ability to conduct a befitting burial is necessary for the mourners to satisfy their psychological, social, and emotional needs (Adamolekun, 2001; Ukeh, 2013). Failure to do this has been linked with heightened grief, stigma and shaming (Ukeh, 2013).

When the features of ‘good deaths’ in Yoruba culture are considered, four things seem to be clear. First, burials are essential for closure, and the dead are buried close to home, if not in the family compound. Second, having contact with the body through washing and adorning the body of the dead with a beautiful dress is a mark of respect for the deceased. Third, the death of a person brings people together and assist in social reintegration and meaningful ongoing living. Fourth, seeking an explanation for the death and understanding the cause of death is part of the cultural idea of healthy grieving (Nwoye, 2005; Ogbuagu, 1989). These features of good deaths affirm the pre-eminence of kin, community and social networks as strong forms of social security (Ololajulo, 2017). Thus, the burial rites for ‘good deaths’ are not only elaborate, but they also constitute a sociocultural performance that brings people together. Any burial ceremonies lacking any of those features have been linked with social stigma, shame and heightened grief (Nwosu, Njemanze, Ekpechu & Popoola, 2017; Ogbagu, 1989).

However, despite the importance of the above for successful grieving in Yoruba culture, it is the opposite that happens to mothers of stillborn babies. Stillbirth violates the definition of a ‘good death’ and as such, proper funeral rites are denied stillborn babies (Olasunkanmi, 2015; Olomola, 1988; Osanyinbi & Falana, 2016). For stillborn babies (known as Abiku among the Yoruba people), the burial is simple, quick and un-ceremonial and without the mother of the stillborn child in attendance (Balogun, 2011). At least three authors reported that it is not uncommon for bodies

of stillborn babies to be thrown into the bush without any burial (Adeboye, 2016; Ebhomienlen, 2015; Olomola, 1988). Interview data from a recently conducted qualitative study with 35 women in Abuja, Nigeria revealed that immediately after a stillbirth diagnosis is confirmed, the mother is quickly detached from the scene, or the "fetus" is quickly removed from the scene; marking the last encounter of the mother with her child (Adebayo et al. 2018, p. 9). Likewise, Kuti and Ilesanmi (2011) reported that none of the 45 women that participated in their survey was given the opportunity to hold, take pictures or name a stillborn infant. Adebayo et al. (2018) found that:

Usually, the father [of the stillborn baby] is privileged to see the child and sometimes if he was willing, he might even accompany those in charge of the burial to the burial site... This does not mean the father would visit the site again or even show the specific spot to his wife. The graves are purposely unmarked to deter the parents from locating the burial spot (Adebayo et al., 2018, p. 9-10)

Adebayo et al. (2018) reveal that Yoruba mothers of stillborn babies are forbidden from laying claim to a stillborn infant because people worry it will affect the ability to conceive in the future. This is strongly linked with beliefs about the malevolent spirit of 'Abiku', and because so much value is attached to motherhood, women are eager to conform to social norms so that they can achieve another pregnancy (Adebayo et al., 2018). Thus, Yoruba mothers of stillborn babies are implored not to cry for the child, and no one supports the woman regardless of whether she is showing signs of grief (Kuti & Ilesanmi, 2011). Unlike 'good deaths', no one is allowed to cry or weep publicly for stillborn babies, and there is no cooking or drinking (Olasunkanmi, 2015). A mixed-methods study conducted by Balogun (2011, p. 249) among Yoruba Muslims revealed that Abiku children "are not mourned; rather they are buried unceremoniously and casually". Osanyinbi and Falana (2016) even wrote that traditionally, those who are unrelated to the family impacted by stillbirth such as professional undertakers mostly take care of the bodies of stillborn infants and this means the family is far removed from burial arrangement for stillborn babies. This is even worse for the mother of the stillborn child because even though she carried the pregnancy for certain period, she is not included in any decision regarding the stillborn (Adebayo et al., 2018).

Stillborn babies are denied proper burials because of cultural beliefs, and the first of these beliefs is that of the 'Abiku' belief interpreted literally as a 'child that is predestined to die' (Adeyemi et



al., 2008, p. 1463). The 'Abiku' belief is that a pregnancy that results into stillbirth was possessed by wicked spirits who of their own volition just wanted to see the pregnant woman suffer and cry (Doris, 2006; Mobolade, 1973). Burying the 'Abiku' child in the most inhumane way, which sometimes involves bodily mutilation is a deliberate attempt to discourage the wicked spirit of 'Abiku' from entering the mother again (Adeyemi et al., 2008; Osanyinbi & Falana, 2016). Pertaining to stillborn babies, Adeboye (2016) wrote that

A series of dying infants is called an abiku (born-to-die), and these are not given decent burials to discourage them from dying prematurely if they ever come back again. They are often mutilated at death and thrown into the bush. Nobody mourns them (p. 2)

Culturally, mothers of stillborn babies, as well as those associated with her are not expected to mourn the child because of the belief that the child would never have been beneficial to the family (Adeyemi et al., 2008). Findings from oral interviews conducted among indigenes of an ancient Yoruba city (Akure) revealed that people believe that stillborn babies give their parents a lot of psychological problems because it is the same child recycling itself through some cycle of life and death (Osanyinbi & Falana, 2016). This belief about the 'Abiku' children is well captured by a series of poems dedicated to the phenomenon of 'Abiku' in a special issue of Writers Connect Quarterly Journal. One of the poems aptly summarises the Yoruba belief about the stillbirth phenomenon (Ayeyemi, 2017, p. 11):

A: Away I go to where I came from

B: Because this place is not my home

I: I pray thee mortals let me go

K: Keep not my name in thy lips and

U: Untie my soul from yours and weep not for I never was here.

The second of these beliefs are related to the societal response to the high rates of maternal and child mortality in Nigeria, as Lofland (1985) has argued. Historically, pregnancy has never been a safe event for women in Nigeria, and the Yoruba way of dealing with pregnancies that results into stillbirth is to admonish the affected woman that she should be thankful for her own life because whatever killed her child could have taken the life of the mother as well. This way of comforting mothers of stillborn babies is closely related to the cultural interpretations of pregnancy, which is

explained through the concept of 'pot and water'. A pregnant woman is likened to a pot containing water, and the understanding is that perinatal losses such as stillbirth and miscarriage are like water spillage from a pot or container (Adebayo et al., 2018; Kuti & Ilesanmi, 2011). As long as the pot is not broken (maternal mortality), the belief is that the pot can be filled with another round of water (becoming pregnant again). Therefore, the purpose of telling a woman that it is only the 'water that poured away' is helping her to make a 'downward comparison' that she is more fortunate than women who died during childbirth (Adamolekun, 1999; Nwoye, 2005). Kuti and Ilesanmi (2011) in their study about the experience and needs of Nigerian women after stillbirth noted that mothers of stillborn babies in Yoruba communities are considered "fortunate" for surviving childbirth by their family, friends and society. Thus, mourning and wailing a stillborn child is frowned upon by the public and it is considered as ingratitude (Kuti & Ilesanmi, 2011).

All these beliefs and justifications for denying stillborn babies full funeral rites means culture has an impact on stillbirth grief, and these beliefs are still maintained to some degree among the Yoruba people despite the influence of Islam, Christianity and globalisation (Akomolafe, 2016; Osanyinbi & Falana, 2016). As an illustration, a study that examined the extent of Yoruba Muslims' beliefs in syncretic practices found that 18.5% of the 200 participants believed strongly in the superstitious belief of Abiku (Balogun, 2011). Likewise, another study that investigated attitudes to Yoruba taboos among residents of two Yoruba ancient cities revealed that 15.5% of the 600 participants believed that there is some sense regarding the concept of 'Abiku' (Adebileje, 2012).

#### **2.4.1 Cultural understandings of stillbirth among other cultures in Nigeria**

The cultural beliefs and practices that discount and stifle stillbirth grief are not only peculiar to the Yoruba ethnic group. Rather, some of these beliefs spread across other ethnic tribes in Nigeria. As an example, Egbunu (2014) observes that among the Igala tribes of Nigeria, stillborn babies are not accorded elaborate funeral rites. Instead, their burials are usually very brief and characterised by less wailing. Likewise, Izunwa (2016) also reported that the bodies of stillborn babies in Igbo society are often mutilated to prevent re-incarnation and are "thrown into the evil forest so that their memories can fade away quickly" (p. 130). Among the Igbo tribe of Nigeria, families who have been devastated by high intra-family infant mortality are more likely to believe in the concept of Abiku, which is termed Ogbanje in the Igbo Language. This was the finding from interviews

conducted with 200 parents who believed they had children who have been possessed by the evil spirit of Ogbanje despite investigations revealing that the children's deaths were due to hemoglobinopathies (Nzewi, 2001).

#### **2.4.2 Cultural understandings of stillbirths in other contexts**

Pregnancy loss is always taking place within sociocultural contexts and understanding how local attitudes and beliefs shape stillbirth grief from other contexts can assist in understanding women's experience of stillbirth. Some research in other contexts outside Nigeria have revealed that local practices, beliefs, perceptions and norms intersect pregnancy and its outcomes. From the review of the literature, age-based mourning practices seem to be a characteristic of many societies, but still, there are variations in cultural beliefs targeted at stillbirth loss. As an example, findings from a descriptive phenomenological study that described the experiences of ten Muslim women with the experience of stillbirth in Somaliland revealed that women are allowed to see and hold their stillborn children; but they are excluded from the burial (Osman et al., 2017). In Ethiopia, the findings from 30 focus group discussions conducted among 207 women to understand the social consequences of stillbirth revealed that stillborn infants are treated as strangers, and they are not openly mourned or buried the same way as adults (Sisay et al., 2014). Similar to Yoruba culture, Sisay et al. (2014) also found that indigenous beliefs in Ethiopia deny women the right to see the body of the infant or know the baby's burial place. This is believed to be necessary to protect mothers from psychological harm as well as to protect future pregnancies. However, unlike in the Yoruba society where graves of stillborn infants are banished into the forests and far away from home, stillborn infants in Ethiopia are buried in the house or the backyard instead of the church cemetery which is reserved for adults and baptised children (Sisay et al., 2017).

Like in other contexts such as Nigeria and Somaliland, the belief in Tanzania is that stillborn infants are "fated not to live" (Haws et al., 2010, p 1767) and as such, stillbirth is not appropriate for public discussion. This is the finding from in-depth interviews conducted with 50 women in seven rural villages in Tanzania to understand how pregnancy losses are defined and socially managed. Haws et al. (2010) further reported that women are not expected to talk about their experience of stillbirth and they only talk about it to those who are likely to support them. Likewise, Kiguli et al. (2015) conducted in-depth interviews with 29 individuals to explore local definitions of stillbirth as well as coping mechanisms used by families affected by stillbirth in a

rural part of Uganda. Qualitative content analysis of the interviews revealed that women attributed the cause of stillbirth to witchcraft and like other parts of Africa, Kiguli et al. (2015) reported that stillborn infants in Uganda are not buried in the same graveyard as adults or babies that cried. So, instead of honouring the stillborn babies with dignifying burials, they are buried in holes and mock graves to taunt the family. However, unlike in Nigeria and Somaliland where only men are allowed to handle the bodies of stillborn infants, Kiguli et al. (2015) reported that it is women that conduct burials for stillborn infants in Uganda. But it is done quickly and without the knowledge of the community.

In Ghana, Attachie, Mwini-Nyaledzigbor, Affram & Adjei (2016) explored the experiences of 19 mothers who lost their babies during delivery using a qualitative exploratory design. Data were collected with a semi-structured interview guide, and interview data were analysed using content analysis. The findings revealed that women were dissuaded from mourning their stillborn babies because of the myth that crying over a stillborn child brings infertility. Like in Nigeria and other places, Attachie et al. (2016) found that burial services were not given to any of the stillborn infants. Instead, the bodies of the stillborn infants were abandoned for the hospital to bury. However, unlike in other African countries previously discussed where it is a taboo for women to see, hold and bury their children, women with stillbirth in South Africa were supported to make memories from their stillbirth loss. The findings from an exploratory mixed-methods study in South Africa that explored the access of 15 women with a stillbirth to bereavement services revealed that 80% of participants were given footprints of their babies when leaving the hospital and another 26.7% had their babies baptised (Prinsloo & Conry, 2008). Similarly, Modiba and Nolte's (2007) qualitative descriptive study among 10 South African mothers of stillborn babies also corroborated that women are allowed to hold and make memories after suffering a stillbirth in South Africa. This suggests that even within Africa, there is variation in social expectations and norms surrounding stillbirth and this reinforced the need to consider the sociocultural contexts where stillbirth is happening in order to understand the experience of it.

Some other countries outside Africa also have similar beliefs about stillborn infants. As an illustration, in Israel, a child that dies before birth is considered not to have lived at all and no mourning practices are observed (Dickstein, 1996). This finding from an extensive anthropological study that includes observations and personal encounters revealed that the bodies of stillborn

infants in Israel are usually buried in unmarked graves (Dickstein, 1996). Similarly, findings from an ethnographic study of 27 women from Hmong tribe of Laos living in Australia revealed that the Hmong people believed that a baby that died upon birth does not wish to live in this "mundane world" (Rice, 2000, p. 49). For this reason, stillbirth is treated as non-significant in Hmong culture and therefore, there is no burial ceremony or mourning because stillborn babies are not "true human beings" (p. 51). Without burial, the soul of the dead child cannot reincarnate, and that means the child will not have rest (Rice, 2000). Similarly, the results of a four-year anthropological study about the implications of competing religious and customary beliefs about miscarriage and stillbirth among six Pakistani Muslim women in the UK revealed that stillborn babies are denied full recognised Islamic personhood because they did not breathe (Shaw, 2014). Stillborn babies born to these women were buried in unmarked graves in burial grounds that are untended and overgrown with weeds (Shaw, 2014).

Other studies conducted in Asian countries introduced another dimension to the diversity of beliefs surrounding stillbirth. Studies from Taiwan and Japan reported that mothers were prevented from seeing their stillborn babies, but they were allowed to observe rituals. This is very different from findings from other African countries and among the Jewish people as earlier discussed. As an illustration, Hsu, Tseng and Kuo (2002) explored the experiences of 20 Taiwanese mothers of stillborn babies, and their coping strategies using an interpretive ethnographic design. The thematic analysis revealed that women were prevented from seeing the body of the stillborn infant because it was thought to cause bad luck. However, there was a provision in the Taiwanese cultural grief that allowed women to perform rituals as a form of remembrance and women found this helpful because it allowed others to acknowledge the loss (Hsu et al., 2002). Also, in Taiwan, findings from a qualitative descriptive study exploring the meaning of stillbirth rituals among 16 mothers of stillborn mothers added that Taiwanese folk culture believes in life after death, even for stillborn infants (Tseng et al., 2018).

Thus, unlike some African countries like Nigeria where efforts are meant to separate the stillborn infant from the family forever, rituals in Taiwan are geared towards facilitating the reincarnation of the stillborn infant back into the family (Tseng et al., 2018). The ability to perform this ritual means a lot to mothers because stillborn babies who are not remembered through rituals are believed to wander and suffer in the land of the spirits and this brings misfortune to the mother

(Tseng et al., 2018). Similar to Taiwan, findings from a grounded theory conducted among five Japanese women revealed that women reared their stillborn babies as part of their families and this entails rituals such as talking to a Buddhist altar about the stillborn baby every morning (Yamakazi, 2010). Through these rituals, mothers develop a relationship with the dead child, and this is achieved by keeping memories that provide proof of the birth such as photographs, umbilical cord and footprints of the baby (Yamakazi, 2010). The revelations regarding several beliefs and taboos attached to stillbirth in different contexts suggest that issues such as stillbirth are best understood from cultural points of view.

## **2.5 Social consequences of stillbirth: Shame, guilt and isolation**

Considering the existence of some beliefs and taboos that tightly regulate stillbirth grief and burial practices for stillborn babies in many countries, it is unsurprising that the occurrence of stillbirth has negative social consequences for women. Although some scholars have commented on the sociocultural meanings of stillbirth in Nigeria, there is a shocking absence of information on how the beliefs and norms surrounding stillbirth impact women's life. This further illustrates that little attention is being paid to grief resulting from stillbirth in Nigeria. Findings from the limited studies in Nigeria and elsewhere have demonstrated that stillbirth impacts negatively on women's well-being. The revelations from interviews conducted among 35 women in Nigeria suggest that community members sometimes think a woman deserves to experience stillbirth because of "wayward lifestyles" before marriage, such as having an abortion (Adebayo et al., 2018, p. 12). As a result, mothers of stillborn infants reported that they were ridiculed, blamed and stigmatised after their stillbirth experience. Sisay et al. (2017) complemented the findings from Nigeria by reporting that the community does not recognise mothers of stillborn babies as needing support and as such, stillbirth-affected women reported neglect, stigma and shame.

Other studies from Asia also added that the occurrence of stillbirth changes the relationship between women and others. As an illustration, a qualitative descriptive study that aimed to describe the process of stillbirth recovery of 21 Taiwanese women revealed that women felt isolated after stillbirth (Tseng et al., 2014). Tseng et al. (2014) reported that the family members of the stillbirth-bereaved women avoided talking about the loss and mothers were also prevented from showing any emotionality such as crying. This resulted in shame, uncertainty and isolation from social interactions. Yamakazi's (2010) grounded theory study among Japanese women also revealed that

mothers of stillborn babies stopped going out and were hesitant to meet those who had attended their baby showers because of shame. These findings were not different from what was reported from India and Bangladesh. In India, findings from key informant interviews and focus groups with 37 individuals that comprised mothers of stillborn babies, their family and local health providers highlighted how women were despised because of their failure to bring forth a live baby (Roberts, Anderson, Lee & Montgomery, 2012). Roberts et al. (2012) reported that people looked down on mothers of stillborn babies and this prevented them from physically socializing with their neighbours due to disparaging remarks.

In the same vein, a prospective study of 476 women that included 122 women who have lost their pregnancies to perinatal deaths in Bangladesh found that mothers of stillborn babies experienced worsening of social relationships with others after stillbirth (Gausia et al., 2011). In the same fashion, studies from the UK and North America also corroborated that women's social networks became smaller because of stillbirth. For instance, de Montigny et al. (1999) reported that most women in their study who had lost a baby to perinatal death suffered permanent losses of relationships with friends, colleagues, and extended family members in Canada (de Montigny et al. 1999). From the interviews conducted about the impact of perinatal loss on the social networks of 20 parents (14 mothers and 6 fathers), de Montigny et al. (1999) revealed that familiar platitudes like 'you are young, you can have another one' (p. 153) and the reluctance of friends and family to engage in discussion about perinatal loss led to fracturing of relationships. In like manner, interviews conducted with 22 parents (16 mothers and 6 fathers) who had experienced perinatal losses in Canada revealed that the flow of goods and services that typically accompany births or deaths in Canadian societies did not occur for women after stillbirth, and this led women to believe that the loss of their babies was insignificant (Malacrida, 1999). Malacrida (1999) specifically focused on the material exchanges that occurred due to stillbirth loss, and it emerged that parents experienced perinatal losses in virtual solitude because of the limited support that was received from their social networks even during funerals.

The findings from a survival analysis that was prospectively conducted over ten years on 7770 married or cohabiting women after experiencing live births, miscarriages or stillbirths in the US revealed that parental relationships have a higher risk of dissolving after miscarriage or stillbirth, compared with live births (Gold et al., 2010). Although the number of women with stillbirth in the

study was just 136 (2%), statistical analysis revealed they had an unusually high risk of relationship dissolution, and this risk persisted for up to 10 years (Gold et al., 2010). Similarly, an interpretative phenomenological analysis of in-depth semi-structured interviews collected from parents (12 mothers and 5 fathers) of stillborn babies about their experiences in Ireland revealed that mothers of stillborn babies did not tell anyone beyond their close family about the diagnosis of stillbirth because they wanted to protect themselves from ordinary social interactions (Nuzum et al., 2018). In addition, Nuzum et al. (2018) found that the occurrence of stillbirth impacted negatively on the relationship of 14 of the participants, with many finding it hard to communicate with their partners. In contrast, survey data from 55 Swedish parents (33 mothers and 22 fathers) with perinatal loss revealed that majority of the participants (78% women and 89% men) became closer because of stillbirth loss and most expressed satisfaction with their relationships (Avelin, Rådestad, Säflund, Wredling & Erlandsson, 2013).

Other studies in the US found that social expectations regarding how mothers of stillborn babies were expected to grieve resulted in a gradual withdrawal of their nuclear system of support and kinship during stillbirth adjustment period (Cacciatore, 2007). This cross-sectional mixed-methods study of 47 mothers of stillborn babies about the effects of social support on stillbirth grief showed that lack of responsiveness and sensitivity from others resulted in irreparable damage to women's social relationships. Similarly, after experiencing stillbirth, women in the US reported a feeling of "not fitting in with their usual group of friends" (Cacciatore, DeFrain & Jones, 2008, p. 450). This was the finding from the thematic analysis of focus group data that was collected from 74 people (grieving mothers, fathers, and family members). Cacciatore et al. (2008) reported that some women had a whole new set of friends after stillbirth loss because of unhelpful comments and clichés that led to their alienation from others. In a related study by the same author, Cacciatore (2010) revealed that limited social support available to mothers of stillborn babies in the US was because they “recoiled” from the social environments because of shame and lack of trust in their social circle (p. 145). Both closed and open-ended responses from 47 women about the impact of stillbirth revealed that women became disconnected from friends and families because of social isolation, disenfranchisement, guilt, and blame.

The ambiguity surrounding perinatal loss meant some women with a perinatal loss in the US could not continue with their previous jobs because of lack of answers to questions from people asking



about their pregnancies (Van & Meleis, 2003). This grounded theory study which was conducted among 20 African-American women revealed that insensitivity from those who are in the social circle of the mothers forced them to abandon the social networks they had before stillbirth in favour of closer relationships with spouses and close friends (Van & Meleis, 2003). Similarly, interviews conducted with 15 American women about how their work colleagues responded to their perinatal losses revealed themes relating to disenfranchisement, shame, secrecy and social sanctions that led to isolation from colleagues and others (Hazen, 2003). Hazen (2003) reported that insensitive comments like "your child might have been brain-damaged. It is best that he died" (p. 152) alienated women from the social networks they belonged to before perinatal loss.

Like previous studies, two qualitative studies in the UK also found that women's social networks became smaller after stillbirth. Murphy (2012) qualitatively explored the experience of 32 individuals (10 couples and 12 mothers) in the UK through interviews and found that women's relationships with others changed irrevocably after stillbirth because of the negative attitudes of others, shame and the stigma that accompanied the loss. Women in the study detailed how friends, neighbours, colleagues and even family members avoided them and stopped talking to them, leading to the loss of some people in their social networks.

## **2.6 The social networks of mothers of stillborn and the dominance of the family**

Social support was a salient issue in the reviewed studies as some studies found that social support interacted with all the adverse sequelae of shame, guilt, blame and stigma to ensure positive bereavement outcomes for women. However, the family was the most frequently cited source of support by mothers of stillborn babies. This was expected because as previously demonstrated, women faced questions and scrutiny about their motherhood identity, as well as doubts surrounding their ability to produce live babies. This forced some women to shy away from social interactions, as many did not know how to respond to questions about what happened to their pregnancies, as well as perceived lack of understanding and insensitivity from others.

No study specifically examined the support systems of mothers of stillborn babies from Nigeria, but some studies that sought to identify causal factors related to depression in mothers of stillborn infants highlighted the importance of the family. For instance, Kuti and Ilesanmi (2011) surveyed 45 Yoruba women to determine the type of care women find useful after stillbirth. The results of

the descriptive statistics revealed that the spouse was the most supportive person for over half of the participants 23 (51.1%); followed by other family members for 17 (37.8%). Likewise, Adeyemi et al. (2008) used two validated self-rating scales (Hospital Anxiety and Depression Scale and Edinburgh Postnatal Depression Scale) to investigate variables associated with depressive symptoms among 69 Yoruba women who lost their pregnancies to stillbirth. The findings from the regression analysis revealed that poor support from husbands and previous perinatal losses increased the risk of depression after stillbirth. Also, findings from the logistic regression performed on data collected through a self-rating depression scale among 202 Nigerian women to determine their level of depression revealed that women who expressed satisfaction with the support received from husbands and children had lower risk of depression (Obi et al., 2009). This suggests that spousal and family support are significant for women after stillbirth in Nigeria.

Findings from other African studies also emphasised the importance of the family for women facing stillbirth loss. In Tanzania, women were not allowed to discuss the subject of stillbirth publicly, but counselling was permitted from female elders (Haws et al., 2010). In Uganda, Kiguli et al. (2015) reported that there were no formal health system mechanisms to support or care for families affected by stillbirths and as such, women received the most support from their husbands and extended family. As in Tanzania, Kiguli et al. (2015) found that older women in the extended family were important because they assisted with household chores, and this gave the bereaved mother time to recover from the loss. Interestingly, Kiguli et al. (2015) also found that women who had the support of husbands coped better than those without such support.

In the UK, Shaw (2014) found that Muslim women affected by perinatal loss coped by bonding only with their husbands for support. Shaw (2014) explained that participants were unwilling to disclose their miscarriages or stillbirth because of fears of losing their marriages since reproductive failure is a common ground for a man to take another wife (Shaw, 2014). Thus, trust issues about malicious gossip that could spread to family members prevented them from using the bereavement counselling services even though it was available to them. Findings from another study in the UK that examined the incidence of Post-traumatic stress disorder (PTSD) and psychiatric co-morbidities among 50 British women revealed that most women received support from either spouse or partner (94%), family members (82%) and friends (94%) (Chung & Reed, 2017). A lesser proportion reported that they received support from midwives (52%) and health visitors

(32%). In terms of professional help, less than 10 participants received any form of counselling, medication or psychiatric intervention, despite that over 60% of the participants met the criteria for PTSD and co-morbidity (anxiety and depression) (Chung & Reed, 2017).

Family support is so crucial for mothers of stillborn babies that some studies have shown that it is the only form of support that makes a statistically significant difference in determining whether women will have PTSD, anxiety disorders or depression after stillbirth. As an example, a cross-sectional study conducted among 769 American women to investigate the correlation between social support, maternal anxiety and depression after stillbirth revealed that only family support remains associated with substantially lower levels of maternal anxiety and depression in the period after stillbirth (Cacciatore et al., 2009). The data for the study was collected through online questionnaire, and descriptive statistics showed that family support was the most common, with 91.7% of respondents reporting that they had received either 'great support' or 'support' from their families in the period after stillbirth (p. 171). The next most common sources of support were provided by nurses (90%), doctors (67.9%) and support groups (53.4%). However, while support from physicians and nurses were significant, inferential statistics showed that the most important and impacting form of social support is the one provided by family members. Thus, women without the support of their family after stillbirth were at a higher risk of anxiety and depression, no matter how much professional support they may receive.

Likewise, findings from a single measure post-test group design that evaluated whether there were differences in grief reactions between 83 mothers in an intervention group and 53 mothers in a control group in Finland showed that less spousal support was associated with more grief reactions after a miscarriage or stillbirth (Raitio et al., 2015). The data was collected with the Hogan Grief Reactions Checklist, other validated instruments and the differences between the two groups were tested using the Mann-Whitney test. The findings revealed that over 80% of mothers in both groups had more than six persons in their networks that provided support. Spouses provided the most support in both intervention (91%) and control (83%) groups, followed by parents (55% vs 49%), friends (59% vs 47%) and other parents with similar experience of perinatal loss (58% vs 36%). Health professionals were less represented as they accounted for 34% and 21% of support in both intervention and control groups respectively. Although more support from spouses and health professionals enhanced personal growth in both intervention and control groups respectively, only

spousal support was statistically significant for personal growth (Raitio et al., 2015). In other words, less spousal support increased grief intensity after miscarriage or stillbirth even in the presence of adequate support from health professionals.

Other studies from Asia also highlighted the dominance of family in women's networks after stillbirth. As an example, Sutan et al. (2010) conducted a cross-sectional study aimed at evaluating the psychosocial impact of stillbirth on 62 women who lost their babies to stillbirth in Malaysia. Data were collected with the Edinburgh Postnatal Depression Scale (EPDS) and self-administered questionnaires. The statistical analysis revealed that almost all women received support from husbands after the perinatal loss (93.6%) (Sutan et al., 2010). Also, three-quarters of the participants received support from their parents (87.1%), followed by friends (53.2%) and siblings (46.7%) (Sutan et al., 2010). However, support from friends was the only support that had a significant relationship with depression. The support from the family came in the form of encouragement (43.6%), counselling (40.32), emotional support (35.5%) and openness (30.7%).

Similarly, findings from a qualitative exploratory study that collected focus group data from 16 women in Malaysia revealed that family members play essential roles in providing consolatory and informational support (Sutan & Miskam, 2012). Likewise, some close friends of the bereaved women gave support in terms of listening, and the participants felt happy when their friends were willing to listen to them and understand them. In the same vein, mothers of stillborn babies in Taiwan singled out their husbands as the most critical source of support after stillbirth (Tseng et al., 2014). Tseng et al. (2014) reported that support for stillborn mothers came in the form of emotional comfort and this assisted women greatly after stillbirth. Lastly, in Iran, Allahdadian et al. (2014) performed qualitative content analysis on in-depth semi-structured interviews conducted with 15 Iranian women to explore the role of social support in stillbirth bereavement. The qualitative content analysis revealed two broad themes suggesting that women derived support from relatives and close friends in the form of sympathising, practical support and companionship. As in previous studies, Allahdadian et al. (2014) also reported that mothers of stillborn babies singled out the counselling, emotional and advocacy support provided by their spouses. Also, some participants discussed receiving support from family and friends in the form of companionship, sympathy and all these allowed them to escape loneliness (Allahdadian et al., 2014).

## **2.7 Factors associated with poorer outcomes after stillbirth**

Just as isolation and disenfranchisement can impede the ability of a woman to deal successfully with stillbirth loss, the connections that mothers of stillborn babies' form with others and the support they derive from these connections can help them deal with stillbirth grief as revealed above. Some research studies have identified some factors that can contribute to poorer outcomes for women grieving stillbirth loss. In the study conducted by Adebayo et al. (2018) in Nigeria, it was noted that women who had no answers to questions like "what went wrong, and what happened to the dead fetus/baby" coped poorly with stillbirth loss (p. 14). Likewise, Obi et al. (2009) revealed that in Nigeria, women with no living children, and those with losses after 20 weeks had pronounced symptoms of depression. Cacciatore et al. (2009) also added that American mothers who were single, divorced or widowed experience higher levels of depression after a stillbirth than those who are married or cohabiting. Likewise, being black, being single and having lower levels of education were all significant predictors of not having a physician/midwife or family members present at the delivery of stillborn babies in the US (Gold et al., 2017). Gold et al. (2017) found that African-American women were significantly less likely than Caucasian women to report the presence of family at the time of delivery and were also more likely to be isolated in the hospital.

In the same vein, findings from a cross-sectional comparative study that investigated factors predicting complicated grief between 26 women in Brazil and another eight women in Canada also highlighted that certain demographics could predict diminished support after stillbirth (Paris et al., 2016). Paris et al. (2016) found that women who had fewer years of formal education (less than 12 years of formal schooling), those without any religious affiliation, those who were single or who were not satisfied with their relationships and those who were not part of any support group were more likely to have complicated grief after stillbirth (Paris et al., 2016). Likewise, Gausia's et al. (2011) cross-sectional survey study in Bangladesh also complemented earlier studies that poor support from husband independently predicted depression in women after stillbirth.

Many other studies highlighted that lack of trust in specific individuals or organisations contributes to a collapse of women's social networks after stillbirth and thereby leading to diminished social capital. For instance, Hazen (2003) reported that mothers of stillborn babies in the US knew they could not trust everyone with their feelings. Thus, the lack of trust disrupted their social ties and resulted in a weakening and abandonment of their social networks. Likewise, Sutan and Miskam

(2012) revealed that some mothers of stillborn babies in Malaysia “did not tell everything to their friends” (p. 7). Their degree of openness to any friend depends on the “confidence” they had in the individual (p. 7). In other words, trust determined whom they talked to about the loss. Kelley and Trinidad (2012) in the UK also highlighted how trust played a role in those whom mothers associated with after stillbirth. Kelley and Trinidad (2012, p. 9) illustrated this with this quotation from one of their participants “when people ask me, do you have kids, or how many, I have to check myself. It depends who I’m talking to”.

Women who experienced guilt and shame because of stillbirth were also likely to have fewer people in their networks. As an illustration, Gopichandran et al. (2018) conducted in-depth interviews with eight Indian women in order to understand the psychosocial impact of stillbirth and the response of the health system. The thematic analysis of the interview transcripts revealed that insensitive comments from friends, family and neighbours led to isolation and feelings of stigma, and relationship problems after stillbirth loss. In their phenomenological study in Israel, Golan and Leichtentritt (2016) also found that mothers of stillborn babies were disenfranchised from their networks because of dismissive comments that trivialised their grief. Golan and Leichtentritt (2016) revealed that the inherent ambiguity experienced by mothers of stillborn babies was fuelled by the invalidation of their grief by those whom they thought should understand.

## **2.8 Women’s experience of health professionals’ support after stillbirth**

Since an increasing number of women are now giving birth in health facilities, it is unsurprising that some studies have examined women's experiences of health professionals care after stillbirth. Although the care provided to parents after a perinatal loss varies by country and culture, all parents want hospital staff to be sensitive and empathetic to their needs. However, research continues to demonstrate that women who have experienced stillbirth do not receive adequate support from health professionals and there are reports of substandard bereavement care even in high-income countries. Women's encounter with healthcare professionals were not even the focus of many studies, but mothers of stillborn infants discussed how their interactions with health professionals impacted on their grief experiences. The dominant theme was the poor and insensitive communication practices of health professionals, and this has contributed to low trust in health professionals.

Only two studies from Nigeria reported on women's interaction with health professionals after stillbirth. In the study conducted by Kuti and Ilesanmi (2011), it was revealed that only 3 (6.7%) of the 45 mothers of stillborn babies who participated in the study considered the health institutions where they delivered their stillborn babies as supportive. Likewise, Adebayo et al. (2018) also highlighted that medical professionals failed mothers of stillborn babies in Nigeria through the use of demeaning utterances that many said was insensitive to their emotional state. In Uganda, Kiguli et al. (2015) reported that mothers of stillborn babies perceived health professionals as rude and negligent and that they also used vulgar language during their interactions with them. Likewise, Modiba and Nolte's (2007) study in South Africa also revealed that mothers experienced lack of sensitive and emotional care in the hands of health professionals which was made worse by health professionals lack of communication and therapeutic listening. Similarly, more than half of mothers of stillborn babies (53.3%) in Prinsloo and Conry's (2008) South Africa's study were unsatisfied with the information that health professionals provided about the cause of death, as only one out of the 15 participants in that study received any form of counselling from the hospital.

Studies conducted in the UK have also highlighted poor communication, both verbal and non-verbal as the main reason for women's poor perception of health professionals after stillbirth. As an illustration, findings from a grounded theory conducted among 25 bereaved parents in the UK concerning their perception of clinical interactions with health professionals after stillbirth revealed that parents were sensitive to the messages that professionals send out through both verbal and non-verbal communication (Downe, Schmidt, Kingdon & Heazell, 2013). Thus, when these messages were poorly communicated, women questioned the clinical judgement of health professionals and lost trust in them (Downe et al., 2013). Likewise, a cross-sectional mixed-methods survey conducted online among 547 women with knowledge of maternity care in the UK after stillbirth or neonatal death reported that 20% of the participants changed hospitals in subsequent pregnancies (Mills et al., 2016). The descriptive analysis of the closed-ended questions revealed that 40.2% of those who changed hospital did so because they were treated poorly by health professionals after stillbirth and another 21.5% of mothers did not go back to the same facility because of painful memories associated with the setting. Like the previous study, negative experiences of mothers in the study was because of communication failure from health professionals and poor awareness of the lasting impact of perinatal loss exhibited by healthcare professionals (Mills et al., 2016).

The kind of care received in the hands of health professionals is so powerful that it can affect the outcome of the bereavement period. As an illustration, mothers of stillborn babies in a UK study claimed that assault to their motherhood identities started from the hands of health professionals in healthcare facilities and continued into the community (Brierley-Jones et al., 2014). This mixed-methods study of 162 women found that medical professionals came across as lacking compassion and this fuelled feeling of shame, guilt, and stigma, with one of the participants describing that she felt like a "leper" (p. 150). Women also expressed that immediately after stillbirth diagnosis was confirmed; they were abandoned in solitary rooms, with no reassurances from health professionals nor any opportunities to ask questions. This made some of the participants felt like they had lost the identity of a regular patient (Brierley-Jones et al., 2014). Similarly, findings from focus group discussions conducted with parents of stillborn babies (12 mothers and 2 fathers) in relation to their experience of clinical encounters after stillbirth also revealed the confusion and disorientation that marked parents stay in the hospital, as well as the lack of communication from the clinical team (Kelley & Trinidad, 2012).

Studies conducted in Europe highlighted the need for health professionals training in stillbirth bereavement care. As an example, findings from a survey conducted among 750 healthcare providers across 11 Italian hospitals for the purpose of assessing stillbirth bereavement care revealed that only 55% of health professionals routinely bathed and dressed stillborn babies for parents to see, and 44.4% immediately took the babies away without allowing parents to properly say goodbye to them (Ravaldi et al., 2018). Also, more than half of the participants' felt they were inadequately prepared to provide adequate support and bereavement care for families affected by stillbirth (Ravaldi et al., 2018). Thus, nearly all the health professionals in the study (90.2%) expressed the need for bereavement training (Ravaldi et al., 2018). Likewise, the analysis of online questionnaires completed by 796 mothers of stillborn babies in Spain revealed that 17.6% of health professionals prevented the partner or family members of mothers of stillborn babies from entering the delivery room (Cassidy, 2018).

Furthermore, Rådestad, Malm, Lindgren, Pettersson and Larson (2014) found that women in Sweden experienced the verbal report of their babies' death as unclear and blunt. This study collected interview data from 26 mothers of stillborn infants about their experience of stillbirth diagnosis. The findings from the qualitative content analysis showed that after clinicians knew of



the baby's death, they gestured with each other, but did not communicate with the mother. During the breaking of the news, clinicians also delegated other staff who had not been interacting with the woman before and women interpreted this as dishonest and that it showed lack of respect for the situation (Rådestad et al., 2014). Other studies conducted in the US and Australia also reported a similar trend regarding parents' distrust in health professionals after stillbirth. In a study conducted in the US, nearly half of the participants blamed their medical team for the loss of their stillborn babies (Gold, Sen & Leon, 2018). Gold et al. (2018) evaluated the demographic, psychosocial, and reproductive factors associated with guilt in a cohort of 311 perinatally bereaved women by collecting self-reporting information and analysing their responses with summary statistics. In the study, 47% of all women believed that if the physicians or nurses had done something differently, their baby would not have died (Gold et al., 2018). Considering the high number of women blaming health providers for the losses, Gold et al. (2018) argued that such negative perception of health professionals negatively affects women's willingness to trust health providers in their next pregnancy.

An Australian study complemented earlier studies regarding women's lack of trust in health professionals' ability to respond appropriately during stillbirth turmoil. Findings from a focus group discussion with 14 parents of stillborn babies in Australia revealed that women do not trust the motives of health professionals, especially when health professionals advise against autopsy (Horey, Flenady, Conway, McLeod & Khong, 2012). Horey et al. (2012) reported that mothers of stillborn babies expressed "suspicion" of health care providers because of the tactics used in dissuading or encouraging autopsy request. This qualitative descriptive study about factors influencing the decision of Australian parents about autopsy revealed that healthcare providers do not provide factual information about autopsy procedures and were insensitive to parents needs with statements such as "you're just going to have to face it. You're losing your baby (Horey et al., 2012, p. 539). However, it is difficult to tell if all mothers of stillborn babies, regardless of their demographics had similar experiences and this is because Horey et al. (2012) did not present the demographics of the participants and consider demographics in their data analysis. In India as well, it was reported that the experience of mothers of stillborn babies with health professionals contributed to feelings of failure, guilt and isolation (Gopichandran et al., 2018). Gopichandran et al. (2018) reported that the participants believed health professionals often lie that a woman's life is in danger so that the family can give health professionals the credit for saving the mother's life

after stillbirth. This contributed to low trust in the health system, as well as in the healthcare professionals (Gopichandran et al., 2018).

Other studies in Iran added to reports of substandard care that women received after stillbirth. In Iran, Sereshti et al. (2016) assessed mothers' perception of the quality of care received from health centres after a perinatal loss in Iran. Forty women who had experienced miscarriage, stillbirth, or neonatal death were interviewed, and the interviews were analysed using qualitative content analysis. The major theme was dissatisfaction with the quality of care received, and this was because of poor communication and threats from health professionals about the mother's survival. Sereshti et al. (2016, p. 2009) revealed that a physician told one of the study participants that "if you go home, you'll have internal bleeding, and you will not make it back to the hospital." Other participants also stated that the poor level of support received in the hands of the health professionals heightened their sense of guilt, hopelessness and worsened their distress (Sereshti et al., 2016).

Likewise, in Iran, Allahdadian et al. (2016) interviewed 20 mothers of stillborn babies for suggestions about strategies that can assist health professionals to provide better bereavement care for those affected by stillbirth. The interviews were analysed using a content analysis approach, and the findings revealed that women desired to have their family members beside them during stillbirth diagnosis and delivery. Also, they expressed the need to be cared for in a fair and non-discriminatory way, they also want attention to be paid to their emotional and spiritual needs, as well as a desire for information about the cause of death (Allahdadian et al., 2016). In situations where health professionals failed to meet the bereavement needs of mothers, Allahdadian et al. (2016) reported that women became dissatisfied and lost trust in health professionals. Lastly, findings from oral history interviews conducted with seven Brazilian mothers of stillborn babies revealed that women did not receive any support from health institutions and they described their relationships with health professionals as cold, dehumanising and insensitive (Santos, Rosenberg & Buralli, 2004). These findings provide a basis for the need for stillbirth bereavement training among health professionals so that women can be cared for in sensitive and respectful ways. The failure of health professionals to meet the bereavement needs of women impacted by stillbirth can impact their bereavement outcome and means that some women may not rely on healthcare professionals for any support.

## **2.9 What helps women cope with stillbirth**

Regardless of any belief, taboos or social sanctions that discounts the stillbirth grief, mothers of stillborn babies still need to grieve their loss regardless of the settings that they may find themselves. As a result, several studies have highlighted several factors and mechanisms that assist women to deal with their loss. There is strong evidence in the reviewed studies that many women cope by turning to their religious beliefs. In Nigeria, Adebayo et al. (2018, p. 12) found that clerics are an important player in stillbirth bereavement because they are armed with "religious playlists". These 'religious playlists such as ('everything happens for a reason') are powerful information that everyone says to mothers of stillborn babies. Religion also emerged as the dominant theme for mothers of stillborn babies in Somaliland, as Osman et al. (2017) found that women interpreted stillbirth through the lens of religion as they believed that a stillborn child has been pre-destined to die by Allah. Thus, trust in Allah was the most important factor in women's coping with stillbirth in Somaliland. In Ethiopia, Sisay et al. (2014) report that women use "traditional remedies such as taking herbal medicine or holy water and wearing necklaces made of parchment which had religious writing in it" (p. S115).

In Taiwan, Tseng et al. (2014) observed that women coped with stillbirth by observing religious duties and folk customs, as well as taking new jobs and taking care of the next child (Tseng et al., 2014). Along the same lines, from the oral interviews conducted with Brazilian women, it emerged that the church provided the foundational support upon which women cope with perinatal bereavement (Santos, Rosenburg & Buralli, 2004). Santos et al. (2004) found that women primarily coped by interpreting their losses within the framework of their religious beliefs and by believing that God will give them another baby. Women, therefore, appreciated the prayers, visitation and advice of their pastors which centred on putting the loss behind them and moving on. Likewise, the thematic analysis of the phenomenological interviews conducted with ten Jewish women revealed that interpreting stillbirth loss as a test of personal faith in God enabled them to face the consequences of stillbirth (Hamama-Raz, Hartman & Buchbinder, 2014). Along the same line, findings from the constant comparative analysis of the in-depth semi-structured interviews conducted with women with perinatal losses in the US also revealed that religious and spiritual beliefs were necessary for coping among the participants (Van & Meleis, 2003).

Other studies have also identified support groups as an important source of social support for mothers of stillborn babies. As an illustration, a cross-sectional mixed-methods study that explored the effects of a support group on traumatic stress responses of 47 American mothers of stillborn babies revealed that women joined support groups because of lack of support from family members (Cacciatore, 2007). The participants of the study expressed that the connections they established with other bereaved women in support groups ameliorated "the sense of aloneness and fostered intimate relationships, interdependence, and reciprocity" (p. 85) and that these helping connections alleviated the traumatic stressors associated with the child's death. In contrast, however, some women in Australia found support groups unhelpful, and many left because group members were in different stages of grief, making it harder to cope with loss (Inati et al., 2018).

Although memory-making through seeing and holding the body of the stillborn baby, as well as creating memories such as footprints and pictures was helpful for some women, others reported that it aggravated their grief. Sun, Rei and Sheu (2014) conducted a descriptive phenomenological study aimed at understanding the decision-making process of 12 Taiwanese couples regarding their decisions about seeing the body of their stillborn infant. Data was collected through in-depth interviews and participants' observation, and the interview transcripts were analysed using Giorgi's methods. Although Taiwanese folk taboo prevents viewing of the body of stillborn infants, some of the parents in this study said they viewed the body because it was an opportunity to ascertain that the baby indeed died, to say farewell, and to reconcile their imagined idea of their child with the real appearance. However, some parents declined to see the stillborn infant because they wanted to sever their attachment to the child, observe cultural taboo and to avoid imprinting the memory of a deformed, abnormal or emaciated baby (Sun et al., 2014). The practice of making memories with the stillborn babies through seeing, holding and rituals that have been reported elsewhere is contrary to Yoruba beliefs. In the study conducted by Kuti and Ilesanmi (2011), women found the idea of having pictures of the infant strange and unnecessary. Thus, in the study, only 2 (4.4%) of the mothers took photographs of the infant, and none wanted to name the infant. Yoruba women refrained from keeping mementoes because of fears that it might have spiritual consequences and psychological consequences (Kuti & Ilesanmi, 2011).

Gravensteen et al. (2013) retrospectively investigated how women experienced the procedure of stillbirth diagnosis, the delivery, postpartum period, as well as their appraisal of the care received

at the hospital. Data were collected using standardised self-rating scales from 379 Norwegian women, and the statistical analysis revealed that 98% of the women saw their stillborn babies, 82% also held their babies, and most of the women felt supported by healthcare professionals. Most of the women also had one or more photographs (97%), one token of remembrance (99%), footprint or handprint (85%) and 93% had their babies buried in a marked grave. Gravensteen et al. (2013) reported that seeing and holding the bodies of stillborn infants were strongly protective of post-traumatic stress symptoms.

Erlandsson, Warland, Cacciatore & Rådestad (2013) found that how women are presented the bodies of their stillborn babies determined whether they experience it positively or not. This Swedish study collected survey responses from 840 mothers of stillborn babies and findings revealed that health care providers asked 54% of mothers if they wanted to see the child's body, 32% of the mothers were offered the body without asking and only 12% had to ask health professionals before the infant's body was shown to the mother. The interesting part of the findings was that the mothers who were not asked before they were offered the baby described the experience as natural, and were less frightened, but those who were asked were frightened about the experience of meeting the baby. As such, Erlandsson et al. (2013) argued that health professionals should consider offering stillborn babies to their mothers without asking, in a process called “assumptive bonding” (p. 246). While “assumptive bonding” may seem like a natural thing to do, especially when considered in the light of increasing awareness regarding the benefits of kangaroo care for livebirths, there is however no consensus regarding kangaroo care for stillborn babies and this is due to differences in how each culture treats issues relating to life and death. Along the same line, Lindgren, Malm and Rådestad (2014) conducted semi-structured interviews with 23 Swedish women for the purpose of describing their experience of saying farewell to their stillborn infant after discharge from the hospital. The result from the content analysis revealed that women felt it was unnatural to leave the baby behind in the hospital and to go home empty-handed. However, spending as much time as they could with their stillborn infants assisted them to accept the loss and helped them to start the process of healing.

In contrast, the result of a postal survey conducted with 468 mothers of stillborn babies in the UK revealed that women who held their stillborn baby consistently reported higher rates of poor mental health and relationship difficulties (Redshaw, Hennegan & Henderson, 2016). After adjustment

for demographics, women who held their babies were twice as likely to report anxiety at nine months and were five times more likely to report relationship difficulties. This study supports the concerns about the negative impact of holding the infant after stillbirth. Along the same line, findings from a study that examined whether women valued the post-mortem memento photographs that were given to them after a perinatal loss in the US advised health professionals of the need to be aware of cultural diversity when considering whether women should see or hold their babies (Blood & Cacciatore, 2014). Blood and Cacciatore (2014) applied the open and axial coding strategies of grounded theory to women's responses about memento photographs, and it emerged that while some mothers felt the baby's photographs made their loss real to others, Native American women in the study found the photographs disturbing and against their traditional beliefs. Some women were also upset that the pictures were taken without their permission and they lamented that "the pictures made the child look cold and alone... [and they] did not want to remember him that way" (p. 229).

## **2.10 Summary of the review**

Existing literature related to stillbirth was reviewed and synthesised in this chapter. A number of themes were examined such as cultural understandings of stillbirth, social consequences of stillbirth, social networks of mothers of stillborn and mothers experience of health professionals' support after stillbirth among others. The literature reviewed in this chapter provided arguments by other researchers on the variations in the cultural response to stillbirth grief, and the social impact of stillbirth. However, given that practices surrounding stillbirth bereavement vary from one culture to another, even among African cultures, research has barely touched the connections between culture and the social support system of mothers of stillborn babies. The cultural implications of stillbirth on social support are important, especially in highly cultural contexts like that of Nigeria's Yoruba women, because despite the existence of cultural norms and beliefs that invalidates stillbirth grief, mothers still have to deal with their loss.

The findings from the reviewed literature provided the basis for the need to understand the social capital implications of stillbirth from the cultural perspectives of Yoruba mothers of stillborn babies in Nigeria. Even among high-income countries where strong formal and informal support exist for stillborn mothers, there is strong evidence that mothers are not engaging as they should with available support because of negative experience at the hands of healthcare professionals.

This current research therefore sought to add to the ongoing conversation about the cross-cultural understandings of stillbirth bereavement by extending the theory of social capital and the methodological approach of phenomenography to the issue of stillbirth. The next chapter discussed the theoretical framework of social capital and its suitability for the current research.

## **Chapter 3: Theoretical framework**

### **3.1 Introduction**

This research falls naturally within the theoretical field of social capital for a variety of reasons. First, a common finding in the stillbirth literature is that mothers of stillborn babies tend to be socially isolated and lack individuals in their networks who can provide support. Second, it also emerged from the literature that mothers of stillborn babies have low trust in health professionals and avoid interactions with people they cannot trust with their feelings. Third, one salient issue that was also evident in the review was that the source where women derive social support could make a difference in how they deal with the loss. All these findings from the literature have implications for the theory of social capital. The theory of social capital explains how some aspects of social interactions such as trust can determine who a mother of a stillborn baby will rely on for support, why they will prefer to receive social support from certain people, as well as kinds of support that were accessible to them.

For instance, after a stillbirth event, a woman may need advice on what to do about the breastmilk that is coming in. She may also need someone who can help with putting away all the baby gear in the house, or she may need someone to share her feelings about how hurtful it is seeing her neighbours' neonates. These needs may be met by different people in different ways and at different times. It is possible that a good friend outside town will meet her desire to talk about her feelings through regular telecommunication. Likewise, she may receive information from a colleague about local herbs that can help with lactation suppression. However, her desire to rid her home of all the baby gifts, bassinet, and equipments may only be met by someone in the family or neighbourhood due to physical proximity. So, it is helpful to distinguish the different types and levels of support available through kinship, friendship, professional and institutional networks. This is because the assumption that mothers of stillborn babies rely majorly on the spouses and family for support (Allahdadian et al., 2014; Chung & Reed, 2017; Shaw, 2014; Sutan et al., 2010) may underestimate the significance of other networks that may provide crucial emotional and informational support. This is even more important in stillbirth bereavement because mothers will also have to deal with how others will interact with them after the loss, and this means the needs of stillbirth bereavement are rarely met by just friends and family (Umphrey & Cacciatore, 2011).



A social capital analysis provides a useful lens through which an analysis of the social networks of women and the support they provide after stillbirth loss can be made. Such information can be helpful for health professionals working with mothers of stillborn babies because the mere existence of social networks may not necessarily translate to social support. Thus, having knowledge of where support comes from, the type of support received and what determines women's reliance on certain networks can assist health professionals to identify factors that can impede or facilitate successful grief resolution and such information can be used to formulate both short- and long-term care plans. The conventional idea of social capital is that as individuals, our ability to survive trauma, cope with divorce, bereavement or disability depends on those people in our lives who can support us in one way or the other. Those people that we are connected with can help us adjust to the new demands that we have to face, others can offer to live with us for some time, while others can send us cards, or pray for us.

While most people would agree that mothers of stillborn babies need to be supported to cope with the challenges of baby loss, limited findings from studies conducted among Yoruba women (Adebayo et al., 2018; Kuti & Ilesanmi, 2011) revealed that they are often abandoned to their grief. Eyetsemitan (2002) has also noted that even though Nigeria is a collectivist society, where more people are likely to live in multigenerational households, support is not always available for those with disenfranchised grief like stillbirth. However, little is known about the social networks of mothers of stillborn babies in Nigeria despite that the occurrence of stillbirth represents a social network crisis for them (Adebayo et al., 2018; Kuti & Ilesanmi, 2011). Understanding stillbirth bereavement from a social capital perspective means that we can gain an in-depth insight into the contribution of social bonds to grief resolution from the cultural perspective of Yoruba women. Thus, social capital theory helps in examining how social relationships, social structure and even culture influence grief resolution and reorganisation of life after a stillbirth event. The present study used the theoretical ideas of James Coleman (1988), and Robert Putnam (2000) to provide new insights into the roles of social capital in Yoruba women's experience of stillbirth. Both theorists (Coleman and Putnam) approach social capital through different research areas but came to the same conclusion that social connections are an essential resource for well-being.

### **3.2 Social capital theory: A framework for studying the contribution of social relationships to stillbirth grief**

The conceptual origins of social capital theory can be found in the works of Bourdieu (1985), Coleman (1990) and Putnam (2000), but this research aligned more with the theoretical ideas of Coleman and Putnam and I used their ideas in this study. Social capital is generally portrayed as a multidimensional concept comprising of two components that could be distinguished but not separated, namely structure and content (Cloete, 2014; Ferlander, 2007). These two components of social capital are reflected in the definitions of Bourdieu, Coleman and Putnam as seen below:

the aggregate of the actual or potential resource which are linked to possession of a durable network or institutionalised relationships of mutual acquaintance and recognition (Bourdieu, 1985, p. 248)

a variety of entities having two characteristics in common: [t]hey all consist of some aspects of social structure, and they facilitate certain action of individuals who are within the structure” (Coleman, 1990, p. 302).

features of social life- networks, norms, and trust- that enable participants to act together more efficiently to pursue shared objectives (Putnam, 1995, p. 664)

Social networks are central to how the three theorists conceptualised social capital and this has led to the conclusion that an individual must be connected to others to possess social capital, because those who one is connected to are the actual source of social capital (Lancee, 2010; Portes, 1998; Torche & Valenzuela, 2011). As an illustration, when a woman is befallen by stillbirth tragedy, she might not be aware of counselling services or social support groups that can help her deal with the loss since no one ever prepares for the possibility of stillbirth. Thus, if one of her friends links her with a professional or support group, that friend is a holder of social capital. This means that the mother of the stillborn baby acquired a social capital resource in the form of information due to her connection with that friend. From a social capital perspective, the more people a mother of a stillborn infant has in her networks, the better her chances for successful grief resolution (Bourdieu, 1985). As an example, a mother who has always relied on her spouse may struggle to cope with the loss if her relationship fails after stillbirth because a small network size may mean limited people that could step in to support. It is therefore not surprising that mothers who are

single, divorced, or widowed have been found to have higher levels of depression after stillbirth than mothers who are married or cohabiting (Cacciatore et al., 2009; Paris et al., 2016).

Thus, from the structural analysis of the social networks of a mother of a stillborn baby, one can determine the size of the networks in terms of how many individuals supported her, or whether those individuals are family, friends, relatives, colleague or even health professionals. The ability to distinguish the social networks of an individual based on their characteristics is helpful to understand those who provide support and the type of support provided. However, while there is agreement from the three theorists that the social network (that is, whom an individual is connected with) represents the structural aspect of social capital, Bourdieu, Coleman and Putnam have different ideas about the content of social capital. From the perspective of Bourdieu, the content of social capital are the resources that an individual derives from being connected to others. In this sense, the advice that a colleague gave a mother of a stillborn baby about what she can use to suppress lactation is the content of social capital. Bourdieu (1986) described social capital as a useful support that one acquires through one's relationship with others when it is needed. Therefore, any support given must be relevant to the type of stressor and the need of the individual at that particular time (Cohen, 2004; Gurung, Sarason & Sarason, 2001; Umberson & Montez, 2010). However, even though Bourdieu placed enormous emphasis on the benefits that one can acquire through one's relationships with others, getting support from others depends on the ability of the stillbirth-affected mother. Commenting on Bourdieu's position, Hauberer (2011, p. 39) noted that:

Benefits from these investments can only be gained if the individual understands the genealogical connections and real relations in the group and learns how to use them or retransform the social capital into cultural or economic capital

In this sense, a mother of a stillborn baby in Yoruba society needs to know the right time she can seek support from others and the right person to ask for social support (Bourdieu, 1985). Paradoxically, Bourdieu's idea of cultural capital is that people gain cultural capital through socialisation and he further argued that incorporating cultural capital can reveal one's weakness (Bourdieu, 1985). However, considering that it is culturally unacceptable to grieve for a stillborn infant in Yoruba culture, it may be uncritical to try to understand the role of social capital in Yoruba

women's experience of stillbirth from the standpoint of how mothers tried to create social capital for themselves. Asking for support for stillbirth grief in Yoruba culture may bring a woman social rebuke, alienate her the more and she may even be scared to seek help because of the belief that grieving the loss can affect future pregnancies (Adebayo et al., 2018). However, it is not to say that Yoruba mothers of stillborn babies are passive in an issue that is affecting them, but I also do not want to place them uncritically within an existing framework of social capital that seems to be out of sync with their contextual realities. Realising this opposing view between some of the theoretical ideas of Bourdieu and the cultural and contextual realities of mothers of stillborn babies in Yoruba society, I turned my attention to the theoretical ideas of Coleman and Putnam, especially in relation to their conceptualisation of social capital content.

With regards to the content of social capital, Coleman (1988) and Putnam (2000) have a different idea to Bourdieu. Coleman (1988) and Putnam's (2000) position is that networks alone are insufficient. Instead, trust and reciprocity produce social capital. So, unlike Bourdieu who argued that gift exchanges produce social capital, Coleman and Putnam argued that trust is the precondition for social capital. Rowe and Calnan (2006) illustrated this idea by noting that trust is forward-looking and reflects an attitude toward a new or ongoing relationship. This means that it does not matter whether the mother of a stillborn baby has known an individual before or after the loss, if she does not trust the individual, she will not open up to the individual about her needs. So, it is when trust is established that acts of exchange of emotional support, advice, or practical help can result (Coleman, 1995). Thus, from the perspectives of Coleman (1993) and Putnam (1988), social capital can only be acquired when there is trust between two interacting individuals. The theoretical ideas of Coleman and Putnam regarding trust being the precondition for social capital seem to be valid in stillbirth research as there is evidence that trust is what determines whom mothers talk to about their experience or needs. This is illustrated in some quotes below:

when people ask me, do you have kids, or how many, I have to check myself. It depends on who I'm talking to (A UK mother in Kelly & Trinidad, 2012, p. 9).

When my friends visited me, I feel that I want to share my experience with them. But it is hard. But sometime, I feel unable to do that (A Malaysian mother in Sutan & Miskam, 2012, p. 7)

Trust has been used as an explanatory concept by some researchers to examine the relationship between patients and health professionals (Vahdat, Hamzehgardeshi, Hessam & Hamzehgardeshi, 2014; Rowe & Calnan, 2004; Thom & Rabisi, 1999). For instance, a recent study on health literacy in HIV care revealed that "patients will not fully engage in or participate in care until they trust their providers" (Dawson-Rose et al., 2016, p. 578). As such, Rowe and Calnan (2004) argued that without trust, "patients may well not access services at all, let alone disclose all medically relevant information" (p. 4). The role of trust in social capital, therefore, helps explain why health professionals are less represented in the social networks of mothers of stillborn babies as revealed in the literature review. Trust emerged strongly in women's behaviour after stillbirth (Downe et al., 2013; Gold et al., 2018; Horey et al., 2012), with Mills et al. (2016) reporting that as high as 40.2% of mothers of stillborn babies changed hospitals due to lack of trust in the clinical judgment of health professionals after stillbirth. The issue of trust in health system and health professionals is a big issue among the general population of Nigeria as well. For instance, in 2013 alone, it was reported that Nigerians spent US \$1billion in other countries for the sole purpose of seeking medical care (Price Waterhouse Coopers, 2016). A survey conducted on why people preferred to travel to other countries outside Nigeria for health needs revealed that majority of those seeking care outside Nigeria did not have trust or confidence in Nigerian healthcare system because the healthcare professionals and the health system have never been held accountable for numerous misdeeds (Olatunji, 2016; Abubakar et al., 2018).

Apart from the trust component of social capital, Coleman and Putnam additionally identified 'reciprocity' as another vital element in the content of social capital. Putnam (1993) describes reciprocity as an exchange of favours, and the main idea here is that people help others without expecting immediate favour in return. For instance, before the tragedy of stillbirth, it is expected that a mother of a stillborn baby has a social life which involves being part of a family, being married to another family, and she is also connected to friends, colleagues and may even be affiliated with social groups such as a sports club. Just by her position as a mother, wife, colleague or even member of a church, it is expected that she must have attended baby showers, weddings or birthday parties of friends and family, or played the role of a host to a new neighbour. Through these social interactions and many others, one would expect that the mother of a stillborn baby would have helped some people during their moment of needs. So, during the crisis of stillbirth, it is expected that some of these people that she has always related to, will potentially come together

in solidarity to help her deal with the crisis. Adler and Kwon (2002) and Lancee (2010) explained that the social support that people exchange is a form of investment in social relationships and this investment can be drawn on later as social capital. Coleman described the idea of reciprocity below:

A relation of mutual trust exists if actor A does something for actor B and trusts B to reciprocate in the future. This action establishes an expectation in A and the obligation in B to justify the trust (Coleman, 1988, p. S102).

Dolfsma et al. (2009) argue that the obligations to give, receive and reciprocate are undoubtedly social and, sometimes, it may have moral overtones such as the kind of social exchanges that occur between family members. Reciprocity generates trust and allows for the cultivation of personal relationships and the building of shared memories (Petersen, Roepstorff & Serritzlew, 2009; Sturtevant, 2006). As a result, reciprocation is not something that is immediate (Portes, 1998; Stolle, 2003) and it is not proper to reciprocate with the same thing that one receives (Dolfsma et al., 2009). For instance, before stillbirth, a mother of a stillborn baby may have been supportive to a colleague going through a divorce. The occurrence of stillbirth for the woman means she would expect that her friend whom she supported during her divorce would help in some way even though divorce and stillbirth are two different things. However, while the exchange of favours and support is essential for both the development and maintenance of relationships, mothers of stillborn babies often fail to benefit from the favours and support they have given out to others in the past. It is not uncommon for people to research the kind of gift they intend to give a mother of a stillborn baby carefully. As an illustration, an online user solicited for gift ideas for a mother of a stillborn baby on an online forum in Australia (Essential Baby), and many mothers of stillborn babies who responded to the post stated that they found flowers, sympathy cards or teddy bears insensitive when people gave such as gifts (Essential Baby, 2013).

Because of the sensitive nature of stillbirth and the individuality of the grieving parents, potential social networks may also be in a dilemma on what to give, as demonstrated earlier. From a social capital perspective, Dolfsma et al. (2009) explained that when an individual anticipates that a gift may not be accepted, or that a particular kind of gift will not be appropriate, the gifts will not be given and there will not be any obligation to reciprocate later (Dolfsma et al., 2009). As an

illustration, the friends of a woman facing a stillbirth crisis may refrain from giving her certain gifts such as baby clothes since there was no baby. The limit on what can be given to a woman who has a stillborn baby versus a woman who has a live baby means the mother of the stillborn baby is disadvantaged because she will not be able to reap the benefits of the investments in social relationships that have been formed over the years. Along the same line, Ferray (2003) explained that if a gift is perceived as improper by an individual, the implication is that a relationship that was supposed to be formed or reinforced will be halted and this will also erode trust from the relationship. This means that stillbirth may affect a woman's relationship with others because unlike 'good deaths' in Yoruba culture where there is no restriction on what can be given or not given, how people show support for stillborn mothers is tightly restricted.

Burt (1992) argued that failure to reciprocate leads to excommunication from a network and destroys trust. Since there is no public acknowledgement of stillbirth grief in Yoruba society or any ritualised occasions like funerals, the social networks of mothers of stillborn babies may not be able to participate in gift-giving, and according to Belk and Coon (1993), this is a social loss for the women. The result of the social and cultural limitation placed on mourning and the social expression of grief can easily make people overlook mothers of stillborn babies, and only those very close to them may notice a need for support.

The contextual realities of mothers of stillborn babies in Yoruba culture make the ideas of Coleman and Putnam a better fit for this research. Trust and reciprocity take a special significance in this study because lack of trust can contribute to the collapse of social networks in terms of restricting access to social support and on the other hand, lack of reciprocity can lead to disenfranchisement and social loss. This means trust and reciprocity are measures of social capital in stillbirth bereavement because it determines the social networks of women, the type of support that they will receive and the perception of whether any support meets their expectations. Therefore, in this thesis, I approach the role of social capital majorly from the theoretical ideas of Coleman and Putnam because it allows me to use the concept of trust and reciprocity to explain why the social networks of my participants were patterned in certain ways. In social capital research, it is important to take a position because of the differences in the theoretical ideas of social capital theorists. Besides, some scholars (Claridge, 2004; Adam & Roncevic, 2003; Adler & Kwon, 2002)

have suggested that it is important to discuss the concept of social capital, its intellectual origin and its diversity of applications before adopting a school of thought.

### **3.3 Forms of social capital**

Both trust and reciprocity determine how the social networks of a person will look and the kind of resources that will be accessible to the individual. For instance, in a situation where a mother of a stillborn baby has low trust in others, her networks will be homogenous and most likely dominated by family and close friends. Coleman and Putnam captured the way trust and reciprocity shape the networks of individuals. Drawing on his educational research among young children, Coleman theorised that students in private schools performed better than those in public schools because there was a stronger sense of community and norms that the parents, teachers and students embraced (Coleman, 1988). From this research, Coleman identified three factors influencing social capital. These are: closure, stability and ideology (Coleman, 1998). The closure argument is that social capital is created by a network of strongly connected people (Coleman, 1988). A social structure is therefore described as closed, if relations exist between all members and an example of a closed system has been identified as the family (Coleman, 1990; Lancee, 2010; Sanders & Nee, 1996).

Network closure is argued to do two things: access to information and to social sanctions (Burt, 2000). Coleman believed that in a closed system where all members are interconnected, there will be better access to information among members and that people are more likely to trust those whom they have a relationship with, and this facilitates social sanctions. As an example, the Stillbirth, Miscarriage and Child Loss support group in the UK has 75 members (according to their Meetup site) and for anyone to be part of this group, the person must have suffered a perinatal loss and must be ready to meet regularly. This is described below on their Meetup site:

We are about families who have undergone the bereavement of a child or baby and would like to meet other families for support and socialising. This meet up group is for those with the *same experience to meet regularly [emphasis added]*... it is about knowing that there are others who have undergone what you have been through, but also giving you the opportunity to be able to do other things instead of focusing on just this experience (Stillbirth, Miscarriage and Child Loss group, 2016, p. 1).



The Stillbirth, Miscarriage and Child Loss group is an example of a closed group because only those who have suffered a certain kind of loss can join and this means members would have access to certain information that may not be accessible to those who are not part of the group. But to maintain one's access to all the benefits offered by being a member, one must attend regular meetings, pay membership fees (if required) and observe any norms expected of members. The group exercise their social control by excluding anyone who is not fulfilling their membership obligations. Thus, the structure of relations of an individual is important because that is where social capital resources are exchanged. Second, Coleman argues that social capital depends on the stability of the social structure or relations (Coleman, 1990). Thus, disruptions in social organisations or social relations destroy social capital. This is also significant in the context of stillbirth because isolation and withdrawal from social interactions due to shame lead to a disruption of social relations, thereby resulting in diminished social capital for women, as the literature as revealed. Flanagan, Verdouw and Habibis (2016) and Touraine (1998) argued that the process of stigmatisation could cause the introversion of an individual, thereby breaking down their social networks and subjecting them to family only networks. Chen et al. (2011) added that stigma undermines trust and reduces opportunities for interpersonal interactions. As a result, it has been reported that social stigma interferes with the reconstruction of social capital and this leads to negative health consequences (Lanfredi et al., 2015). Among mothers of stillborn babies, Cacciatore (2010) found that mothers of stillborn babies in the US “recoiled” from the social environments because of shame and lack of trust in their social circle (p. 145).

Third, Coleman (1990) argued that having a particular ideology may awaken an individual to act in the interest of someone or something and he referenced that religious doctrine can lead a person to act in the interest of others. This is also relevant in the context of this research, as it came out strongly in the literature that many women coped with stillbirth bereavement by adhering to certain beliefs and through support from religious organisations (Santos et al., 2004; Hamama-Raz et al., 2014; Sisay et al., 2014). From this perspective, one would expect communities that are high in cultural norms and beliefs to be highly supportive of mothers faced with stillbirth grief because their cultural ideologies is expected to prompt them to act in the interest of the mother.

Following Granovetter's (1977) notion of strong and weak ties, and Coleman's idea on closure, Putnam made a distinction between bridging and bonding forms of social capital (Putnam, 2000).

Bonding social capital is often used synonymously with strong ties, and it is found among people who engage in mutual and intense interactions such as kin and confidants (Lancee, 2010; Lin, 2005). Lin (2005) contended that the members of a bonding social network are obligated to reciprocate exchanges and services to one another. For instance, when a woman suffers a stillbirth, her spouse or immediate family members has no choice but to support in some way. This may be different from outsiders like colleagues who do not share that kind of obligation with the woman. Sanders and Nee (1996, p. 233) highlighted that “cooperation in the family [does] not simply stem from self-interest, but from a moral order in which the accumulation of obligation among members builds a form of solidarity described as “household communism”. As such, bonding social capital is good for people needing emotional support, solidarity, and personal empowerment in dealing with a crisis (Wuthnow, 2002).

In bonding social capital, trust and reciprocity are very high because people know each other very well, have common memory of events and are always doing one favour or the other for one another (Hughes, Bellamy & Black, 1999; Torche & Valenzuela, 2011). Bonding social capital is also associated with homogenous networks because it brings people with similar characteristics together such as mothers of stillborn babies in a support group for perinatal loss (Gittell & Vidal, 1998; Murphy, 2002; Putnam, 2001). However, while bonding social capital is a powerful source of social capital, some have argued that its benefits are limited. It has been suggested that strong bonding networks can be a source of strain, leading to conflicts, envy and disappointments, and resulting in negative effects on health (Due, Holstein, Lund, Modvig & Avlund, 1999; Ferlander, 2007; Portes, 1998). Obligations placed on individuals to reciprocate in a deprived community may serve as a source of stress and burden and the information in bonded networks also tends to be redundant information (Briggs, 1998, Woolcook, 1998, Putnam, 2000). It has also been argued that bonding social capital is usually the main source of social capital for people who are unable to access formal sources of support (Aberg, 2000; Putnam & Gross, 2002; Rose, 2000). In this sense, one would expect mothers of stillborn babies who are living in societies that disenfranchises stillbirth grief to rely more on bonding social capital such as family.

Bridging social capital, on the other hand, refers to heterogeneous individuals whose ties are weaker, but which provides access to a wider variety of resources. Putnam (2000) believed that trust is developed through interactions with formal associations. Health professionals are generally

considered as weak ties or bridging social capital because patients' interactions with them are transient, briefer, transactional and with less connection (McKinlay, McDonald, Darlow & Perry, 2017; Rogers et al., 2011). Bridging social capital provide individuals with ties that go beyond their immediate, narrow identities, and tend to be more interconnected with other networks, thus providing their members with valuable links and prospects for getting ahead (Ferlander, 2007; Putnam, 2000). For instance, McKinlay et al. (2017) and Rogers et al. (2011) explained that having connections with health professionals can allow patients to seek specific, yet socially distanced support without the constraints of bonding social capital. Although social capital theory has not been previously applied to stillbirth bereavement or any perinatal loss, research among widows suggests that losses that result into identity change such as stillbirth requires a larger network with a greater number of weak ties, and greater heterogeneity (bridging social capital) (Bankoff, 1983; Sullivan & Fenelon, 2014).

Just as in stillbirth where adjustment is needed for a new identity, Walker, MacBride and Vachon (1977) found that widows in Canada made use of bridging ties to reorganise around a new status, and it was also bridging social capital that made it possible to make new friends, find new jobs or develop new lifestyles. However, in contexts where women have no access to formal support, bonding capital may be the only form of support, and some women have claimed they coped with child loss with only bonding social capital. As an illustration, Lau (2014) conducted eight case studies with women who lost their only child to an earthquake in China to understand the role of bonding and bridging social capital in alleviating the pain of bereavement. Most of the women coped well with the support of husbands and parents and the few women who sought formal help did so because of lack of support from husbands or parents (Lau, 2014).

### **3.4 Social capital in research**

The theoretical ideas of Coleman and Putnam have been tested empirically among women in general, mostly in high-income countries and it appears that bonding and bridging social capital lead to different outcomes.

#### **3.4.1 Bonding social capital in research among women**

Neblett, Davey-Rothwell, Chander and Latkin's (2011) conducted a cross-sectional study in the US to assess the association between social network characteristics of 513 sexually active African

American women and high-risk sexual behaviours using the social network inventory tool. The findings from the bivariable and multivariable logistic regressions revealed that women with a larger total network size had a greater risk of contracting HIV because they had more than two sexual partners with high-risk behaviours such as the use of cocaine and heroin. Likewise, in Moscow, Ferlander et al. (2016) examined the association between different forms of social capital and self-rated depression by using self-rating depression scales which was analysed using logistic regression. A total of 1190 individuals completed the questionnaire, of which 680 were women. Women had higher rates of depression than men (48% versus 36%), but depression was higher among women whose networks were dominated by individuals outside the family. In both studies, bonding social capital protects women from HIV and depression and having larger networks did not translate to any benefit for women.

Findings from another study in the US among women diagnosed with breast cancer revealed that the size of the network does not matter for cancer survival, instead, it is the quality of the support and the source of the support (Kroenke, Kubzansky, Schernhammer, Holmes and Kawachi, 2006). Kroenke et al. (2006) prospectively followed 2,835 women with cancer diagnosis over ten years (1992 to 2002) to examine the association between changes in the social networks and mortality. The data was collected with Berkman-Syme Social Networks Index, and women were stratified into four groups (socially isolated, moderately isolated, moderately integrated and socially integrated) based on their marital status, number and frequency of contacts with children, close relatives and close friends and membership in organisations. The descriptive and multivariate-adjusted analyses of the data revealed that 224 women died during the study period, 107 of which died because of breast cancer. Most socially isolated were significantly more likely to die from any cause and to die from cancer than women who were socially integrated. Being married, being a member of religious or community group or losing social networks were unrelated to survival, but women who lacked close relatives, friends or living children had a significantly higher risk of mortality.

Also, from the US, Vega, Kolody, Valle and Weir (1991) surveyed 679 immigrant Mexican women in the US to identify the characteristics of their social networks and how these characteristics are related to emotional support and personal distress. Data were collected with a questionnaire that asked participants about their networks, role of their relationships, the frequency

of contact with social networks and the participants' satisfaction with personal relationships. The statistical analysis revealed that family only social networks were more common than those including friends. Findings from the bivariate analyses also revealed that emotional support from the family and income were the two best predictors of depression. In other words, it was not the size of the social network itself that predicted depression, instead, it was the source of the support.

Reisig, Holtfreter and Morash (2002) investigated the differential distribution of social networks in terms of size and resources of 402 adult female felons in the US to identify the social groups most likely to benefit from social capital. The design was longitudinal as data were collected at different times with a three single-item scale that measured emotional support (total number of people available to talk to), social support (total number of people they spent time with) and instrumental support (total number of people that could be turned to if they needed something). Statistical analysis revealed that friends provided the most emotional and social support, while the family provided the most instrumental support. Also, the race of the participants did not have any influence on the social network size of the participants. Rather, it was education that determined the size of the network. Better educated women offenders had a higher number of network members to turn to when in need of help, but this was not the case for poorly educated offenders who had smaller and less diverse social networks and received lower levels of support.

### **3.4.2 Bridging social capital in research among women**

In contrast, findings from interviews conducted among 20 American women for the purpose of understanding the characteristics of their social networks revealed that women who had diverse networks (bridging social capital) received the most frequent and broadest range of support, whereas, women with kin-dominated networks received fewer and less frequent support (Fudge, Neufeld and Harrison, 1997). Fudge et al. (1997) also found that women who relied primarily on kin-dominated networks (bonding social capital) were less satisfied with the support they received from family members and reported more conflicts with their network members than those in diverse networks. Similarly, Negron, Martin, Almog, Balbierz & Howell (2013) explored the social support networks of 33 postpartum women in the US for the purpose of identifying the barriers and facilitators of support. Four focus groups were conducted, and the thematically analysed data revealed that the immediate family, particularly partners and mothers were the principal sources of instrumental and emotional support during the postpartum period. Notably, it

was found that the principle of reciprocity acted as a barrier to receiving social support because women felt support should come naturally from their immediate family without asking. Women perceived asking for help as a sign of weakness of their motherhood roles, and they refrained from asking people. Also, Negron et al. (2013) revealed that people with smaller networks were more likely to suffer in silence because of limited resources available in their networks. This suggests that when it comes to reproductive issues, women may be reluctant to ask for help because of social expectations.

Levendosky et al. (2004) compared the structural and functional social capital of 145 pregnant women who experienced domestic violence with those of another 58 women who were not in abusive relationships. The structural aspect of social capital was measured in terms of the total number of people in the networks while the content was measured in terms of emotional or practical support that was received from their networks. Beck Depression Inventory, Severity of Violence Against Women and Norbeck Social Support Questionnaire were some of the instruments used to collect self-rating responses from the participants. Findings from the descriptive and correlation statistics revealed that women in abusive relationships and those not in abusive relationships had similar network size. However, the social networks of women in abusive relationships comprised majorly of other women who were also victims of relationship violence and this significantly increased their risk of PTSD. Levendosky et al. (2004) explained that bonding with other women in abusive relations did not help the participants because those in their networks had fewer psychological resources to offer. Thus, bonding with other victims of social abuse was not helpful for pregnant women who are also undergoing domestic violence.

Hagan (1998) conducted a three-year ethnographical study detailing how 74 immigrants from Guatemala attained legal status in the US, with a particular focus on gender, social networks, socioeconomic adaptation and mobility. The participants comprised 32 women and 42 men. Men in the study gained legal status faster than women because they had a mixture of both strong (bonding) and weak ties (bridging) that enabled them to hear information faster and to gather necessary documentation. Women, on the other hand, were much less informed than men because of their live-in domestic positions which restricted their interactions with others in the community. The bonding type of social capital that characterises women's social networks meant they only had

access to redundant information and as such, they were unable to access the documentation that could have allowed them to achieve legal status (Hagan, 1998).

### **3.4.3 Social capital research among African populations and developing countries**

Research on social capital among African populations and in developing countries is scarce. Some authors (Boneham & Sixsmith, 2006; Myroniuk, 2016) have however advocated for more research on social capital among women in developing countries because the absence of welfare programs in these contexts may limit women to informal networks only. Indeed, all the studies conducted from developing countries suggests that women utilise bonding social capital because of trust and gender issues and the collectivist nature of many of these countries. In Nigeria, Oke (2013) conducted in-depth interviews and survey with 74 women entrepreneurs to examine the impact of their social networks on business growth. Family, friends and religious organisations dominated the social networks of these female traders, with 56% of the participants revealing that family and friends helped their business to grow, while another 30% attributed their business success to memberships of religious organisations.

Kane (2013) examined the relationships between microcredit activities and the social capital of 166 Senegalese female loan recipients. Data were collected through interviews, surveys, participant observation and focus group over 8 months. Both deductive and inductive analytic procedures on the data revealed that the ability of women in the study to access loan and thrive in their business is a function of the amount of support provided by their spouses. Women who were married and who had the support of their husbands thrived because spousal support transcends just the monetary aspect of loan securement, to include support with decision making and negotiation leverage. Also, older children, extended family, and formal education facilitated women's success in entrepreneurial activities.

McMichael and Manderson (2004) examined the social relationships of 42 Somali refugees in Australia by conducting in-depth interviews with them over 12 months. The content analysis of the interviews revealed that the Somali women lost social capital and connections because of war in their countries and relocation to Australia. However, McMichael and Manderson (2004) noted that the participants engaged in a constant stream of marriages, engagement parties, women gatherings and religious events and through these gatherings they re-established kinship and

community connections that assisted them to find employment, housing, and secure loan. This means that women with little access to formal support may also use bonding social capital to get by.

In Pakistan, Azhar (2018) examined how personal networks among women in remote areas may improve women's access to business information. Semi-structured interviews on the social networks of women were conducted with 75 women and data analysis included social network analysis, content analysis and documentary analysis. The findings revealed that friends and neighbours were the most influential sources of information, while husbands were the second highest sources of information for women. Most information about income-producing projects came from spouses, while information about social services came from friends, neighbours, or social gatherings. This suggests that it is essential to understand the kind of social capital that comes from different social networks because they sometimes serve different purposes for women.

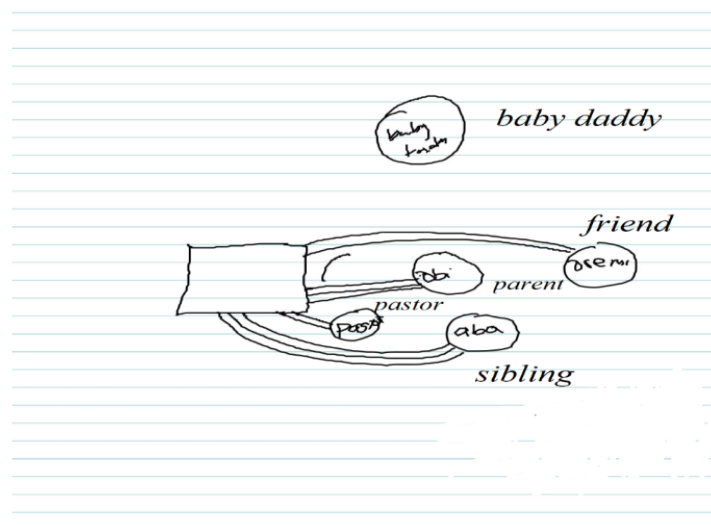
### **3.5 Measuring social capital**

Social capital is multidimensional, and Claridge (2004) argued that it must be conceptualised as such to have any explanatory value. Researchers have typically employed both quantitative and qualitative methods to capture this multidimensionality of the concept (Boateng, 2009; Dudwick, Kuehnast, Jones & Woolcock, 2006; Hodgkin, 2008; Saffer, 2016). Understandably, some dimensions of social capital lean towards quantitative assessment, while other dimensions are best captured through qualitative analysis. As an example, the structural dimension of social capital leans towards quantitative assessments because it better captures variables like the size of the network or density and some researchers have measured it statistically. However, as seen in the literature, the structural component of social capital in itself does not reveal underlying information such as why a mother of a stillborn baby will surround herself with certain people or her perception of those in her networks and the support she received from them. As demonstrated in the previous section, having a large and diverse network increased the risk of HIV and depression for some women (Ferlander et al., 2016; Neblett et al., 2011), and on the other hand, some women with small and homogenous networks had higher risk for PTSD and limited access to support (Levendosky et al., 2004; Negron et al., 2013). These conflicting findings suggest that the role of social capital in women's experience of stillbirth would require research methods that allow for an understanding of complex social interactions. Coleman (1990, p. 304-305) have also questioned



"whether social capital will come to be as useful a quantitative concept in social science" ... [and argued that] the current value of social capital lies primarily in its usefulness for qualitative analyses of social systems and for those quantitative analyses that employ qualitative indicators".

As in other social capital research (Bandeira et al., 2018; Haar-Pomp, Spreen, Bogaerts & Volker, 2015; Lin, 1999; Sanicola, 2009), I have used a name-generating methodology with the aid of diagrams to identify the social networks of the participants (structural social capital). Participants were invited to draw images of anyone that provided any form of support during the stillbirth crisis, including those they expected support from, but did not receive such support. They were then asked to use lines to describe the quality of the support that the individual provided (an example is presented below in figure 9):



*Figure 9: Example of a participant's social networks generated through a name-generator*

From the diagrams, it was possible to comment on the size of the networks, but since this research aimed to understand the roles of those in the diagram in the women's experience of stillbirth, interview questions focused on background information about the identified network members. For instance, questions were asked about the context of their relationships (friend, colleague or relative), purpose and nature of the relationship (what type of support was received), and why an individual was included in the diagram. Information about those they had a stressful relationship with or those whom they would have loved to receive support from was also explored. This information allowed me to comment on the network roles, social support, trust, and reciprocity

like other social capital studies (Haar-Pomp et al., 2015; House, Landis & Umberson, 1988; Umberson, Crosnoe & Reczek, 2010) have done.

### **3.6 Chapter summary**

This chapter provided an overview of social capital, and I started by arguing why the theory of social capital was the most suitable for the current study. I then presented the theoretical positions of Bourdieu, Coleman and Putnam and I aligned my position with the ideas of Coleman and Putnam because of the contextual realities of the setting where this study was conducted. It has been argued that researchers adopting social capital as a theoretical framework should select a school of thought from the ideas presented by social capital theorists and this should be discussed in relation to the present study (Claridge, 2004). Agnitsch (2003) have noted that this would help to overcome any confusion around the concept of social capital and that it will help to maintain the viability of the concept. This was done throughout this chapter to show the fit between the theory and the problem and how this will help in explaining the findings presented in Chapter 5. The theoretical ideas of trust and reciprocity resonated well with the literature review findings and this was discussed in relation to how it can potentially shape the social networks of mothers of stillborn babies in terms of whether it will be bonding or bridging. Findings from the social capital literature on women were also presented to highlight how women have used social capital and the impact it has on their well-being. Finally, I took a position on how I intend to apply these theoretical ideas to my data collection approaches. The next chapter contained a discussion of the methodology of phenomenography and the methods utilized in participants' selection, data collection, and data analysis, as well as ethical considerations, study setting and other methodologic decisions that were taken.

## **Chapter 4: Research methodology**

### **4.1 Introduction**

The previous chapters illustrated that grieving for a stillborn baby is an interpersonal process that is influenced by social relationships. These relationships exist between mothers of stillborn babies and those associated with them. An important decision in this research was to select a research approach that acknowledges this and does not see bereaved women as individual entities existing in their own vacuum. The phenomenon of stillbirth is a social reality for Yoruba mothers of stillborn babies and although this reality can be investigated in different ways; the aim of any study primarily determines the choice of a paradigm. In this study, the aim was to understand the role of social capital in how Yoruba women experience a stillbirth, and I needed to interact directly with these women if I wanted to understand and capture the role that others played in their experience of stillbirth. By interacting directly with these women, the aim was to capture their subjective experience, and the expectation was that this experience would vary from one participant to the other. As a result, there was a need to select a research approach that would allow me to capture the subjective and multiple realities of the participants in terms of the roles that others played in their experience of stillbirth.

To enable an in-depth understanding of the role that social capital plays in how Yoruba women experience stillbirth, the methodological approach of phenomenography was utilised. So, in this chapter, I introduce the reader to the methodology of phenomenography and describe why and how it was the best approach. As phenomenography itself is embedded within the paradigm of constructivism, I start this chapter by highlighting the philosophical underpinnings of the constructivist paradigm and justify the selection of phenomenography out of all other possible methodologies that were considered. The first part of this chapter describes how phenomenography was selected, and I also introduce the philosophical foundations upon which the ontological and epistemological assumptions of phenomenography are built. In the second part of the chapter, I demonstrate how the ideas of phenomenography inform the methodologic decisions taken in this study as it regards to sampling, data collection, data analysis and theoretical integration. This chapter also contains the steps that were taken to ensure the quality of the data, as well as ensuring that the research methods adhered to the highest ethical standards.

## **4.2 Selecting an appropriate methodology**

Constructivism is a philosophical paradigm that asserts that people construct their understanding and knowledge of the world from their encounters with events such as stillbirth (Honebein, 1996; Kivunja & Kuyini, 2017; Schwandt, 1998). Experiencing and adjusting to stillbirth can be seen as a constructivist process because the reality of stillbirth for the mothers in this study was embedded in social, cultural and historical conditions. When a woman suffers the tragedy of stillbirth in a Yoruba community, there is a high chance that she will not see or hold the child, the child will be buried without her knowledge, she is most likely to be told that the child was meant to die and that she should be grateful for her own life. All these are forms of experiences that the mothers of stillborn babies in Yoruba communities have to grapple with. Examining their experiences of stillbirth can, therefore, contribute to a new understanding of the role of others in their adjustment to stillbirth. The constructivist assumption of grieving is that surviving a loss is a function of the roles that others play in the grieving process (Neimeyer, 2009) and because of this, constructivist researchers focus on the social interactions that transpired between the bereaved, their sympathisers and the environment over the course of an event such as stillbirth (Creswell, 2014).

The constructivist paradigm was the the most ideal for this study because there was a need to move away from a focus on the individual mother of a stillborn baby to the social relations and sociocultural factors that made her experience stillbirth the way she did. With constructivism, the reality of stillbirth is not fixed, but instead is socially constructed through social practices (van Rensburg, 2016). In this sense, it is reasonable to expect that no mother of a stillborn baby regardless of the context will experience stillbirth in exactly the same way (Marton, 1988). As an illustration, two of the women in this study had hysterectomies at the same time they lost their babies. Both of these women had two living children, but they had different expectations and experienced the support of people differently. The first woman had complications from the surgical procedures that led to the birth of the stillborn baby, and this meant she was bed-ridden for six months after the surgery. For this woman, being alive was more important than losing both the baby and her uterus, and this was reflected in how she perceived the role that others played in her adjustment. But for the second woman, the loss of her fertility chances was a big deal that she was still struggling to accept three years after the event. This made her very critical of the support she received from others because she perceived the assistance rendered by others as being at

dissonance with her childbearing aspirations. This suggests that what stillbirth meant for these two women was relational (Tsekeris, 2010). That is, both women had their truth of what it means to experience stillbirth, and this truth was not the same for both of them. Law (2004) argued that social truth is both real and constructed because it is generated in daily social activities. Thus, it was important to adopt a methodologic approach that was sensitive to both the internal and external contexts that made the participants of this study experience stillbirth the way they did (Bruce, 1999).

So, to understand how Yoruba mothers of stillborn babies experience and adapted to stillbirth loss, I knew I had to select a methodology that will allow me to:

- Shift the focus of the inquiry from the individual mother of a stillborn baby to the social relations that made them construct their experience of stillbirth in certain ways
- Highlight the social and cultural contingencies of stillbirth in Yoruba culture from the perspectives of those women who have experienced stillbirth in Yoruba society
- Subjectively examine the variation in how different Yoruba women experience the phenomenon of stillbirth
- Develop theoretical insights into women's experience of stillbirth

From the works of other scholars (Dupin et al., 2015; Edell-Gustafsson et al., 2015; Forster, 2013; Stenfors-Hayes, Hult & Dahlgren, 2013; Svensson, 1997), phenomenography is a research approach that can fulfil all the four methodologic desires stated above. First, because this study was theoretically-driven, there was a need to select a research method that allows theoretical framing. Phenomenography fits this methodologic profile because the whole idea of phenomenography is to use the differences that exist in people's experiences of a phenomenon as constructs for problematizing theoretical ideas (Marton & Pang, 1999; Yates, Partridge & Bruce, 2012). Pang (2003, p. 145) argued that phenomenography "shifts the primary focus from methodological to theoretical" and as such, the reason for using theory in phenomenographic research is to develop theoretical insights into people's experience of stillbirth (Yates et al., 2012). The need to frame phenomenographic inquiries with theoretical frameworks has been demonstrated in other doctoral studies (Meckes-Conner, 2011; Gibbings, 2008). As an illustration, Degen (2010) used Parse's theoretical framework of Human Becoming to guide her doctoral study

by using this framework to examine the statements of her participants. Thus, in phenomenography, theoretical frameworks are at the “intersection of a lens and the methodically analytic approach” (Collins & Stockton, 2018, p. 2).

Second, there was the need to select a methodology that is also compatible with the theoretical ideas of social capital theory. Phenomenography targets the relationship between the experiencer (mothers of stillborn babies) and what is being experienced (stillbirth) (Bowden & Green, 2005; Bruce, 1999; Reed, 2006; Smith, 2010). As an example, one of the commonest phrases used by the participants of this study when asked what stillbirth meant for them was that “it was a painful experience”. Indeed, no one can deny that losing a baby to stillbirth is devastating and while this painful feeling is an important aspect of stillbirth experience for mothers, this is not the focus of phenomenography. Phenomenography data collection and analysis try to move beyond what mothers think of stillbirth, to how mothers adapt to the loss and what made the loss take on any particular significance (Gonzalez, 2011; Khan, 2014). So, for instance, after a participant described her experience as ‘painful’, the follow-up question was about why she described her experience as ‘painful’. It was not uncommon for some of the participants to cite financial constraints as one of the significant factors that contributed to why they adjusted poorly to the loss, suggesting the need for financial support.

With phenomenography, questions must be asked about the people who met the financial needs of the woman (if it was met), so that the participants can better describe the role of others with regards to her financial difficulties. This means that researchers in phenomenography “do not try to describe things ‘as they are’; rather, we try to characterise how things appear to people” (Marton, 1986, p. 33). This philosophical principle of phenomenography relates to the theoretical assumption of social capital where capturing of social support, such as financial support is only possible through the relationships that existed between the bereaved mothers and those associated with her. Other possible methodologies failed to fulfil some or all of what I intended to achieve in this research. As an illustration, some methodological approaches like grounded theory calls for the construction of theory from the study findings (Wu & Volker, 2009), but in a highly contextualised study like this one, the absence of a strong theoretical framework can make the research findings devolve into “a story that is difficult to transfer into other contexts” (Collins & Stockton, 2018, p. 6).

Likewise, although phenomenology is also interested in subjective experience, it has its philosophical roots in psychology (Ajiboye, 2012; Giorgi, 1997; Landgrebe, 1973) and as a result, the verb “experience” is used in a psychological and cognitivist sense (Davidsen, 2013; Zalta, Nodelman, Allen & Anderson, 2003). In contrast, the way of experiencing in phenomenography indicate a relationship between the experiencer and the phenomenon, and as a result, the verb “experience” is used in an experiential and sociological sense (Marton & Booth, 1997). This means that while phenomenological researchers aim to determine the essential nature of a phenomenon, phenomenographers aim to analyse the variations between people’s experience of the same phenomenon (Marton & Booth, 1997). In addition, unlike in phenomenology where researchers attempt to “bracket off” preconceptions (Davidsen, 2013, p. 321), the position of phenomenography is that it is not possible to be objective (Sandberg, 1997). Instead, the researcher should “strive actively to be aware of his/her subjectivity and how that might affect the interpretation of what they are doing” (Kinnunen & Simon, 2012, p. 202).

#### **4.3 Phenomenography as a methodology**

Phenomenography, as a research approach emerged from the educational research carried out in Sweden in the late 1960s (Ashworth & Lucas, 1998) and this means phenomenography has been used mostly in education. Marton and colleagues wanted to see the world from the perspective of their students, and they had a group of students read the same excerpt from a passage of text (Marton & Booth, 1997). The result of their research was that the students expressed different understandings of the same material. The conclusion drawn by Ference Marton and his colleagues was that if students had a finite number of qualitatively different perceptions of learning, it was reasonable to expect that people will construct meaning in various ways, even when experiencing the same phenomenon (Marton & Booth, 1997). The phenomenographic approach has been used widely to explore people’s qualitatively different ways of experiencing a phenomenon. For instance, it has been used to study parental sleep in neonatal care in Sweden (Edell-Gustafsson et al., 2014), registered nurses experience of caring in Sweden (Andersson et al., 2015), experience of being a palliative nurse in Australia (Barnard, Hollingum & Hartfiel, 2006) and the experience of waiting in emergency departments in Taiwan (Han et al., 2017) among others. These studies have demonstrated that people experience a phenomenon that is ostensibly the same in different ways and Sjöström-Strand, Ivarsson and Sjöberg (2011) have noted that the findings of

phenomenographic studies are useful for understanding the nature of individual experience in health care.

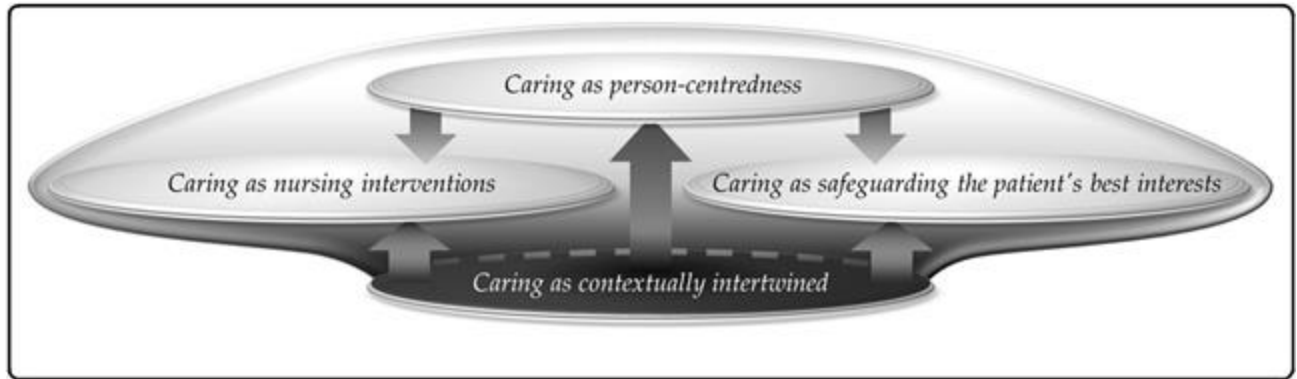
This study was approached from the methodologic approach of phenomenography because of the need to understand the differences that existed in how Yoruba mothers of stillborn babies' experience stillbirth. There is strong evidence in the literature that grieving the loss of one's child is as individual as one's fingerprints (Hone, 2016; Heazell et al., 2013; Kersting & Wagner, 2012) and this necessitated the selection of a research approach that allows capturing of the differences in the way women grieve and adapt to life after stillbirth. Phenomenography is a distinct approach to qualitative research (Andersson et al., 2015; Forster, 2015) which is informed by the constructivist paradigm (Mojtahed, Nunes, Martins & Peng, 2014; Richardson, 1999; Smith & McMenemy, 2016). Phenomenography takes a non-dualistic and second-order position in the understanding of the human experience of a phenomenon (Reed, 2006). From a non-dualistic position, the ontological assumption of phenomenography is that the only reality that human beings can communicate is the reality they have experienced (Marton & Booth, 1997). Epistemologically, phenomenography assumes that people differ in how they experience a phenomenon (Andersson et al., 2015).

Phenomenography, therefore, investigates the variations in the experiencing of a phenomenon (Forster, 2013) and the way this is done is by focusing the inquiry on the relationship between the participants (women who had stillbirth) and the phenomenon (the stillbirth itself). It is this relational view that forms the cornerstone of phenomenography, and this makes the focal point of a phenomenographic research to be the exploration of the relationship between the subject and the object (Reed, 2006, Yates et al., 2012). Phenomenographic researchers look to understand how a phenomenon appears to the participants rather than how it seems to the researcher (Reed, 2006; Smith, 2010). This is the second-order view of knowledge where a researcher is not making statements about a phenomenon directly, but rather about the participant's ideas of the phenomenon (Marton & Pang, 1999; Bruce, 1997). Ashworth & Lucas (1998, p. 415-416) explained that phenomenographers focus on "the experience-as-described, rather than on either the psychological process generating the experience or the 'objective facts' themselves".



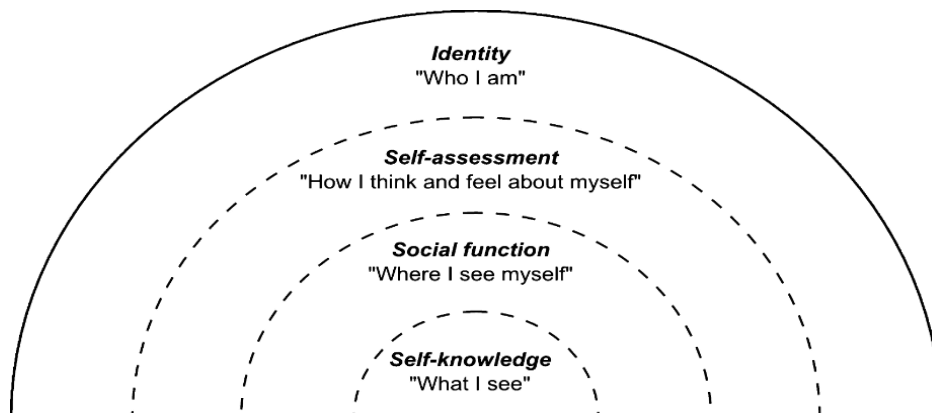
Having highlighted what phenomenography is about, it is important to discuss two key concepts that distinguish phenomenography from other methodologies. The first key concept of phenomenography is termed ‘conceptions’, and this is also known as the ways of experiencing the phenomenon in question. The focus of any phenomenographic study is the ‘conceptions’, and the underlying aim is to reveal the participants’ ways of experiencing a phenomenon like stillbirth (Marton & Booth, 1997; Sandbergh, 1997). These conceptions are relational to each other, and theoretically, the conceptions obtained from a phenomenographical study should be able to capture the full range of opinions held by a group of mothers on the issue of stillbirth at a specific time (Akerlind, 2005). The fundamental assumption underlying phenomenography is that there is a finite number (usually 2-6) of qualitatively different understandings of a phenomenon and participants are a collective supplier of fragments of how a phenomenon is experienced (Larsson & Holmstrom, 2007; Reed, 2006). This assumption has been confirmed in numerous empirical studies (Bruce, 1997; Marton, 1988).

The second key concept in phenomenographic approach is referred to as the ‘categories of description’, and these are formed from the conceptions (Lepp, Ringsberg, Holm & Sellersjo, 2003). Booth (1993, p. 189) highlighted that the “fundamental results of a phenomenographic study are careful descriptions of the categories found”. These categories of description are intended for describing the conceptions (Barnard, McCosker & Gerber, 1999; Forster, 2013; Yates et al., 2012), and this is done by using the categories of description to form what is called an ‘outcome space’ (Marton & Booth, 1997). The means that phenomenography has a unique way of presenting its research findings, often presented visually in a table or figure (Barnard et al., 1999; Han et al., 2016). The ‘outcome space’ is the final outcome of phenomenographic research and it is usually in the form of a diagrammatic representation that shows the relationship between the variations among individual’s experiences of the phenomenon in a logical way (Barnard et al., 1999; Forster, 2013; Yates et al., 2012). To illustrate the outcome space, which is the product of phenomenographic studies, the outcome spaces of two phenomenographic studies are presented below in figures 10 and 11. In the first outcome space, Andersson et al. (2015) revealed that the 21 nurses in their Swedish study understood caring in nursing in four different ways but ‘caring as person-centeredness’ was the core of caring while ‘caring as contextually intertwined’ cuts across the other three categories, as seen below:



*Figure 10: Outcome space of Swedish registered nurses' conceptions of caring. Source: Anderson et al. (2015)*

In the second outcome space below, Jeppson and Thome (2015) found that 17 Swedish registered nurses understood self-image in the context of palliative care in four different ways. Most of the nurses understood self-image as identity, and it was placed outermost in the outcome space.



*Figure 11: Outcome space of how registered nurses in palliative care in Sweden see themselves. Source: Jeppson and Thome (2015)*

This outcome space represents the relationship between the variations in which the participants' experienced the phenomenon in the two studies presented above, and this gives an idea of the collective way in which the participants experienced the phenomena (Akerlind, 2005; Stenfors-Hayes, Hult & Dahlgren, 2013). It is important to highlight that even though the primary aim of phenomenographic methods is to seek out the differences that exist in how a group of individuals experience the same phenomenon, those differences that are similar to each other have to be grouped together and logically connected with each other (Ashworth & Lucas, 1998; Kettunen & Tynjala, 2018). This means that as the phenomenographer is searching for differences in the experiences, similarities are also noted (Andersson et al., 2015; Forster et al., 2013; Lepp et al.,

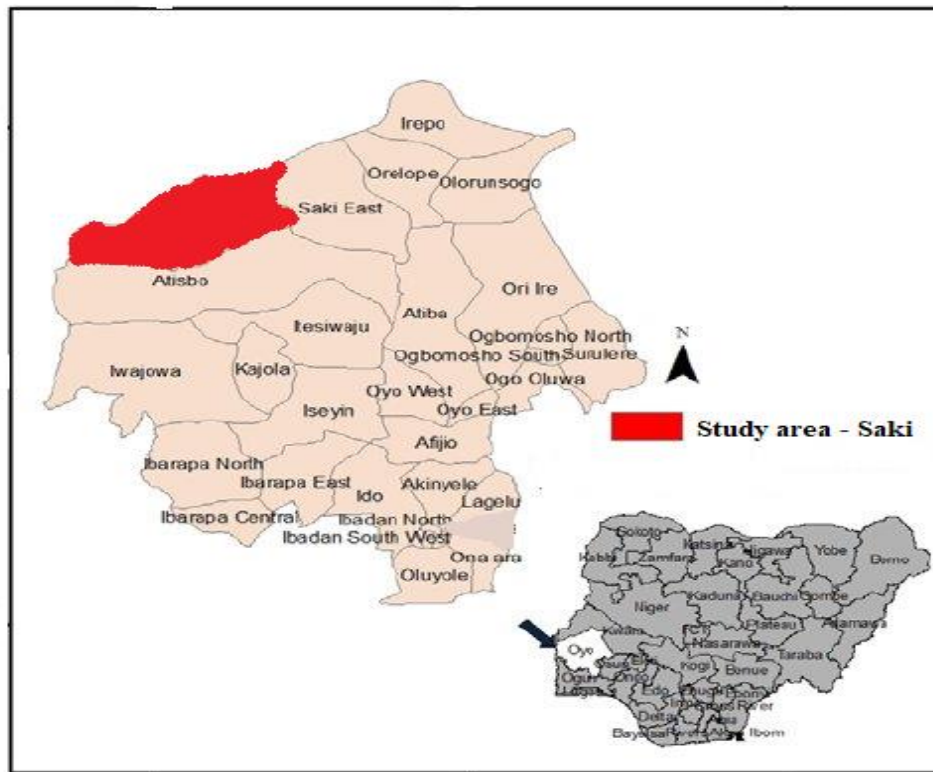
2003). Some researchers (Entwistle, 1997; Webb, 1997) have highlighted this as a ‘paradox’ considering phenomenography’s emphasis on differences. Despite that phenomenography has unique ontological and epistemological assumptions, Svensson (1997) noted that its philosophical foundation was not particularly well developed in the early days. This means that compared to other well-established methodologies like phenomenology or grounded theory, phenomenography is still an emerging methodology.

#### **4.4 Research methods**

This section presents the research design, which includes the study area, participants recruitment, data collection, data analysis and issues surrounding data integration, rigour and ethical considerations

##### **4.4.1 Study area**

This study was conducted in Saki (figure 12), a town in Oyo state, Nigeria. Saki is one of the most ancient towns in Yoruba land (Eliezer, 2014). According to Oloolu (2013), Saki became a Yoruba settlement in 1835, and to date, it continues to occupy a significant place among Yoruba towns because of its history. Since the 18<sup>th</sup> century, Saki town has been governed by a council of traditional rulers and a king (Jegede, 2009) and this monarchical institution remains the bedrock of cultural institution for the nearly 400,000 Yoruba people that live in Saki town (Agiri, 1975; Oloolu, 2013; Salawu, Asaolu & Sowemimo, 2014). Apart from its historical origin and culture, Saki town is just 60 km from the Republic of Benin, and this strategic location means that the local government administrative headquarter (Saki west) is located in Saki (Olugbamila, Oluborode, Famutimi & Adebimpe, 2017; Rasaki et al., 2017). Its border location and being the administrative headquarter of the local government has encouraged population influx from the surrounding towns and villages and even other ethnic groups across Nigeria (Oyesola, 2008).



*Figure 12: Map of Oyo state showing the study area (Saki). Inset: Map of Nigeria showing Oyo state: Source: Oyedotun (2012)*

The major occupation of the Yoruba people in Saki is farming (Onawumi et al., 2016) and because of the enormous agricultural activities that make it an exporter of cotton, tobacco, swamp rice and teak, as well as cassava, yams, maize, beans and sorghum, it is famously called the ‘the food basket of Oyo state’ (Oladele, 2001). In an ethnographical study conducted by Jegede (2009), it was reported that the extended family system is the basis of kinship relations among Yoruba people in Saki and as such, the basic residential units are compounds that accommodate between one to ten nuclear and extended families. Communalism was also found to be the basis of the existence of the Yoruba people in Saki, and as a result, when one member is in trouble, others rally round to assist (Jegede, 2009). The majority of the Saki people practice Islam or Christianity with traditional religion constituting a substantial minority (Rasaki et al., 2017).

#### **4.4.2 Participants**

The participants for this study consisted of Yoruba women who had experienced stillbirth after 28 weeks of pregnancy. Only Yoruba women who were living in Saki were recruited because it was

important for them to have had an established network of support before the stillbirth incident. Any woman with experience of stillbirth was eligible to participate, as long as the stillbirth loss was over six months, but not over three years before data collection. Leaving an allowance of six months since the event happened was necessary to allow the participants to comment not only on the emotionality of the experience but also how their social support networks reacted to the loss. Likewise, I also thought that if data collection occurred within three years of the stillbirth event, the participants would be able to remember better those who played a role in their adjustment and the specific support that was received. Women whose stillbirth experience were less than six months or over three years, those with miscarriages or neonatal death and those who were unable to provide a verbal autopsy of the loss were excluded. It was important for the participants to provide a verbal autopsy of the loss because it is not uncommon for some women to try to repress their experience of stillbirth. As an example, some of the participants in this study could only give the year, but not the day of the event because they do not want to remember the loss. Due to the psychological impact of stillbirth on subsequent pregnancies after stillbirth (Meaney, Everard, Gallagher & O'Donoghue, 2017), women who were pregnant at the time of data collection were also excluded. To ensure uniformity in the experience, all the pregnancies that resulted in stillbirth were singleton pregnancies, and all the participants belonged to the Yoruba ethnicity.

#### **4.4.3 Recruiting the participants**

All the participants in this study were purposefully recruited (Patton, 2002). This is in keeping with the phenomenographic sampling technique, where participants possessing the information relevant to the research objectives must vary in age, parity, educational and socioeconomic status (Kettunen & Tynjala, 2017). Purposeful sampling technique is thought to increase the likelihood that the variation common to a given social phenomenon will be represented in the data (Maykut & Morehouse, 1994). After receiving ethical approval, I made contact with midwives at the State Hospital Saki, a tertiary level public hospital and the Baptist Medical Centre Saki, a private secondary level hospital for assistance with identifying eligible participants. I was communicating with these midwives even before I arrived in Nigeria and I have briefed them on the inclusion criteria through telephone calls. These midwives had approached women with the experience of stillbirth in their facilities and collated the names and contacts of those women who wished to be contacted for study recruitment. The total number of mothers of stillborn babies that signified

interest in the study were 25 and I received information about these women from the midwives that I was liaising with. But from going through the list with them, I discovered that many of them did not meet the inclusion criteria because of the recency of the stillbirth events. Medical records in these facilities were not digitised, and as soon as patients are discharged from hospitals, the records are moved into archives, making it hard to retrieve patients' files. From the list that I was given, ten women were excluded because their stillbirth losses were less than six months at the time of recruitment. The remaining 15 participants were then traced with their addresses because their records did not include phone numbers in most cases. The tracing of the participants was a difficult part of the recruitment because apart from difficult terrains and poor roads; meeting the participants or getting any useful information about them was due to chance. However, this exercise also enlightened me to the plight of Nigerian women and made me understand why public health interventions sometimes do not reach those who need it the most. Many of the participants that were traced to their homes were living in poor neighbourhoods, had no cell or land phones, had limited or no formal education and had no stable source of income, making it incredibly difficult to meet them for recruitment. Eventually, eight women that satisfied the inclusion criteria were recruited through this medium. In order to achieve unique and diverse variations among the study participants, as well as data saturation, recruitment continued through personal networking with friends and families, and an additional 12 participants were recruited, bringing the total number of women that participated in the study to 20.

The sample size of 20 women recruited in this study is in line with the phenomenographic design. Yates et al. (2012) stated that variation in participants' profiles and data manageability are the two factors driving phenomenographic sample size. Some phenomenographic researchers (Akerlind, 2003; Trigwell, 2000) argued that as long as the sample size is selected to maximise variation, 10 to 20 participants is an ideal sample size in phenomenography. Other phenomenographers like (Bowden, 2005; Marton, 1983) proposed a sample size of 15 to 30 participants. One can conclude from the above authors that 10 participants will be the minimum number to recruit in a phenomenographic study, while 30 will be the maximum. However, this has been applied differently in doctoral studies. As an illustration, Degen (2010) only recruited six participants in her doctoral phenomenographic study that explored how nurses understood their own nursing practice in the US. On the other hand, Smith (2010) recruited 41 participants in her doctoral phenomenographic study that investigated how young people experience information in the UK. I

decided that 20 was the best sample size to derive variations in how women experience stillbirth in this study because it was also important to be able to manage the in-depth data that was collected from the participants.

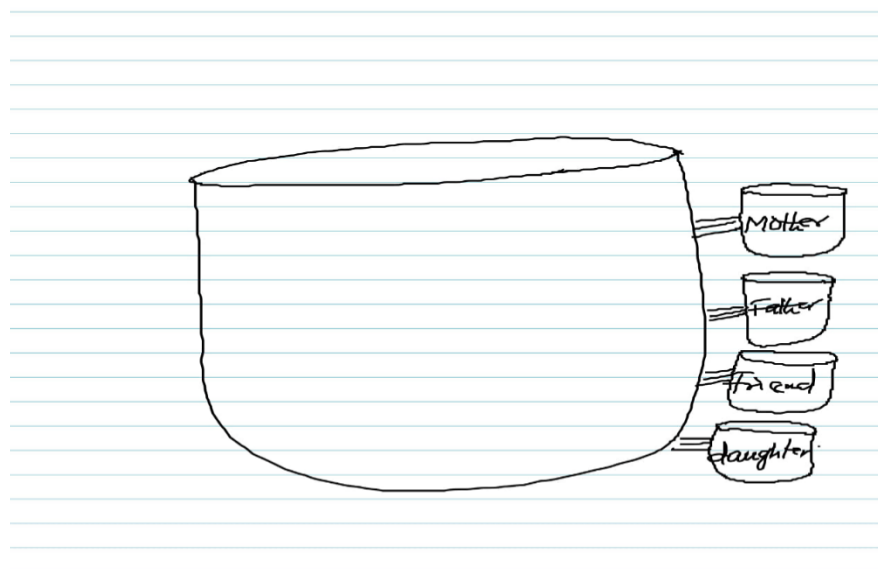
Although all the participants were of Yoruba ethnicity, there were some notable variations in terms of gravidity, age, religion, marital and educational status. During transcribing, generic Nigerian names were used as pseudonyms to preserve the anonymity of the participants. But participants were presented according to their recruitment number using SK# as seen below in table 4.1.

<b>Pseudonym</b>	<b>Age</b>	<b>Religion</b>	<b>Marital status</b>	<b>Educational level</b>	<b>Gestation age (weeks)</b>	<b>Date and place of stillbirth (Clinic [C] or Home [H])</b>	<b>Gravidity/Parity</b>
SK1	41	Islam	Married	Diploma	32+	2016 C	G6P6
SK2	44	Islam	Married	No education	37+	2014 C	G3P3
SK3	30	Islam	Married	Primary six	37+	2014 C	G3P3
SK4	34	Islam	Married	No education	37+	2014 C	G4P4
SK5	31	Christianity	Engaged	Diploma	37+	2016 C	G1P1
SK6	22	Islam	Single	No education	37+	2014 C	G6P1
SK7	35	Islam	Married	No education	37+	2016 C	G3P3
SK8	37	Christian	Married	Diploma	37+	2014 C	G3P3
SK9	23	Christianity	Married	Diploma	37+	2015 C	G2P2
SK10	41	Christianity	Married	BSc	36+	2014 C	G3P3
SK11	36	Christianity	Married	Primary six	30+	2016 C	G5P2
SK12	27	Christianity	Single	High school	37+	2015 C	G4P1
SK13	29	Christianity	Married	BSc	37+	2015 C	G1P1
SK14	35	Islam	Separated	Primary six	37+	2015 C	G9P9
SK15	33	Islam	Separated	BSc	37+	2016 C	G3P3
SK16	40	Christianity	Widowed	No education	37+	2014 C	G6P6
SK17	33	Christianity	Married	High school	37+	2014 H	G3P3
SK18	38	Islam	Married	No education	31+	2016 C	G4P4
SK19	32	Christianity	Married	BSc	37+	2014 C	G2P2
SK20	30	Islam	Married	No education	37+	2014 C	G4P3

*Table 1: Descriptive data of the participants*

#### 4.4.4 Data collection

Data were collected through interviews, drawings and a focus group discussion from January to June 2017. The need to collect data using three different methods was theoretical, and this is in line with other social capital research. When conducting research on social networks, scholars (McKinlay et al., 2017; Haar-Pomp et al., 2015; Pomp, Spreen, Bogaerts & Volker, 2010) have found that it is important to use various data sources for data validity purposes because it is not uncommon for participants to withhold relevant information if it is going to reflect badly on them. The use of multiple data sources assisted in detecting discrepancies in participants' accounts. As an illustration, during an interview with one of the participants (SK15), she said her husband was very supportive of her during the crisis of stillbirth, providing both financial and emotional support. But when she was asked to represent those who supported her during the crisis, her husband was conspicuously missing as shown below in figure 13.



*Figure 13: Social networks of SK15*

Noticing the discrepancy, the participant was asked to clarify why the husband was not included in her social networks when she had said he was supportive. It was at that point that she revealed that she had separated from her husband during pregnancy and that he did not provide any of the support attributed to him during the interview. The participant later made another diagram that shows the true state of her social relationships before stillbirth in the diagram below:



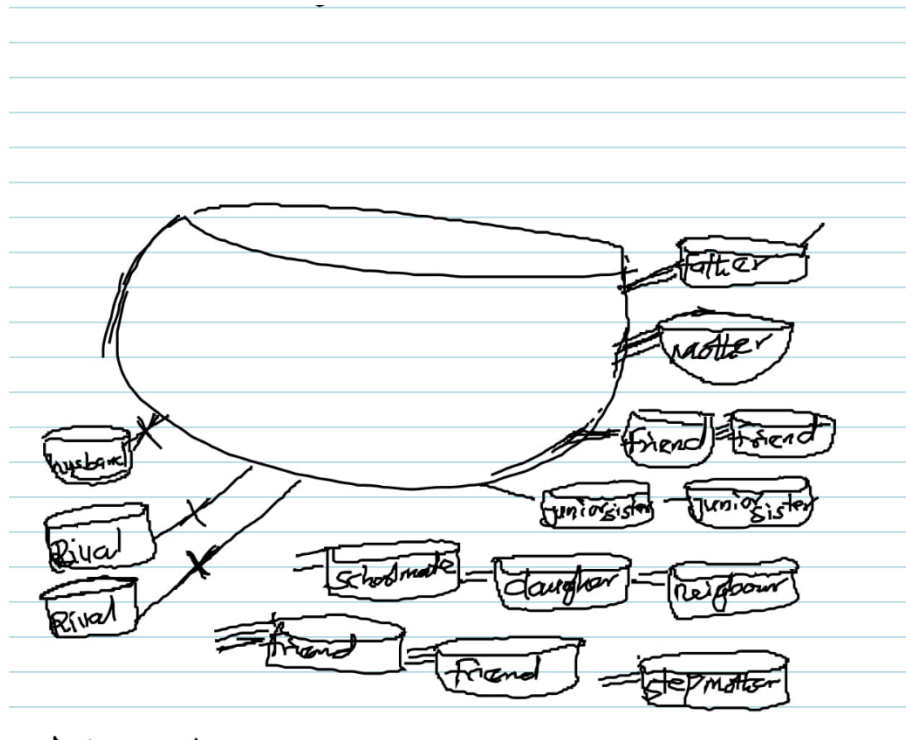
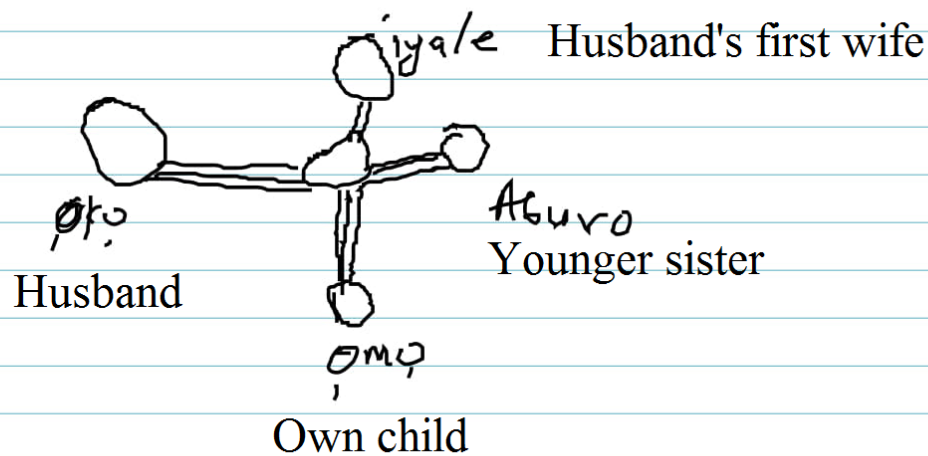


Figure 14: Social networks of SK15 before stillbirth

Without data triangulation employed in this study, this information would not have been revealed. The use of data triangulation also revealed that it is possible for an individual to be in the diagram and still not meet the support expectations of the participant. As an illustration, in the diagram below, the participant (SK16) gave her husband three lines, signifying that he provided strong support during the crisis. However, during the interview, the woman clarified that the husband was allotted three lines for paying the hospital bills, including the money paid for the C-section. However, in terms of emotional support, he was missing, and in fact, he did the most painful thing because of his demeaning, insensitive and cruel words.



*Figure 15: Participant (SK16) showed that her husband provided strong financial support by allotting him three lines*

This means that the images represented much more than what was seen on paper and relying on the images alone would not have revealed the subliminal deeper meanings that accompanied the diagrams. Therefore, integrating the drawings with the interviews allowed the findings to reflect both the direct content of the drawings and the stories and sentiments shared along the images. The following sections discussed the data collection methods in detail.

#### **4.4.4.1 Interviews**

Face-to-face semi-structured interviews were conducted with each of the twenty participants. Apart from the fact that data in phenomenographic studies are predominantly collected through semi-structured interviews (Bowden & Green, 2005; Dahlgren & Fallsberg, 1991; Marton, 1988), semi-structured interview approach was chosen in this study because it afforded me the flexibility to cover topics that were not anticipated before data collection started (Rabionet, 2011). Also, the semi-structured interviewing approach permitted me to seek clarity with the participants as they responded to the interview questions and this was important because the purpose of phenomenographic interviews is targeted at the relationship between the participants and the stillbirth event (Barnard et al., 1999). The interviews were a mix of open and closed questions that began with an open-ended question: when you think of the experience, what comes to your mind? Follow-up prompts focusing on 'how', 'what' and 'can you tell me more' were used to elicit and

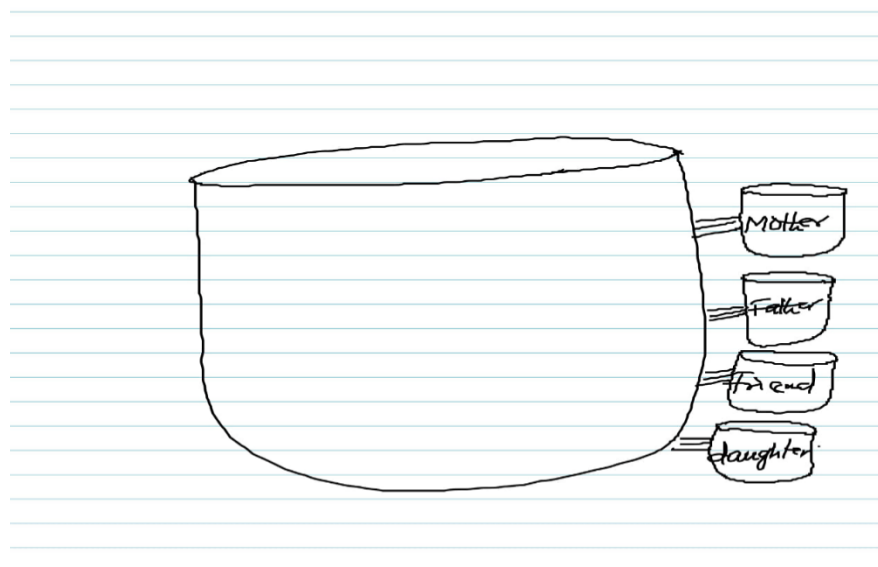
clarify (appendix 8). As an illustration, it was common for participants to say ‘someone tried for them’ during the crisis and clarifying phrases such as ‘in what way exactly’ were used to elicit more information. The interview questions were asked to allow the participants describe their loss (the most recent one if multiple ones existed), talk about their experiences in relation to the social support received or expected, factors that influenced the support that people provided, and their perception of the support received. Two mothers of stillborn babies who are members of Stillbirth and Neonatal Death Society (SANDS) New Zealand reviewed the questions and provided feedback. The interviews were done in English or Yoruba, both of which I am fluent in, and the participants also responded to interview questions in either Yoruba or English. The interviews were recorded with a LiveScribe pen recorder and all the participants consented to the recording of their voices. Most of the interviews took place in the home of the participants, except participant 11, who was interviewed in her shop. The interviews took an average of 45 minutes, with a few being as long as two hours.

#### **4.4.4.2 Drawing activity**

The drawing task was embedded in the interviews. The main reason for collecting drawings of the participants’ social networks was because the relationships and connections that participants formed due to the stillbirth events were best captured through visual elaboration. The drawings also proved useful because it allowed the capturing of the concrete representation of the participants’ social networks which seemed elusive during the interviews. As an illustration, during the interviews, it was difficult for the participants to attribute specific support that individuals provided. But by representing their social networks in the form of drawings, they were able to reflect on the exact role of individuals present in the drawings and allowed me to tease out the participants’ lines of thought. During the interviews, I told the participants that I was interested in having a drawing of people that come to their mind whenever they think of their stillbirth experience. Participants were offered a Livescribe notebook and a Livescribe pen. Instructions were verbally provided to the participants by following a standardised script (appendix 9). These instructions assisted in guiding participants to bring an image of their social support networks to mind and to make this as vivid as possible. Participants were asked to freely draw and surround themselves with those who supported or those who did not support them during the crisis of

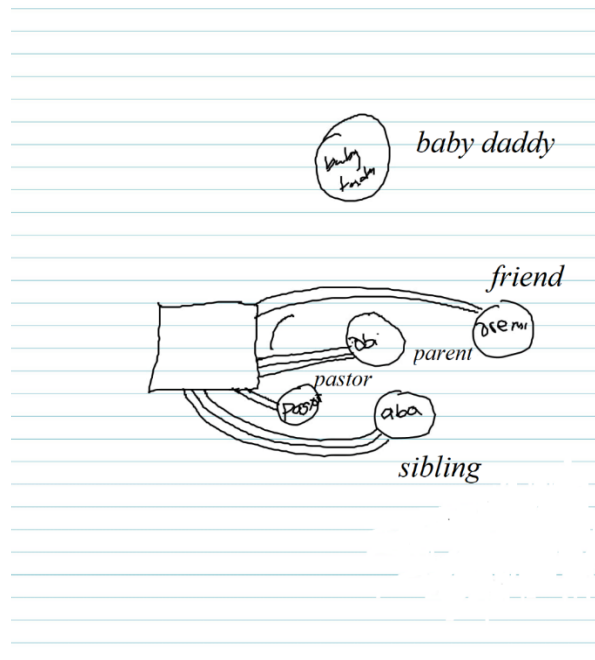
stillbirth. I further explained to them that images might also include things like church, mosque, hospital or anything that defined that time of their lives.

The instructions that were used in producing these images was based on the ideas and concept of communicative ecologies, and this has been successfully used by other researchers (Foth & Hearn, 2007; Piennar, Swanepoel, van Rensburg & Heunis, 2011; Scolari, 2012). This approach aligned with the theoretical ideas of social capital because it opened up the possibility of network analysis between people in an ecology (Foth & Hearn, 2007). Most importantly, the goal of the drawings was to provide a deeper understanding of how social exchanges occurred because of stillbirth and as such, the drawing activities were grounded in the search for meaning rather than causation (Altheide, 1994). Most of the participants initially said they do not have drawing skills, and some said they do not have the necessary education required to make a drawing by themselves. I quickly reassured them that artistic ability was not necessary, instead, their recollection of those who made a difference when they were going through the crisis of stillbirth was the most important. There was no time limit on the drawing activity. Most participants were finished with their drawings within 15 minutes, and when they were finished with their drawings, they were asked to label and describe those who were represented in their picture, as seen below:



*Figure 16: Participant (SK15) showed and labelled her social networks after stillbirth*

The participants were also asked whether someone ought to be in the drawing, but not there. In most cases, participants did not add any new person, and when they did, it is likely those who did not play any supportive role as it can be seen from the image below (figure 17). In situations where participants expect but did not receive support from an individual, participants decided not to give such people any line as seen below (figure 17). The participants were allowed to draw a maximum of three lines for each person, depending on the perception of the quality of support provided by the individual (Pienaar et al., 2011). Three lines represent the strongest perceived support, while one line means the lowest perceived support.



*Figure 17: Participant (SK12) showed that the father of the stillborn child did not provide any support during the crisis*

When drawing is used as a research method, it entails participants' drawing and talking (Guillemin, 2004; Mair & Kierans, 2007). As a result, after the completion of each diagram, the participants were asked to describe their diagrams, and this was helpful for accurate description and interpretation. Open-ended questions were asked about the relational context as seen in the image such as people represented, description of the relationships (family, work, religion or health institution), the help that was received and how those in the diagram were involved in the

bereavement (Hearn et al., 2014; Foth & Hearn 2007). The participants drew all the diagrams used in this study. In situations where the participants used the Yoruba language to describe the nature of their relationships, a translation was provided as seen earlier (figure 17). In instances where a participant was unable to label the drawing due to low literacy (this only happened in few cases), they were asked to describe the relationship, and their description of that relationship was digitally labelled as seen below:

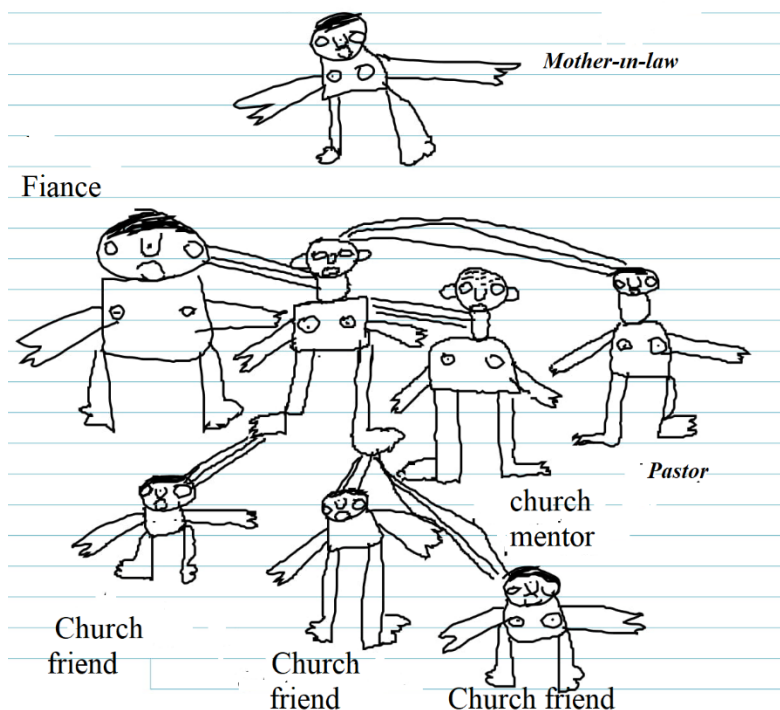


Figure 18: Sample of researcher labelled drawing of a participant

#### 4.4.4.1 Focus group discussion

After the conclusion of the interviews, a focus group discussion was held with seven of the participants who volunteered their interests to be part of a group. The focus group data was inspired by the ideas and techniques of participatory research where participants had the opportunity to locally define the priorities for stillbirth bereavement support (Cornwall & Jewkes, 1995). The agency of the individual is engrained in the Yoruba worldview, and this is expressed as ‘owo ara eni, la fin tun iwa eni ise’, which literally means that ‘the individual affected by an issue is the only one that can state the best solution to the issue’. In this sense, any support interventions

without the input of those affected (mothers of stillborn babies in this research) may not meet their needs. The focus group data was collected for two reasons. First, all the participants in the interviews had declined to accept mementoes intended as a form of appreciation for their time as well as something that they could see as a remembrance for their loss. These mementoes were small hearts of decorated cloth made by a mother of a stillborn baby in New Zealand as seen below in figure 19.



*Figure 19: Mementoes donated to the study participants by SANDS New Zealand*

SANDS New Zealand (Wellington branch) gave me 25 of these Hearts to share with my participants. Second, during the interviews, most of the participants said they would not want to be a member of a stillbirth support group. Most of the participants expressed the reason why they would not join a support group using this Yoruba idiom (*kini idunu elewon to nfi ago si owo*), which means (someone sentenced to life imprisonment should have nothing to be happy about). As a result, I thought focus group discussion would give the participants a platform to step back



from the cultural and social regulation of stillbirth in order for them to discuss the problems of stillbirth, and for them to think about possible solutions and actions to the issue (Bergold & Thomas, 2012).

The data from the focus group discussion added an additional layer of data that was not there in the interview data. As an illustration, during the focus group discussion, the interactional nature of the discussions allowed the participants to present some real impact of stillbirth for women, which included several cases of suicide. The issue of poverty, lack of social safety net for mothers of stillborn babies and the need for more involvement of health professionals, were more pronounced in the focus group, but almost silent in the interviews. This means that the findings from the interviews revealed personal experiences of the phenomenon, whereas focus groups revealed the broader contextual factors that shape the experience of stillbirth. As a result, the focus group contributed to a more comprehensive understanding of the role of social capital in stillbirth bereavement, as well as enhancing data completeness (Barbour & Kitzinger, 1998; Haar-Pomp et al., 2015). The focus group in this study allowed the participants to be in a group of other mothers of stillborn babies for the first time and allowed them to be partners in the knowledge-production process (Bergold, 2007). The interactional data that resulted from the participants' discussion about stillbirth, therefore, has a practical utility in this research (Hollander, 2004, Ritchie, Lewis, Nicholls & Ormston, 2013).

The focus group discussion was semi-structured, informal and conversational in style and mostly directed by the participants themselves. It lasted for two hours, and it was held in a neutral place (in the premises of Baptist Medical Centre). The main question asked in the focus group was: How do you think we can best support a mother of a stillborn baby from your own experience? (appendix 10). All the participants took turns in responding to the question and in most instances, group members built on what other members said using their own experience of stillbirth in terms of the supportive resources that they found valuable. They also commented on support that they did not receive, but that would have made a difference. The focus group discussion was audio-recorded with the Livescribe pen, and the participants agreed to the recording. It is worth noting that all the participants that agreed to the focus group all have surviving children, suggesting that mothers with living children after stillbirth may be more willing to engage with the issue of stillbirth than those who do not have at least one child. The participants that took part in the focus



group discussion were (SK3, SK8, SK10, SK14, SK16, SK17 and SK19). The data from the focus group was presented using the acronym FGD (Focus Group Discussion).

#### **4.4.5 Data analysis**

Data collected (interviews, descriptions of the diagrams and the focus group) were transcribed, translated to English when needed and analysed according to the principles of phenomenography (Marton, 1986). In phenomenographic analysis, the main aim is to capture the range of understandings (variations) in how the phenomenon under investigation was experienced within a group of participants (Bruce, 2000). However, there is no single process or technique prescribed for phenomenographic data analysis (Yates et al., 2012). There is an array of steps that researchers (Akerlind, 2005; Dahlgren & Fallsberg, 1991; Marton & Booth, 1997) have followed in analysing phenomenographic data, but the principles are the same. First, in phenomenographic analysis, the categories of description are not predetermined (Yeo, 2012), and that is why the categories of description presented in the next chapter were organised by the inductively derived categories and not the theoretical constructs. Second, the transcripts are searched across for variation in meaning, as well as the logical relationships between the identified differences (Yates et al., 2012). Third, the focus on the collective experience is maintained by viewing the transcripts and emerging categories as a set, instead of the individual transcript or data source (Koole, 2012; Smith & McMenemy, 2016).

Regardless of these three principles, Bruce (1997, p. 104) described phenomenographic data analysis as an “interplay between the researcher’s understanding, the nature of the phenomenon being studied and the style of the available data”. In other words, the nature of the data determines the choice of analytic approach and the outcome of the analysis. As an illustration, Degen (2010) used generic qualitative data analysis technique to analyse observations and interviews collected from participants in her doctoral study in the US, and she argued that existing phenomenographic analysis techniques were not compatible with the observational data that was collected in her study.

In this study, the analysis was done according to Alexandersson’s (1994) four-phased guideline for phenomenographic data analysis. In the first phase, I familiarised myself with the data by transcribing all the data myself, and through repeated readings, I gained an overall impression of the data. In the second phase, I noted the similarities and the differences in the statements made

by the participants. For instance, participants account of the role of family members such as “*with my husband, I did not feel pressured. I grieved the way I wanted*” was compared with other quotes such as “*I can’t say he [husband] knows the value of the loss... he preferred being with friends than to stay at home with me*” and coded under “family is central”. The reason for coding even unsupportive husbands under “family is central” was to underline the significance of the family for those without such support. In the third phase, the descriptive categories for the conceptions were identified, and finally, the structural relationships between the descriptive categories were examined and determined. The third phase of the data analysis was achieved by searching for the connectivity among the codes and merging them to create categories. As an illustration, the category of “relationships change” was created to capture conceptions such as “social bonds decrease”, “family is central” and “experiences are diverse”, because they share the same underlying assumption. This is because the changes in relationships that resulted into the decrease in social bonds after stillbirth enabled the family to emerge as the central supportive figure, despite the differences that existed in the participants’ experiences of stillbirth. I also considered recurrence and repetition in the quotes (Owen, 1984) when developing the categories. For each category and conception, verbatim quotes from the interviews were chosen to provide support for the analysis.

Participants’ descriptions of their images were transcribed and analysed alongside the interview and focus group data as described above. Since drawings can be abstract and interpreted subjectively in various ways, the analyses were grounded in the participants’ own accounts of their images and presented alongside the findings of the whole dataset. When presenting the diagrams, comments were made on the people that appeared in the diagrams. Also, comments were made on the composition, size and homogeneity of the drawings. For instance, some participants only had two people in their networks, some had seven, and while some participants only had family members in their social networks, some had friends and colleagues. This approach to the analysis and presentation of drawings collected in this study is similar to what has been done in other phenomenographic doctoral studies. As an illustration, Smith (2010) used specific images drawn by the participants to illustrate the interview and the focus group findings in a phenomenographic doctoral study that examined the ways young people in the UK experienced information. This approach is also similar in other qualitative studies (Cheung, Saini & Smith, 2018; Philips, Ogden & Copland, 2015) that have collected drawings and interview data.

It is not uncommon for researchers (Philips et al., 2015; Guillemin, 2004) to employ some forms of visual methodological frameworks such as those that allow analysis of the image in terms of how an image was made, what it looks like and how it is seen (Guillemin, 2004). Such frameworks were not possible to analyse the diagrams in this research because unlike in other studies where features such as colour and light, organisation and expressive content are considered in the analysis of the image, the images produced in this study were regulated by the instructions and the materials given to the participants. Only a Livescribe notebook and a Livescribe pen were given to the participants of this study. But in other studies that have utilised drawings, it is not uncommon for researchers to provide participants with a sheet and several coloured pencils (Pelander, Lehtonen & Leino-Kilpi, 2007) or a range of drawing materials (graphite pencils, coloured pencils, crayons, ballpoint pen, eraser, sharpener) (Cheung et al., 2018; Pienaar et al., 2011; Smith, 2010) or an A4 page only (Philips et al., 2015). If participants are not restricted in how they can produce their images or what they can use to create it, it is possible for researchers to comment on some features of the diagram such as colour.

As an illustration, Philips et al. (2015) collected diagrams from 54 patients with chronic pain in the UK to explore whether they can generate the image of pain. In the analysis, one of the participants said he annotated his drawing with red colour, explaining that the use of deep red colour was because of his imagination of pain as something so hot. While such information can be useful for health education, the aim of this study was about social interactions, and hence, the participants were only supplied with a Livescribe book and pen. As it will be seen more in the next chapter, participants were very creative in their diagrams. Some differentiated men from women in their diagrams, some positioned the direction of their social networks in unique ways, and the participants employed varying shapes such as vessels, cubes, or tree-like structures to represent themselves and others, but this was not part of the analysis. It is also important to note that two diagrams were collected from each of the participants (social networks before and after stillbirth) for data validity purposes. However, the analysis was mostly focused on their social networks after stillbirth as this was the focus of the study. As a result, most of the diagrams presented in the following chapter were the social networks of the participants after stillbirth, and this was labelled as such when two images of the same participants are presented, as seen below:

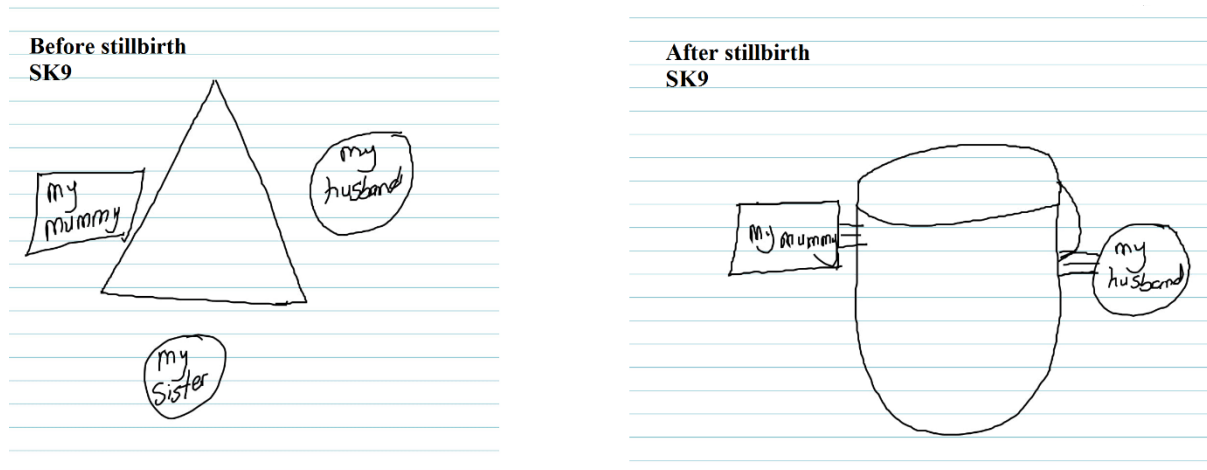


Figure 20: Diagram showing the social networks of a participants before and after stillbirth

#### 4.4.6 Methodologic issues with data collection with different methods

When data are collected with different methods in the same study, it has been argued that researchers need to consider some fundamental principles in data analysis and presentation (O’Cathain, Murphy & Nicholl, 2010; Onwuegbuzie, Slate, Leech & Collins, 2007; Tashakkori & Teddlie, 2003). The first principle is to declare whether the data analysis was concurrent (the result from one phase of the analysis does not inform the other phase) or sequential (the result from one phase informs the other phase). In this study, the analysis was carried out concurrently because all the three datasets were analysed at the same point during the study and the findings from the interviews and diagrams did not inform that of the focus group. Secondly, the priority given to each component of the data has to be declared (Bryman, 2006). For instance, for those researchers mixing methods across paradigms, the analysis can assume a quantitative-dominant or a qualitative-dominant depending on the priority given to each component of the research (Onwuegbuzie & Combs, 2011). This is important for researchers who are mixing methods across paradigms because they must make decisions on data transformation, where one component of the data is either qualited or quantised to fit the epistemological domain of the dominant paradigm (Onwuegbuzie & Combs, 2011; Onwuegbuzie & Dickson, 2008; Tashakkori & Teddlie, 1998). In this study, there was no need for data transformation because the three data sets shared the same epistemological domains. Also, the datasets were treated as a whole, and that means there was no need for hierarchical categorisation of data.

The third issue with data collection from different methods relates to data integration. Integrating data from different data collection methods comes with both advantages and challenges even though it can yield richer data and interpretations. The challenge with data integration is that the researcher will have to connect data generated by different methods which may be from different paradigmatic domains and which might have required different levels of analysis (Bryman, 2006, Weick, 1995). For this reason, there have been some attempts by scholars (O’Cathain et al., 2010; Onwuegbuzie et al., 2011; Tashakkori & Teddlie, 1998) to develop frameworks that researchers can use to integrate data in mixed research. Most of the existing frameworks for data integration have been purely for methodologic reasons, and this means it has specifically targeted studies that are mixing quantitative and qualitative data within the same study. Incorporating data from methods that share the same theoretical and paradigmatic domain is deemed less paradoxical (Barbour, 1998) and some researchers like Onwuegbuzie et al. (2007) even think data integration is not possible. For instance, Onwuegbuzie et al. (2007, p. 12) argued that when data analysis involves

either a quantitative analysis of quantitative data or a qualitative analysis of qualitative data, only data reduction and data display stages are possible because only one type of data is collected and the only analysis that occurs is a traditional one-in which both the type of data and analysis can be classified as representing the same paradigmatic tradition... Data correlation, data consolidation, data comparison or data integration is not possible

This means data integration in mixed research is mostly done purely to address the differences in paradigmatic assumptions underlying positivist and interpretivist paradigms (Lambert & Loiselle, 2008; Onwuegbuzie & Combs, 2011; Onwuegbuzie & Dickinson, 2008; Onwuegbuzie et al., 2007). However, with an increasing number of researchers (Henderson & Redshaw, 2017; Whitehead & Schneider, 2007) treating both positivist and interpretivist paradigms as complementary in the answering of broader research questions, the debate has shifted to theoretical integration. Theoretical integration is growing in importance because of the blurring of the sharp distinctions between different paradigms and the increasing need for researchers to articulate insights from empirical analysis into a coherent, succinct theoretical explanation (Brickson, 2005). As an illustration, Tunarosa and Glynn (2017, p. 229) argued that

theoretical integration is more than a process of simple addition or the stacking of various building blocks. Rather, theoretical integration involves combining separate, often distinct empirical observations in a sensemaking activity to craft a coherent, logical, plausible, or more complete explanation; ideally, that explanation should tie together different elements into a credible rationale or account of the data

Integrating data with theory was important in this study because the study was theoretically driven and there was a need to connect the empirical and theoretical dimensions of the study logically. By integrating the empirical data with the theoretical framework in this study, there was an opportunity to explain the role of social capital in the experience of mothers of stillborn babies in ways that matched its complexity. This was crucial because identifying relationships between conceptual domains is a foundational aspect of theory development (Boxenbaum & Rouleau, 2011; Tsang & Ellsaesser, 2011). Thus, integrating the three data sets with the theory in mind allowed me to shift the conversation from the methodologic justifications of combining methods from the same paradigmatic tradition (Onwuegbuzie et al., 2007, p. 13) to the theoretical significance of theory-driven research. In order to highlight the theoretical value of social capital theory in this research, there was a need to highlight how the theoretical framework enhanced the understanding of the data, as well as highlighting how the data problematised the theoretical ideas of social capital (Mason, 2006). The only way to achieve this is through data integration as other researchers have done. As an illustration, some researchers have shown that they achieved an enhanced data interpretation and conceptual density by mapping emergent themes from inductive analysis of individual interviews and focus groups onto Social Cognitive Theory (Edwards, Jepson & McInnes, 2018; Joseph, Ainsworth, Mathis, Hooker & Keller, 2017), Normalization Process Model (MacFarlane & O'Reilly-de Brun, 2012) and Theory of Planned Behaviour (Omura, Stone, Maguire & Levett-Jones, 2018).

In mixed research studies, Onwuegbuzie et al. (2007) noted that findings obtained from different methods may be interpreted separately (parallel interpretation) or combined and interpreted at the data interpretation stage (integrated interpretation). In this study, integration occurred at the data analysis stage. The datasets were concurrently analysed inductively by oscillating continually between the three datasets throughout the data analysis stage. After the inductive analysis, I could see a resonance between the findings and the theoretical framework. Walsh (2000) argued that

phenomenographic analysis is more than just recording the differences in the way participants talk about a phenomenon; rather, the researcher needs to delve behind what is said. The theoretical framework was used to explain the findings, and this enhanced conceptual density (MacFarlane & O'Reilly-de Brun, 2012; Tunarosa & Glynn, 2017). This process was an iterative process that involved moving back and forth between the inductively derived categories and the theoretical framework (Edwards et al., 2018; Joseph et al., 2017). Through the identification of the inductively derived categories, there was a switch from the empirical to the theoretical and Bendassolli (2013, p. 6) called this the “inductive leap”. By leaping inductively into the theoretical framework, data interpretation emerged simultaneously, and this was grounded in the narratives of the participants (Tunarosa & Glynn, 2017). Thus, the theoretical integration fostered an understanding of the relationship between the theory, the methods and the data (Bryman, 2006).

#### **4.5 Rigour in phenomenographic studies**

Although phenomenographers (Collier-Reed, Ingerman & Berglund, 2009; Kettunen & Tynjala, 2018; Sin, 2010) also adopt the principles of trustworthiness in qualitative research as set out by Guba and Lincoln (1985), there are some slight variations in the language used to communicate rigour. Credibility in phenomenography relates to the extent to which the aim of the goals of the study align with its design and execution (credibility of the method) and the researcher's ability to make persuasive arguments for the interpretation of the data (communicative credibility) (Booth, 1992; Collier-Reed et al., 2009; Kettunen & Tynjala, 2018). However, data interpretation in phenomenography is not about whether the interpretation is right, but whether the researcher can defend his or her interpretation of the data (Marton & Booth, 1997; Sandbergh, 1997). Therefore, to achieve communicative credibility in phenomenography, other researchers with knowledge of the phenomenon under study should be able to recognise the legitimacy of the interpretation made of the data (Collier-Reed et al., 2009). One widely recognised method to achieve communicative credibility is through conference presentations and peer-reviewed journal articles (Akerlind, 2005; Collier-Reed et al., 2009; Kettunen & Tynjala, 2018). Communicative credibility was achieved in this thesis through conference presentations in New Zealand (SANDS national conference, 2017; Perinatal Society of Australia and New Zealand annual congress, 2018) and in the US (Stillbirth Summit, 2017). In addition, the participants were also allowed to make changes to their transcripts, and those that checked their transcripts were satisfied with the transcription.

With regards to the credibility of the method, Collier-Reed et al. (2009) recommended that strong rationales should be made for all the methodologic decisions, including whether the sample size was appropriate for the research aim. All the methodological decisions taken in this study were sufficiently backed up with valid reasons and appropriate sources. Also, the methodology of phenomenography was the most suitable for this study and all the data collection methods, analysis, the use of the theoretical framework, data presentation and the sample size aligned with the methodological tradition of phenomenography. Dependability has also been adopted by phenomenographers (Booth, 2002; Collier-Reed, 2009; Kettunen & Tynjala, 2018) and this refers to the extent the researcher provides readers with evidence that the research process has been logical, traceable and clearly documented. Dependability was achieved in this thesis through several discussions and feedbacks from my supervisors. Their comments and feedback with regards to the unfolding data, data integration and the presentation of the data, assisted me to stay true to the methodological underpinnings of phenomenographic research.

Akerlind (2005, p. 331) noted that the experience of participants in phenomenographic research is “context sensitive”. As a result, I provided in depth information about the research setting and also used two to three illustrative excerpts from the transcripts to support the conceptions and categories as seen in the following chapter (Chapter 5). This was important to provide evidence of the link between the data and the interpretations, and this contributed to the achievement of confirmability.

#### **4.6 Ethical considerations**

Permission to conduct this research was given by both the Human Research Ethics Committee at the Victoria University of Wellington (HREC# 23450, appendix 1) in New Zealand and the Baptist Medical Centre in Nigeria (appendix 2). However, despite independent ethical approval, there are often unanticipated challenges and dilemmas that spring up when conducting research with African populations (Shaibu, 2007; Wassenaar & Rattani, 2016). While I acknowledge that broad ethical principles apply even with research in Africa, there are some contextual realities that I had to negotiate in this research in order to conduct the study in an ethical manner. Autonomy is central to the western perspective of decision making (Jegede, 2009) and in this research, it means that the participants decided on their own to participate or not to participate in the research after considering the information given to them (appendix 3). Jegede (2009) argued that researchers



conducting research with Yoruba people must understand that an individual does not exist alone but within a web of social and cultural relationships.

This was evident in this study because before the participants made the final decision to participate in this study, they consulted with others before making the decision. Some of the participants said they discussed and took permission from their husbands before they could participate in the study. One of the participants (SK20) said the husband wondered whether the information she was going to provide was safe and whether it would reflect poorly on their Islamic beliefs. This is understandable when considered from the Yoruba perspective because participation in any research is a risk that the woman was taking, and this can eventually affect the entire community. This suggests that seeking permission from the husbands is culturally appropriate because apart from patriarchy that dominates Yoruba societies, the community assumes a protective role in the interest of its members (Jegede, 2009). However, individual autonomy was not compromised in this research because Yorubas will say ‘won kii fa ori l’ehin olori’, meaning that ‘decisions are not made in the absence of the person concerned with an issue. This means that all the participants took the final decision to participate after consulting with those that needed to be consulted.

Another issue that I had to deal with in this study was the issue of confidentiality. As previously stated, nearly all the participants were interviewed in their homes, but the communal nature of these homes is such that people just drop by without making appointments. This means there are often many interruptions during data collection, as it was common for friends or family members to just wander to where the interview was being conducted. In such situations, the participants controlled the flow of the interviews, by stopping to talk when someone approaches. As an example, when interviewing Participant 5 (SK5), some of her neighbours walked into the yard, and she told me that we should move the interview to the car.

Respect is a strong indication of compliance with societal norms and values, and as a guest in the participants’ home, I have to comply with social and cultural conventions that bound the conduct of guests. In the Yoruba culture, because I was a guest in the participants’ home, I am not allowed to go with refreshments. It is the host that gives refreshments and not the visitor and this means that if I have gone with some form of refreshment that the participant can nibble on while we talk, it would be seen as a lack of respect to the context. Also, since it is a communal setting, it would

also not be appropriate to single the participant out for refreshment or gifts, as the family members can interpret this as an inducement. Because of this, any compensation for participation in research among Yorubas is directed at the family unit or the community and not the individual. With this knowledge, a decision was made not to give any form of compensation to the participants. At the conclusion of the interviews, I informed them of the mementoes that I brought from New Zealand and all the participants refused them.

Speaking of traditional ethics among the Yoruba society, Ayantayo cited in Jegede (2009, p. 247) argued that “African traditional ethics is not founded on religion but on consideration for human welfare”. In other words, the fundamental principle in African ethics is pursuing goodness by helping to reduce the level of harm that participation in research can cause. With this awareness, pregnant women were excluded from the research to avoid causing them unnecessary anxiety and trauma. Also, snowballing was also avoided because even though it might have benefitted me as the researcher, this might have increased harm for the woman making the referral. There was no direct benefit for the participants of this study, but every decision or interaction that any Yoruba person gets into is interpreted based on the Yoruba concept of ‘anfani’ (translated literally as ‘benefit’. This ‘anfani’ concept, would literally mean that the participants must gain something for sacrificing their time for interviews and the focus group. To achieve this, I informed the participants that their information could help improve bereavement care for other women in the future, and this was a satisfactory explanation because it illustrates how their participation can benefit women in the community (Henderson, Corneli, Mahoney, Nelson & Mwansambo, 2007). Wassenaar and Rattani (2016) have also argued that demonstrating the social value of the research to the participants is part of ethical requirements when conducting research in Africa.

Both the English and the Yoruba versions of the informed consent forms were made available to the participants, and the language employed in the consent used simple terms that were easy to understand (see appendices 4-7). The Yoruba version of the consent form carried the same meaning as contained in the English version, and although it was short and precise, it contained every necessary piece of information needed for them to make an informed decision. I realise that the participants had some level of trust in me and that is why they volunteered to talk to me, and the least I could do was to ensure that they understood their rights. By trusting me with their experience, I was in a kind of entrustment-style relationship (Richardson, 2008), and one of my

obligations to them was to ensure the confidentiality of their identity. Pseudonyms were used throughout this report, and all the identifying information that was written on their diagrams were erased. Ethical consideration also involves the fair selection of the participants, and this began through the selection of Saki itself. Selecting Saki for this research was a fair choice because the issue of stillbirth constitutes significant harm for the social and psychological wellbeing of women in Saki. I also ensured that all the participants that participated in the study were carefully selected to ensure that they met all the inclusion criteria mentioned above.

#### **4.7 Positionality and subjectivity**

The positioning of a researcher can manifest in the form of personal characteristics such as gender, race, beliefs, linguistic tradition and as well as emotional responses to participants. These positionings are important because they affect access to the field, the researcher's relationships with the participants as well as the lens used by the researcher in filtering the information gathered. As a male midwife, many people have been curious to know the significance the issue of stillbirth has for me and my interest in stillbirth research. People's curiosity regarding my position in this research is understandable considering that many are not used to the concept of a male midwife (or a mid-husband as many people have jokingly referred to it.). The gender divide between me and my participants who are women no doubt raised some curiosity and questions. For instance, some may argue that the participants may be more willing to discuss sexual and reproductive issues with another woman. Likewise, since it turned out in this study that women in Saki did not perceive health professionals as supportive, some may also argue that it is possible that the participants could disclose other information to a non-medical professional.

Like any reader of this thesis, the participants were also aware of the gender divide between me and them and they tested me on why they should open up about their feelings, why I care about the problem and whether they should trust me with confidential information such as sexual and reproductive histories, child loss and sanctioned grief. The participants wanted to know if I was going to treat their information with the confidentiality and the respect that it requires. These are rites of entry into the participants' experience that I both expect and respect. These rights of entry that I went through were a constant reminder for me that my male gender means that I will never know what it means to be pregnant with a child and lose the child to stillbirth. My awareness of these limitations meant I was constantly aware of my own values, beliefs, and perceptions that are

shaping the research process and prompted me to engage in a kind of dialogue that made it possible for the participants to not only be comfortable sharing something dear to their hearts, but to also trust me with such information.

Truly, when I decided that the issue of stillbirth bereavement will be the focus of my PhD research, my interest in the subject was spurred through my professional practice of midwifery in Nigeria. As an individual who lost his father at the age of 15 and who was unable to talk about it because of the circumstances surrounding my father's death, I felt strongly that the approach of midwives and healthcare professionals generally to the diagnosis and care of stillborn mothers was insensitive, poor and inhumane. This meant I had to draw from my own experience of grief, my fluency in Yoruba language, my work as a midwife and my perpetual interest in disenfranchised grief to transcend what seems to be the gender divide between me and my participants. Sharing my experience of grief diminished the distance between me and the participants and enhanced my willingness to go to places that I otherwise would not have and also sensitized me to address certain topics more easily or even be aware that I should address them. This openness about my own background fulfilled the wish of the participants who wanted to know more about me and my interest in the study. This shifted the participants' perception of me as a researcher to that of someone who is genuinely interested in learning about stillbirth grief which is vastly different from my own experience of orphanhood. However, my insider's position and familiarity also carries the risks of blurring boundaries, imposing my own values, beliefs and projection of biases. I had to guard against assuming that my participants and I share the same language.

My knowledge of the historical terrains and the contextual realities of Saki community was an advantage because it also facilitated my acceptance by the participants of this study. I was born in Saki and the first 25 years of my life lived in Saki town. I believed that this insider knowledge of the culture and people of Saki community gave me an identification and connection that was an advantage in the research process. Being a midwife was also an added advantage in gaining access to the participants' experiences because the participants felt my midwifery knowledge could be handy in their quest to know more about what could have led to their stillbirth and what they could do differently in subsequent pregnancies. The participants' awareness of my midwifery knowledge made them give as much information as they could and this might explain why they did not hold back on personal and sensitive information such as that of their stillbirth experience, and as well

as sexual, family and reproductive histories. My knowledge of the context and as well as my health background allowed me to understand the responses in a nuanced and multileveled way. I was able to probe more efficiently, and ferret out hints that others might miss.

I acknowledge that qualitative research is prone to a degree of subjectivity since the interpretation of the participants' behavior and collected data is influenced by the values, beliefs, experience and interest of the researcher. Indeed, since 2012 till now, I have lived in three different countries (both western and non-western) with different cultural practices and response to stillbirth bereavement. This cosmopolitan experience may have impacted the way I looked at the data since I now have knowledge of how stillborn mothers are cared for in other contexts. It is therefore important for me to acknowledge that my background and worldview may have played a role in how I constructed the realities of the participants of this study and as well as how I posed interview questions to them. However, while the process of coding and culling findings demanded tedious work, it showed me the value of being concise and accurate in identifying the core differences in how participants experienced their loss, and to be mindful of detaching my own interpretation at these stages of data processing. As I listened to the participants' stories and views of stillbirth, I came to appreciate how the participants can simply define stillbirth not only of the children, the resources and the relationships they have lost, but also of their resilience to live like nothing happened. There were a number of times during the data collection when I felt I could do nothing but to empathize with the plight of the participants and assure them that the study can definitely serve as a tool for change if utilized accordingly by policy makers and health professionals. I realized that I was not only challenged to develop my skills as a researcher, but even my virtues as an individual. The findings of this research made me realize how those affected by an issue can use their own experience to highlight that social change is only possible when health professionals and stakeholders are willing to change their perspectives and equip themselves with tools that are necessary to facilitate social change.

#### **4.8 Chapter summary**

The central objective in this chapter was to introduce the methodology of phenomenography and how this was implemented in the methods. By doing this, I demonstrated that I was familiar with the phenomenographic approach and I also demonstrated that the methodologic decisions that I took in implementing the research adhered to the philosophical traditions of phenomenography, as

well as the theoretical framework. The participants were purposefully selected, and data were collected with three different methods to ensure data completeness, as well as data validity. The analytic procedure was also detailed in relation to the theoretical framework, especially with the need to integrate the findings. Finally, I also discussed the quality related issues, such as credibility and dependability, as well as demonstrating how the research was conducted to the highest ethical standards possible. In the next chapter, I present the major findings of the research.

## Chapter 5: Findings

### 5.1 Introduction

The findings of the research are presented in this chapter. Four main categories were derived from the data analysis, and these represent the four different ways of understanding the role of social capital in Yoruba women's experience of stillbirth. These categories are; relationships change, relationships matter, material support help and health professionals neither help nor support. There are also a total of 11 sub-categories, which added to the understanding of the phenomenon and these were described and evidenced by quotes from the participants. The outcome space, which is a diagrammatic representation of the relations between the four categories is also presented and described in this chapter. The presentation and interpretation of the findings in this chapter provided the empirical evidence to discuss the implications of this work, presented in the final chapter. While presenting the results, this chapter also offers more detail about the participants, as well as a clearer picture of the characteristics they brought to the study.

### 5.2 Relationships change

In thinking about her experience of stillbirth, one of the participants said “*igba iponju la n m’ore; ojo to ba buru la nme’ni to fe ni*” (SK11). That is, “*it is during tough times that true friends are known; it is when things are difficult that those who truly love one can be identified*” (SK11). In this sense, a stillbirth is an event that not only tests the quality of relationships, but it also reveals the true nature of relationships, and it was not surprising that the relationships that some participants had formed with others such as in-laws, colleagues and even spouses were affected after stillbirth. Using diagrams, the participants captured the changes that occurred in their relationships, by separating themselves from those individuals who they no longer have relationships with, as seen in the diagram below:





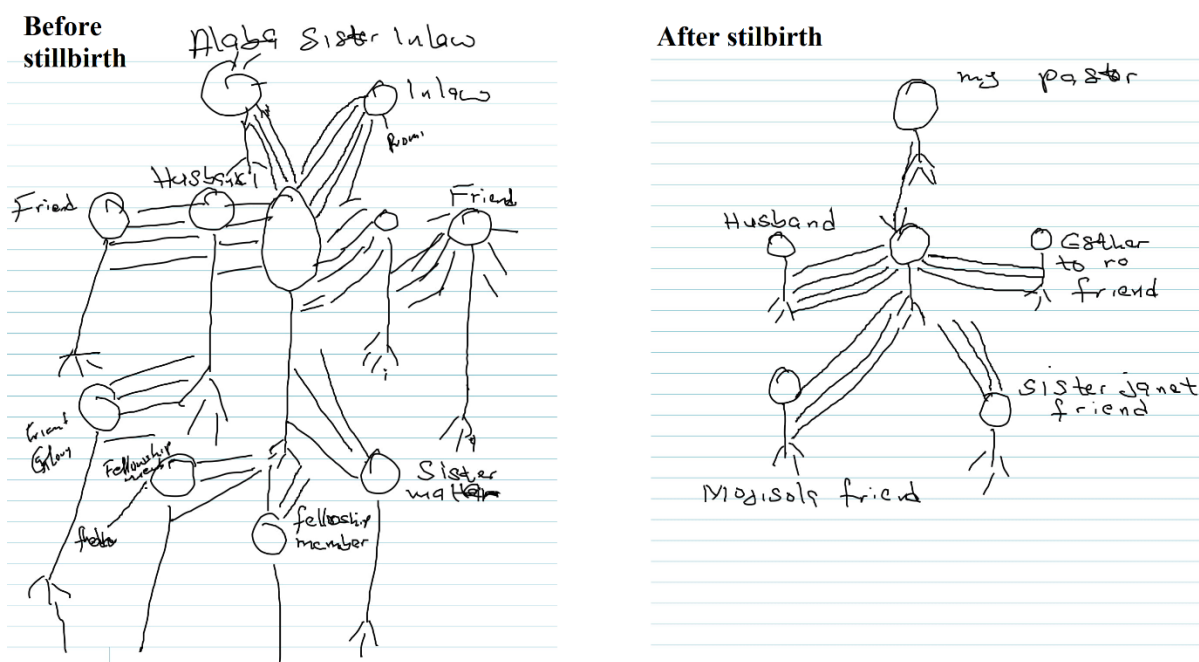


Figure 22: Participant (SK17) illustrates the loss of some relationships after stillbirth

The participants that experienced a remarkable decline in their social networks after stillbirth expressed a perceived feeling of shame and this forced them to abandon some social relationships. However, the pathway through which shame interacted with stillbirth to force substantial losses in social bonds differs from one participant to another. As an illustration, one of the participants (SK18) relocated from home because her stillbirth coincided with the successful live births of other women in her family compound. When discussing why she had to relocate, she said “*iku ya ju j’esin lo*”, and this means that “*I would rather die than experience shame*” (SK18). In the context of this participant, she expressed that she would rather commit suicide than be a witness to other mothers being celebrated with their children, suggesting that she likened stillbirth to a form of dishonour and shame. The participant further explained that:

I did not go home from the hospital, I was too ashamed of what people would say... and it was too hard for me to imagine being around on the 40<sup>th</sup> day when my other sisters-in-law are being celebrated with their babies. Not that I am not happy for them, but I also don't want to dishonour myself, and that is why my husband agreed with me that I should stay away for some time (SK18)

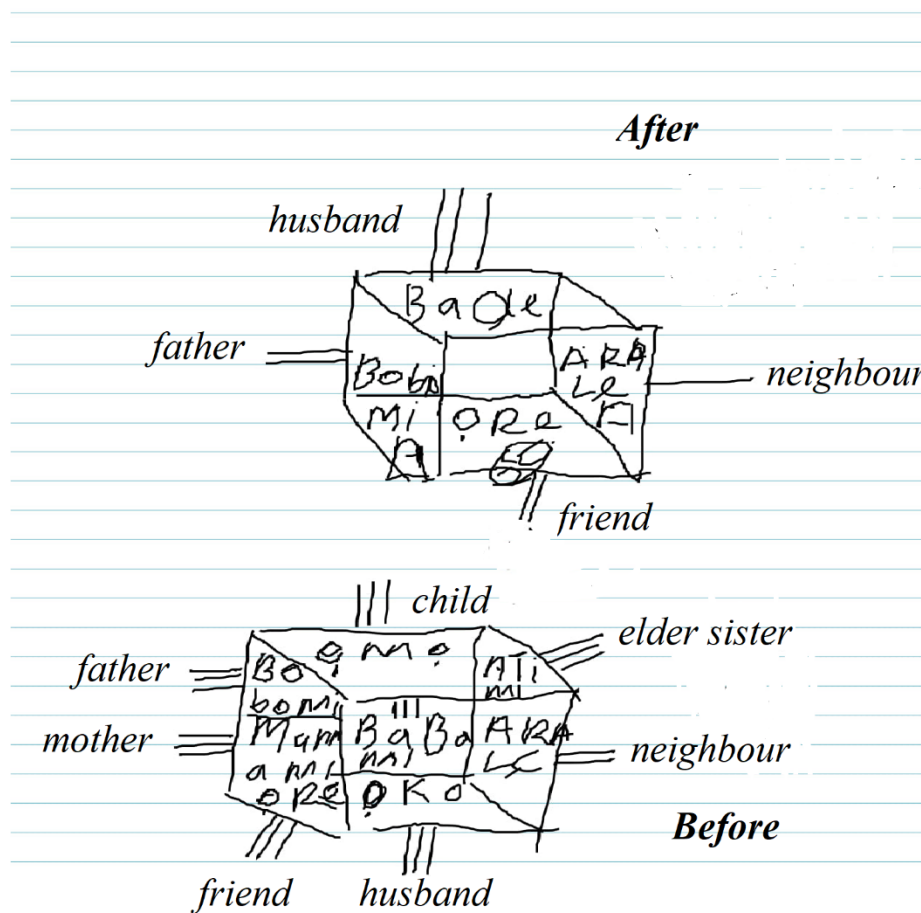
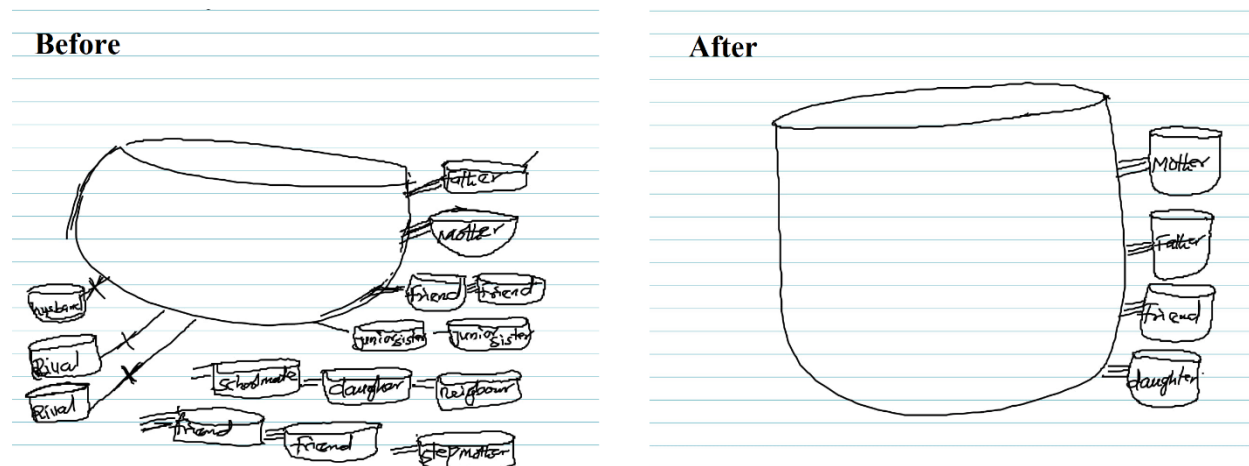


Figure 23: Participant (SK18) illustrates the loss of relationships after stillbirth

However, while the sole intention of relocating from home was to avoid being a witness to the celebration of other mothers and their children, which is 40 days after birth among the Yoruba, the indirect consequence of moving away from home for this participant was loss of support and connections with those who could have been supportive if she was near. From the diagram above, aside from the husband's support which remained strong after stillbirth, the level of support that she received from a friend, a neighbour and her father reduced by one line each, suggesting that the social bonds not only reduced in numbers but also in the perception of the degree of support

In another example, one of the participants (SK15) abandoned her social relationships because of the anticipation that stillbirth was going to put her failing marriage on the spotlight. This participant had been putting up an appearance that all was well with her marriage as many people in the neighbourhood had been wondering why she moved in with her parents during pregnancy. The

occurrence of stillbirth means she can no longer continue to make excuses about the absence of the child's father, and this forced her into cutting ties with her social networks, as seen in the diagram and quote below:



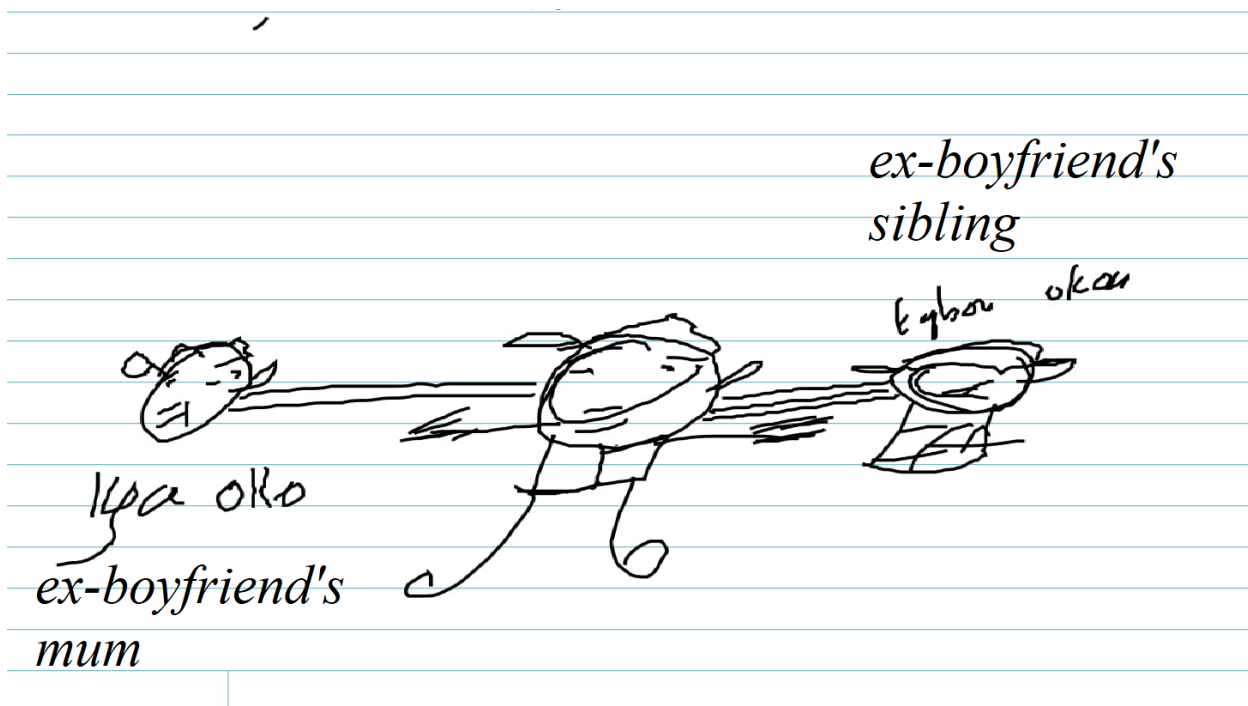


Figure 25: Participant (SK6) illustrates her social networks after stillbirth

This participant narrated how the pregnancy itself was a subject of controversy between her family and that of her boyfriend's. Her family's disapproval of the pregnancy meant that she had to move in with her boyfriend's family and this means that her own family was not involved during the pregnancy, childbirth and even after the stillbirth. She described that:

My in-laws insisted that I am better off giving birth at the home of a traditional herbalist. I was at this place for almost 24 hours labouring and in severe pain, but the only intervention given to me by the herbalist was to kneel and get up again several times which was yielding no result. By the time we reached the hospital, it was too late. Throughout all these processes, my parents were excluded, and this did not help matters because my parents alleged that the choice of a herbalist for the childbirth was for monetary reasons and not in my best interest (SK6)

The above quote typifies the additional social disadvantage that can accompany pregnancy outside wedlock because it not only disempowers the woman but also alienates her from critical sources of support. This participant was at the mercy of her ex-in-laws, and without a job or money, she

does not have the agency or the autonomy to demand better care. Since her parents have also abandoned her, she had no one to advocate for her even after stillbirth, and this explains why her social networks were restricted to two individuals, and she explained below:

...my in-laws prevented me from stepping outside the house for 41 days, and the only support available was the one provided by them. The worst thing was that at the expiration of the 41 days of seclusion, I was ordered back to my parent's house... They literally packed all my things and drove me home... at home, they just kept saying 'we told you so, but you won't listen' (SK6).

This means that single mothers of stillborn babies in the study area may lose out of support from both their own family, that of their would-be in-laws and even that of partners. The likelihood of suffering relationship breakdown with spouses was higher for single mothers, and this was another source of social stress that magnified the burden of stillbirth. The existing relationships between unmarried participants and their partners can be severely tested during pregnancy because strong societal disapproval against pregnancy outside wedlock delegitimises the relationship, thereby increasing the risk of breakdown after stillbirth as shown below in the following quote and diagram:

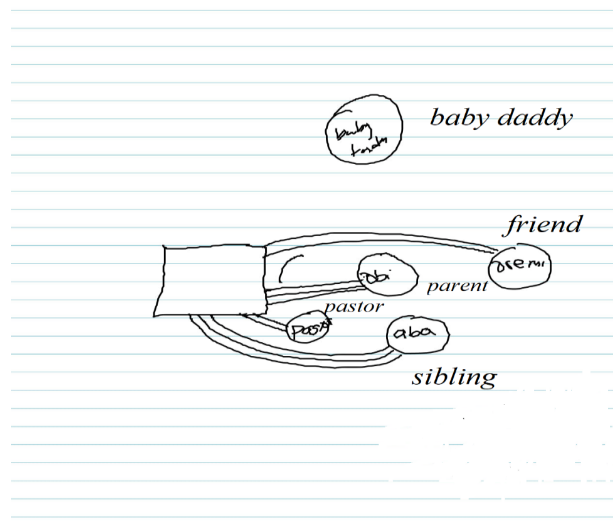


Figure 26: Participant (SK12) illustrates the loss of relationship with the child's father

The participant described that:

I had two choices: either to stay at my parents' home or move in with him. I decided to stay at my parents' because he was pressuring me into doing an abortion and I did not want to do it since people already knew that I was pregnant... He then started to maltreat me and would not answer my calls or give me money for antenatal care. When the baby died, he did not even show up, he only sent a text, and that was it (SK12).

This means that pregnancy outside of wedlock may contribute to a decline in social bonds after stillbirth, due to the societal disapproval of the pregnancy which then works on multiple levels to strain the relationship.

While perceived feelings of shame and marital status accounted for severe losses of social relationships and small size of social networks after stillbirth, the deterioration in social relationships that some participants experienced also relate to unfulfilled expectations about supportive needs, as seen below:

I was expecting much support from him, but it was not forthcoming. I think he was naïve and irresponsible (SK15).

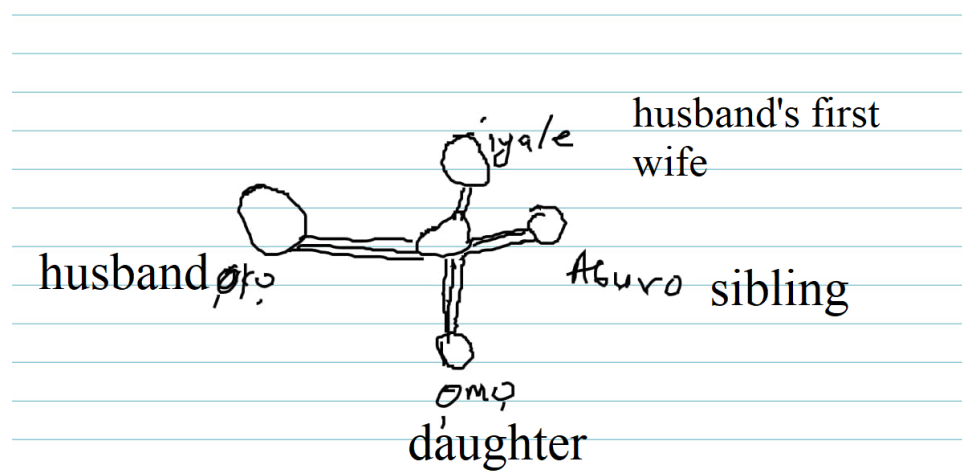
We have been family friends for a long time, and we have always been close. He [pastor] knows everything about us, and I was expecting him to be there for us during the crisis. But he was not, it was when we needed him the most that he turned his back against us (SK17).

Up till today, my mother-in-law did not ask any questions about the pregnancy, but she was aware that I was pregnant. Maybe she does not know what to say or do as well (SK10).

In summary, perceived shame and unfulfilled needs for support from those connected to the participants worked on multiple levels to cause changes to the participants' social relationships, as well as a steep decline in the size of social relationships. Also, the unmarried participants had the smallest social networks size because of social shaming and disapproval that accompanied the pregnancy itself, making it difficult for them to secure the necessary support after stillbirth.

### 5.2.2 Family is central

As social bonds decrease, family support becomes the most viable support for the participants. There is agreement among the three data sources that women's adjustment to stillbirth is a function of the family. The social networks of the participants were predominantly composed of family members, a clear indication that there is a strong sense of family commitment to helping mothers readjust to the loss. The centrality of the family members as the most likely to provide support after stillbirth becomes clearer when one considers that at least four of the participants (SK1, SK7, SK9 and SK 16) received support from only family members after stillbirth, while another four participants (SK2, SK13, SK15 and SK20) had just one person outside the family in their social networks. This means that nearly half of the participants were totally reliant on core family members for support after stillbirth. In general, sixteen of the participants had two or more immediate family members in their social networks who provided quality support and only one participant (SK6) did not receive any support from her family members. The dominance of the family in the participants' social networks is illustrated through the diagram below:



*Figure 27: Participant (SK16) illustrates how the entire support that she received was from the family*

Also, from the diagrams, it was seen that when participants lose social relationships after stillbirth, they are more likely to retain the support of family and the relationships with family members as seen below:

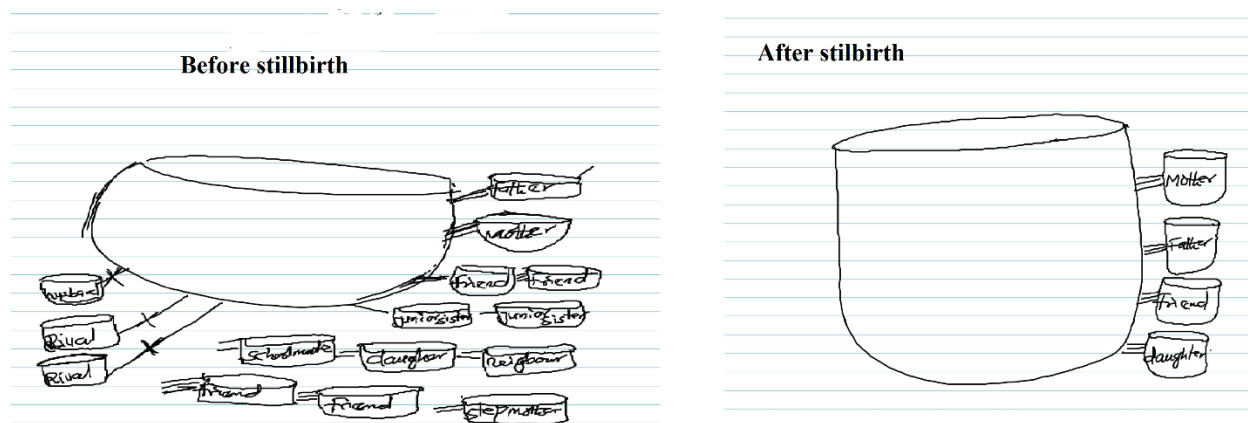


Figure 28: Participant (SK15) illustrates the dominance of the family after stillbirth

The findings from the drawings were also strongly corroborated by the interview and the focus group data, where participants believed that the support of the family can make or break the adjustment effort of any woman affected by stillbirth. As an example, one of the participants said, “*everything really depends on what your family can offer because there is not so much out there*” (SK6). In this sense, the participants were aware that there is hardly alternative support to the one provided by the family. During the interviews, it became clear that what really set the family apart from all other sources of support was the family members ability to be present in the grief. One of the participants even said that “*money is not everything*” (SK10), suggesting that the physical presence of people is more valuable than money or gifts. Unlike other kinds of relationships like colleagues or friends, family members are uniquely positioned to provide the most meaningful support during stillbirth crisis because they have the advantage of ‘physical presence’ and their support also has moral obligations, as described below:

My sister was with me the whole time. We cried together, we prayed together. She did everything to show that she was as devastated as I was (SK11)

Even though he [uncle] was far, he regularly called to the extent that I was always looking forward to his calls. Hearing his voice was so soothing... he says the right words at the right time (SK1)

My parents really tried because I had nowhere to go, I had no income of my own. It was that bad... They were responsible for all the hospital bills and even my father who wanted nothing to do with me came from overseas to show his sympathy (SK12).



Apart from being present in the grief, participants also valued family members that enabled them to take time off to rest and grieve properly, as described below:

I am grateful that my husband allowed me to stay with my brother for some time. I did not have to worry about the kids or business... That was helpful for my mind (SK18)

My younger sister was responsible for getting water ready for baths and did all my personal cares... She also made sure that the kids were well taken care of while I recover (SK16)

My junior sister was helpful. Because of her, we did not have to close our small business (SK8)

Although the family featured prominently as the primary source of support for the participants, it was the spouse that was singled out as the foundation upon which the outcomes of bereavement depends. Some of the participants described that they had no other choice but to rely on spousal support because the role of outsiders such as friends, neighbours were time-limited, as described below:

At some point, my friends moved on with their lives. It was like they had a timeframe for me. I remember one of them saying to me “I think you are now spending too much time over this issue. Let it go before it leads to something else” ... but with my husband, I did not feel pressured. I grieved the way I wanted (SK17)

Everyone left, the only person that remained was my husband. We were alone, trying to console each other... His presence and support made the difference because my moods were unpredictable. One minute I am fine, the next minute, I am drowning in tears... When I was down, he tried to be strong (SK11).

The sentiment that spousal support is important for adjustment to stillbirth was also echoed during the focus group discussion, as described below:

... I believe that any woman passing through the misfortune of stillbirth needs the support of her husband. Women can't do it alone, and that is why the woman and her husband need to be at peace with each other, stay away from trouble and embrace each other in love (FGD)

To add to what has been said, I think anyone with this experience requires closeness with her spouse. That is the ultimate support (FGD)

The husband needs to be closer to his wife during stillbirth... most women want their husbands to be there for them (FGD)

Because of the meaning attached to spousal support, the consensus during the focus group discussion was that spouses of stillbirth-bereaved women also need to be supported so that they can effectively support the grieving mothers, as described below:

Pastor and friend will leave, only the husbands remain, and that is why the husbands also need to be supported. I know of a friend who faced constant humiliation from the husband because of stillbirth, and I think this contributed to her suicide... stillbirth is not a time for bullying, insensitivity and lack of understanding from the spouse (FGD)

... I believe stillbirth calls for stronger relationships with spouses because it seems to be the only form of relationship that is constant... Both the mother and the father need to be educated on what to expect during the time of mourning and how conflicts can be managed (FGD)

However, not all the participants enjoyed the support of their partners, as described below:

... I can't say he knows the value of the loss, despite that the pregnancy was all his idea... He preferred being with friends than to stay at home with me (SK1)

The only help I would have loved to have then was that of the child's father... I spent days in the hospital before I finally delivered the baby on my own. During this period of waiting, I expected him to be there for me. I felt so ashamed that my parents were the ones running around (SK12).

Grieving a stillbirth can be an isolating experience because those connected with the bereaved mother did not meet the child that was being grieved for. As a result, the participants valued the presence of others during the grieving period, and the need for the physical presence of others was mostly met by family members because of their physical presence and moral obligations that characterise family relationships.

### **5.2.3 Experiences are diverse**

Although having a stillbirth is what connected all the participants in this study, stillbirth was experienced differently by the participants. Even among the participants that had a similar pathway

to the loss of the babies, the way they experienced stillbirth varied from one person to the other. As an illustration, two of the participants (SK4 and SK8) are no longer able to get pregnant by themselves after stillbirth because of hysterectomies that accompanied the births of their stillborn infants. However, they still experienced the loss differently as shown in the quotes below:

It is not the baby that died that made me sorrowful. I mean, babies always die. What is painful is that I can't have another child. When you can't have a baby again, it is worse, it is permanent, you have no hope, you are no longer a woman (SK8).

The doctor said my womb was removed with the baby... He said it was too thin, but that did not bother me because I almost lost my life after surgery. All I wished for was to regain my health and for God to spare the lives of my two children... I would rather be alive than die in the name of having children (SK4).

The two participants whose quotes were presented above had an almost similar profile in that they already had two living children before losing their abilities to conceive. However, for participant 4, losing her fertility was the least of her worries. She narrated that the baby's death was confirmed by the doctor before she was taken in for C-Section. However, the doctor did a partial hysterectomy alongside the C-Section because he assessed that she was at increased risk of uterine rupture in subsequent pregnancies due to multiple histories of C-Sections in previous pregnancies. But she developed life-threatening complications after surgery that left her bed-ridden for six months. By the time she fully recovered, no one even remembered that there was a child that died because she was at the brink of losing her own life. This means all the support that she received was towards her physical recovery and not the emotional aspect of the pregnancy loss itself, as she explained

by the time I eventually became well, it was no longer appropriate to talk about it [stillbirth]... I had a sense of gratitude for being alive after everything, and I knew that was how everyone felt (SK4)

But unlike the situation of the participant above, where the doctor took the decision to remove her uterus while she was still under anaesthesia, participant (SK8) consented to having a hysterectomy performed alongside C-Section. She (SK8) narrated that the space between the pregnancy that resulted into stillbirth and her second child was just four months apart and a doctor, who was a family friend advised her to consider hysterectomy alongside C-Section. The doctor also made the

idea of a hysterectomy more desirable by promising that he was willing to treat both procedures as one and this means that they would not have to pay separately for two different surgical procedures. This was a huge favour for this participant and her husband because of their low socioeconomic status, and besides, they have always wanted to have just three children. Without thinking it through, they happily consented to the hysterectomy, thinking that the child would survive. However, things did not go as planned as the child died during the C-Section and instead of the doctor to at least re-assess informed consent for hysterectomy with the participant's husband, he went ahead with the hysterectomy. It was almost three years since the loss when she was interviewed, and she has not come to terms with the hysterectomy itself, suggesting that the loss of her fertility chances was greater than the baby's death itself as she discussed below:

Whenever I think about the whole issue, I always feel like I sabotaged myself... but notwithstanding, I wanted my husband to support me for solutions. I wanted us to try to reverse it if it was possible, but he said it was not necessary... He feels that it would be a waste of money (SK8).

The implication for the differences in the experience for these two women lies in how the two women were supported after the event. In the case of the first participant, it was clear to everyone that pregnancy and childbirth was not a safe event, and this means that the cultural platitude of 'pot and water' where she would have been encouraged to put the loss aside and get pregnant again was irrelevant. Rather, all the support from people was anchored on the need for her to re-direct her love towards the children she already has, and she said everyone was saying "*Oluwa yio da awon to ku si*", meaning "*God will spare the others*" (SK4). However, for the second participant, people were consoling her with platitudes like "*you will give testimony of another pregnancy soon*", "*God will definitely restore what you have lost, and you will carry another baby*" (SK4). Because of all these platitudes which did not resonate with her reality and the fear that people will blame her if she divulges the hysterectomy, she tried to remove herself from social interactions that were reminding her of the loss, and she described this below:

I deleted all the pregnancy apps on my phone, I left all the birth clubs that I have joined during the pregnancy, and I unsubscribed from all the pregnancy sites that were sending

emails... anytime I receive any notifications about pregnancy, I remember my loss and I cry like never before (SK8).

Some participants also narrated how social and personal expectations shaped their experience of stillbirth. Participants who had not achieved a successful birth before their experience of stillbirth narrated how those associated with them struggled with the social ramifications of the loss. The reason for this relates to the sociolinguistic functions of Yoruba greetings. As an illustration, one of the participants said as people noticed that she was heavily pregnant, they started saying “*eku ipalemo, asokale anfanni*” (SK13). This literally means, “*hope preparations are going well for the delivery*”. An individual does not have to be closely related with the pregnant woman before saying “hope preparations are going well for the delivery” and this shows the interactional nature of Yoruba greetings because the pregnant woman is obliged to respond to the greeting in such a way that conveys information about her preparedness for the childbirth. This means that there is a degree of social skill in greeting in the right way since every activity, weather, time of the day and events such as pregnancy, deaths have their own special greeting. The sociolinguistic functions of the Yoruba greetings which have been extended to pregnant women during their pregnancy period have important ramifications for their experience after stillbirth, as described below:

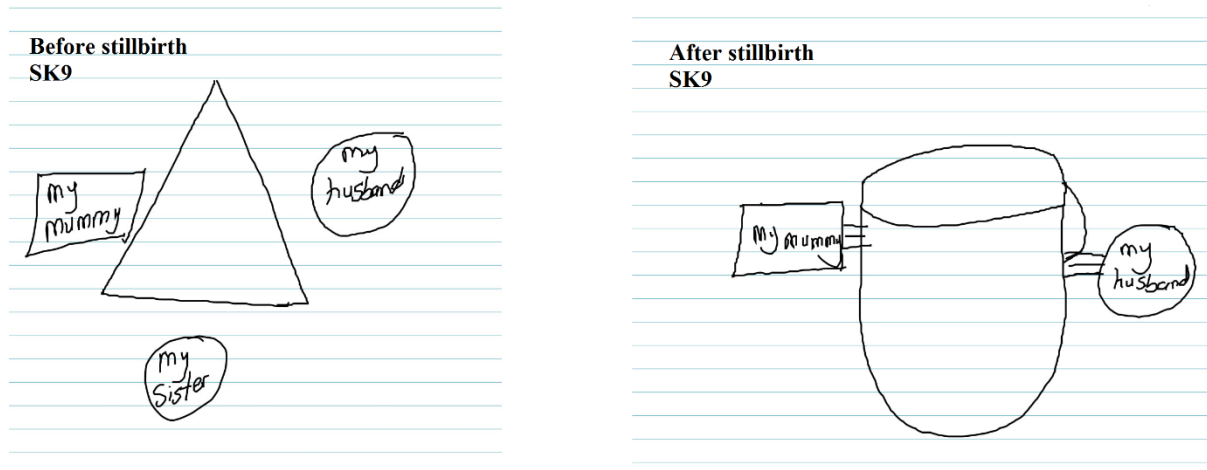
The most terrible thing for me was unpacking the baby’s bag... When I was unpacking the bag that we have packed for the baby, my hands were trembling... I did not know whether I should keep them or give them away and it was at that moment that I realised how things have changed for me within a short time... I noticed that people who have given me pregnancy-related names started avoiding me because they no longer know how to address me (SK13)

... whenever I tell people that I have mentally calculated what I still needed to get, how we were going to re-arrange the house and all other plans that we have had, I noticed that people don’t want to engage with that kind of conversations, they just wanted to say sorry and leave... one of my friends later advised that if I need to cry or express myself, I should do it in private (SK11).

This experience is culturally symbolic for the participants because the interactional nature of the greetings that typically accompanies the death of a child was missing in the context of stillbirth.

For instance, many of the participants said people that sympathised with them only said “e pele, a o ni ri iru re mo” (SK1) and this means, “I am sorry for your loss, may you not witness such again”. However, the right way to sympathise with a parent experiencing the death of a child is to say “e kú órò omo” (SK10) (greetings for this unbearable loss of a child) or “e kú àkénù omo” (SK2) (salutations for this sad loss of a child). In both variants of the greetings, there is the acknowledgement of the child ‘omo’ and the ‘oro’/ àkénù which is the incredible sacrifice of parents towards their children. These greetings are then followed up by ‘May God console you’, which is an acceptable way for the sympathiser to acknowledge his or her own limitation regarding the loss and projecting that only the bereaved can understand the severity of the loss. This gives the bereaved the power to express grief in any way that he or she likes without anyone saying the reaction was excessive. The implication of the nature of the greetings that the participants received is that the stillborn infant was not recognised as a child, the participants were not recognised as parents that lost a child and most importantly, the greeting received by the participants was passive in nature. This means that they have little opportunity to interact with their sympathisers about how the child died, what happened at the hospital or how the child was buried. Thus, there was no acknowledgement of the motherhood pursuit that ended with stillbirth and this is especially painful for primigravida women because having a child grants access to certain discourse, as described by one of the participants “*there are certain discourses you are not allowed to contribute to, if you are not a mother to a child*” (SK19).

Unlike some other participants that lost a significant amount of their social networks after stillbirth, one of the participants narrated how stillbirth positively transformed what happened to be a fragmented relationship with others to a strong and mutually beneficial relationship after stillbirth, as it can be seen in the diagram below.



*Figure 29: Participant (SK9) illustrates how she became closer with her family members after stillbirth*

This participant had a tumultuous pregnancy experience because she became pregnant outside of wedlock and this exposed her to a severe criticism from the church, as well as shaming from community members. She got married to her partner as a form of damage control to smother what was becoming a severe and continuing public humiliation even from her own family members as can be seen in the image above (figure 29). The circumstances surrounding the pregnancy made her consider herself as not having any form of meaningful relationships with others, but this changed after stillbirth, narrating how both her mother and husband moved closer to her to offer the much needed support, as described below:

My mum was very supportive... she moved closer to me and listened to my views about how I felt about the whole situation. During that time, I needed someone to talk to, not just people who would tell me it will be alright (SK9).

This sub-category illustrates the different ways of experiencing a stillbirth and the differences in meaning that each participant attaches to stillbirth. Every participant in this study had a particular expectation about their pregnancies, and this means that the loss of the baby has different ramifications for each participant and this affected the way they went about the issue.

### **5.3 Relationships matter**

This category is about what was possible for the participants, in terms of the support that was available to them because of their relationships with others. The support that was available to the

participants through their relationships with others was presented in three sub-categories, which are: encouragement and empathetic help; forgetting and moving on can be both helpful and harmful advice; and looking to religion for meaning. Together, these sub-categories illustrate how the role of others in the participants' grief shaped their experience of stillbirth. The experience of stillbirth allowed some of the participants to appreciate the value of social relationships, as well as the social support that was derived from these social relationships. As an illustration, when the participants were asked about those things that assisted them in adjusting to the loss, one of them (SK7) said “*taja ba leni leyin, a pobo*”, and this literally means that “*if a dog enjoys the backing and the support of people, it will kill a baboon*”. This analogy used by this participant suggests that a hunting dog on its own cannot kill a baboon, because apart from the baboon's ability to climb trees, it is also bigger, stronger and faster than the dog. In this sense, stillbirth represented a bigger problem for a woman, and this means without the support and backing of people, she cannot overcome the challenges of stillbirth.

Along the same line, another participant (SK5) used this expression “*eniyan laso mi, timo ba weyin timo reni mi, eniyan laso mi*” which literally means “*people are my covering, when I look back and see my people, I know I am not naked*” to highlight the value of social relationships after stillbirth. From the traditional Yoruba sense, a mother of a stillborn baby without people to support her during the crisis is like being ‘naked’, and this sums up the vulnerability of women without the support of others after stillbirth. The meaning of people being a form of protection and covering for a mother of a stillborn baby can be further understood from the image below:



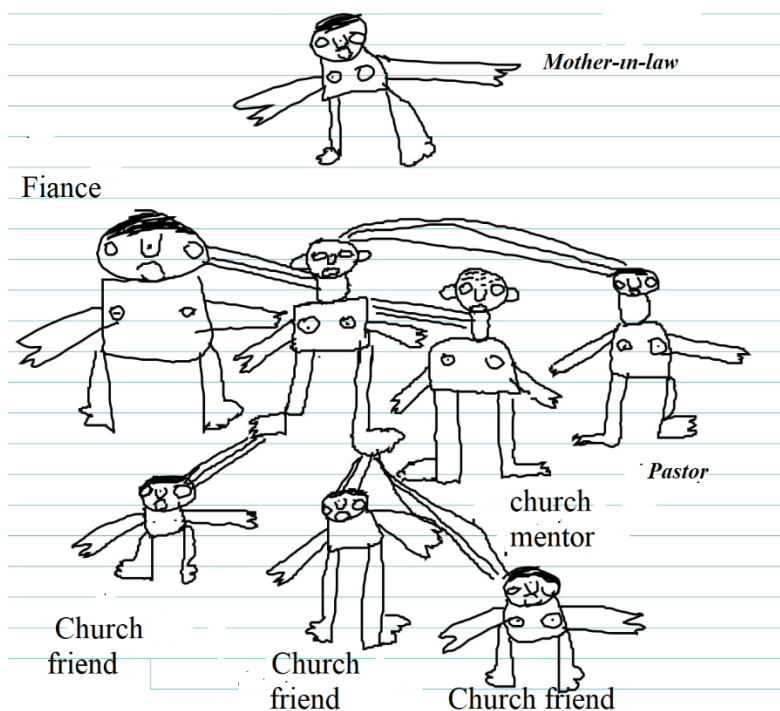


Figure 30: Participant (SK5) illustrates the value of relationships

Aside from the fiancé of the participant, who was not even around during the crisis, all the support that the participant received was from her church. When thinking of the support provided by her church friends, she said *"if not for them, the child would have been buried anyhow"* (SK5). Considering that the fiancé was not around to collect and bury the child, the church friends were the ones that assisted her in fulfilling her wish, which was for the child to be buried in a respectful and dignified manner. This means that if the five people from church who made a dignified burial possible were taken away from her diagram, the participant would be 'naked'. This is because the hospital would have taken possession of the body and they were likely to treat it as hospital waste, meaning the child would not have been buried at all. Social relationships, therefore, matter for the participants of this study as seen in the three sub-categories below.

### 5.3.1 Encouragement and empathy help

During the interviews, the participants discussed that people not only encouraged them but also showed empathy. People used several strategies and analogies such as drawing on religion, citing examples of women who have died during childbirth and women who have previously had stillbirths but later went on to have live births to encourage the participants. All these strategies

were meant to make the participants feel better than those women who died during childbirth or women who are barren, as seen in the quotes below:

My dad gave examples of those that have once been affected by stillbirth in the past who went on to have children (SK19)

My mother said, “it is the water that spilt, the pot is unbroken, God can still bless you with another child” (SK1)

One of my friends asked me, “how long are you going to grieve for?”. What if you have also died with the baby?” (SK13)

These analogies that the sympathisers used in encouraging the bereaved women are culturally acceptable because they reinforced the Yoruba belief in the restoration of life after a tragedy, thereby projecting hope for the survivors. By citing examples of those who had died from childbirth and those who recovered from stillbirth to have successful childbirth, those associated with the participants not only encourage the mothers, but they also validate the feelings of the mothers which is culturally centred on the fundamental assumption that not all hope was lost with the stillbirth experience. This form of encouragement which extols the value of the life of the bereaved mother over the child that died places emphasis on the dignity of the survivor and her right to embrace a changed world that is independent of the dead. As such, sympathisers help the bereaved women in making a downward comparison, and this influences self-beliefs that achieving a live birth is possible in subsequent pregnancies, such as in the following examples:

When she [friend] told me that she had three stillbirths before she finally had her four surviving children, I started believing that things will be alright for me as well (SK17)

The pastor was in our house several times to encourage me with the story of Hannah in the Bible (SK9)

Assuring participants that suffering a stillbirth does not mean they could no longer have children was a concrete form of support for the participants of this study because of the importance attached to motherhood and childrearing in the research setting. Depending on the situation of women, society has two dominant narratives that are used to console women facing stillbirth. The first narrative relates to first-time mothers, and this narrative is to remind women in this category that they can still bear children and that stillbirth is just a temporary setback. This relates to the

traditional view of pregnancy, where the survival of the mother means there is hope for her to become pregnant again as expressed in this quote “*My nephew used the Quran to encourage me. He said the incident was permitted by God for a reason and that God will surprise me with another pregnancy*” (SK16). In the second narrative, the goal is to assist the woman to re-focus her thoughts and energies from the loss to other things such as existing children. This is more suitable for women who already have surviving children. In the second narrative, since the motherhood status has already been achieved, women were encouraged to re-direct their love to surviving children. Some participants narrated how surviving children became the focus of attention after stillbirth:

... at least I have two children that prove that I am a woman. This is what everyone was saying, and that is what I kept reminding myself of whenever my mind wanders to the stillbirth (SK4).

She [younger sister] said I should take comfort in the children that are already here. “You need to be strong for them in order not to make them feel abandoned” was always her message (SK20)

These forms of encouragement put a form of duty and responsibility on the bereaved mother because it subtly reminds them of the need to shun any thoughts of self-harm and stay alive for the surviving children. Apart from encouragement, there were also instances where relationships with others facilitated opportunities for the participants to open up about their feelings and this allowed them to feel the empathy of others, as described below:

I told my mother that it seems my body does not understand that I lost the baby. I was producing milk; my breasts were swollen, and they ache. My womb was contracting, and it was like I was in labour all over again. Speaking about it with my mom assisted her to know what I was going through (SK13)

I opened up to my close friend. I needed something to blame; I needed someone to blame. I told her maybe the baby died because of the stress that I went through during pregnancy or because I missed antenatal classes. She just sits and listens to me (SK14).

When a baby survives labour, it is sometimes easier for people to appreciate the physical, emotional and even the social adjustments that the mother would have to make. As an example, the new mother would have to fit new responsibilities into her routines and try to achieve a balance

between her own self-care and that of her baby. Such efforts at adjustments by the new mother do not go unnoticed and these usually prompt people who are connected to the mother not only to be helpful but also to be empathetic to the new changes. In the case of mothers of stillborn babies, many people automatically think that not having a baby to nurture means that the mother of the stillborn baby does not have to make any significant adjustment. This means that without open conversations about their feelings, it may be difficult for people to be empathetic the way they should be. As an example, one of the participants (SK13) who was entitled to four months of maternity leave said she resumed back to work three weeks after the incident because people did not understand why she had to stay at home when she does not have a child. She explained that some of her colleagues told her “*why waste your maternity leave, when you can keep it for the next one [next pregnancy]*”, “*staying at home won’t help you since no one is even there with you*” (SK13). Another participant (SK10) said her brother told her “*ko ara n’le, se ara giri*”, meaning “*you are too slow to get over the loss, pick yourself together*”. This suggests that women may sometimes be subjected to pressure from both friends and family to adjust faster to the loss and that is why it was important for participants to open up about the experience. Openness, therefore, assisted some of the participants in gaining the empathy of others.

### **5.3.2 Forgetting and moving on can be both helpful and harmful advice**

The dominant advice that the participants of this study received was to forget the loss and move on with life. This advice is in line with the cultural interpretation of pregnancy and child loss, which argues that a stillborn infant can be replaced if the mother is alive. Thus, the societal idea of healing from stillbirth is firmly embedded in the need for the woman to move on from the loss, as described in the following example:

People said to me “start eating good food, do hot compress, drink hot water and don’t think about it if you want to get pregnant soon” (SK16)

I had a trance whereby I was carrying and breastfeeding the baby, and when I told my husband, he said I should not say anything about the baby again. He then got me some concoction from our Imam so that I can forget about the baby (SK2)

This means that there is a certain expectation from mothers of stillborn babies and as such, women who failed to accommodate the need to forget and move on may be avoided, criticised and flagged as mentally deranged. More so, the centrality of the advice also hinges on the basis that forgetting

that the loss occurred is the only pathway to becoming pregnant again. As a result, some of the participants narrated how they tried to hide their grief and their true emotions because of what people might say, as seen in the examples below:

People told me to take my mind off it, and I initially did. But when everyone left, and I was left alone in the room, I cried. I looked back on all the sacrifice, the frequent hospitalisations and I can't help but cry (SK18)

I initially blocked it off my mind by trying not to remember the exact date, but recently I have started reaching out to people who can remind me of the date (SK3)

Despite people's advice on the need to forget and move on, the participants confirm that forgetting about the loss is impossible and one of them described that "*it is maternal instinct to think what if my baby was alive, he or she would have been like this or that*" (SK2). However, despite many of the participants believing that it is even pointless trying to forget the loss, the participants also did not want to keep any memorabilia because it was culturally incompatible, and they also argued that many things in the environment naturally reminds mothers of their babies, as described below:

It is impossible to forget but keeping something as remembrance is not part of Yoruba culture. When you do that, the wound in your heart will not heal (SK3)

Those children born when we lost ours, are our daily reminders... If we keep any object to remind ourselves, we will be overloading ourselves with too much, and I don't think that would help (FGD)

... there is no way one can forget it, we only try as much as possible to leave the feelings behind (FGD)

The society is also aware that women can rarely forget they had a pregnancy that resulted in stillbirth, but instead of acknowledging this, they consciously act to remove any remembrances and signposts about the death of the baby. Some of the ways of achieving the erasure of memories are by denying women the chance to see their babies and preventing any form of conversations about the burial of the child or the experience itself, as described below:

When we got home, I asked how and where the body was disposed, and they quickly replied, “God will not allow you to know the grave of your child”. That was the end of his story (SK6)

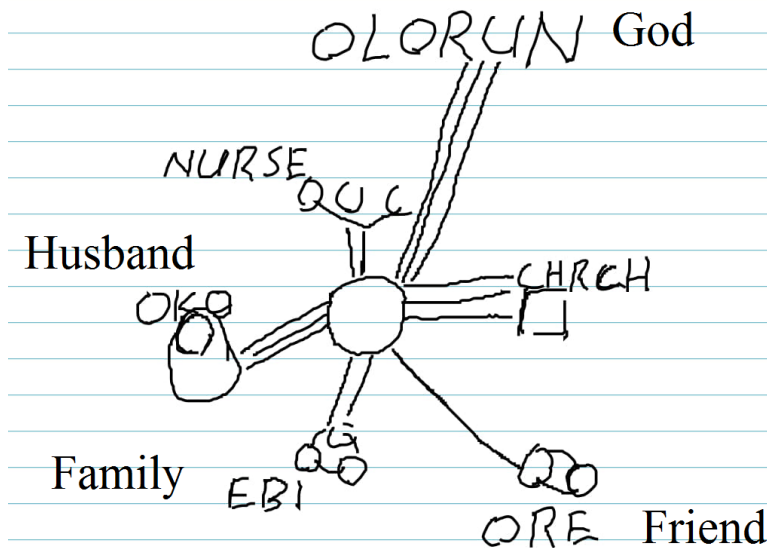
... you are not allowed to ask questions about how the baby was buried. So, no one briefed me or asked permission before the baby was taken away (SK14)

As long as the baby did not suck my breasts, it means he was never here. There is no place for him in our conversations (SK2)

Even if the mother wishes to put the loss behind her, there are many triggers such as other people's children, especially those of similar age group with the stillborn infant that will keep reminding the mother about the loss. This means that even though women are urged to forget and move on, it may not be entirely possible or helpful depending on the woman's circumstances. As an illustration, participant 5 (SK5) was not sure about the continuity of her relationship because of the hostile attitude of the fiancé's family and the prolonged absence of the fiancé. Because of the uncertainty, she said *“I gave everything away, clothes, swaddles and everything that belonged to the baby”* (SK5). However, in the case of another participant (SK17), she said *“I did not discard the baby items in the house because I thought another child could use them when I get pregnant another time”*. This suggests that beyond the advice of moving on, personal aspirations of the participants can also complicate whether they hold on to the memories of the child or whether to physically get rid of items that can remind them of the loss.

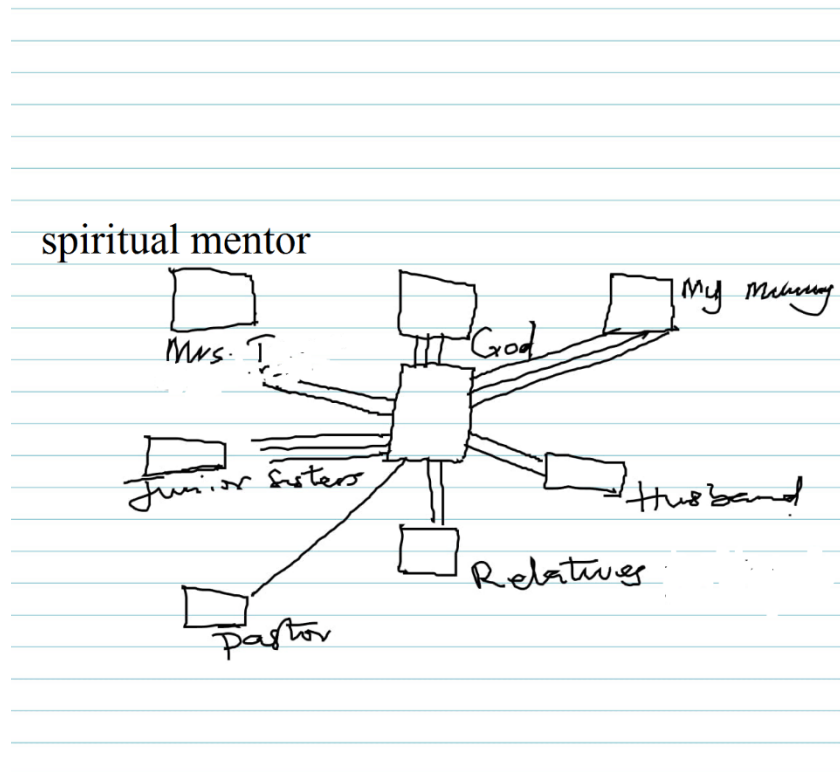
### **5.3.3 Looking to religion for meaning**

There is evidence from the diagrams and the interviews that many of the participants derived inspiration for coping with stillbirth from their faith. As can be seen in the diagram below, the participant symbolically positioned ‘God’ above every other source of support to show that the ultimate source of support was her faith in God.



*Figure 31: Participant (SK11) illustrates the role of faith in her adjustment*

The inclination that many of the participants showed towards their religious faith was not surprising because the participants had little opportunity to talk about the loss. Religion as a source of meaning was more pronounced for participants that professed Christian faith to the extent that eight out of the 10 Christian participants included at least one person from the church as a source of support in their social networks' diagrams. This means that nearly all the Christian participants (SK5, SK8, SK10-SK13, SK17 and SK19) derived some form of support from places of worship, as can be seen in the diagram below:



*Figure 32: Participant (SK8) illustrates the influence of support from religious sources*

The church, church friends and spiritual leaders like pastors are important figures for some of the participants because they teamed up with the participants to problematise the issue of stillbirth in spiritually acceptable ways such as through prayers, home-visitations, and house fellowships as seen below:

The church really stood by me... Throughout that time, the pastor and the sisters come to our house once a week to join hands with me in prayer about the issue (SK11)

There was a lot of prayers going on, but I think God knows why he allowed it. I could have also died with the baby, so, it is by God's mercy that I am alive today (SK16)

I found it helpful when the pastor and even my friends remind me of God's promises from the bible. Their words of encouragement also helped my own faith and attitude to the problem (SK17)

Unlike the Christian participants who showed their spirituality and influence of religion in their diagrams, none of the Muslim participants included people from Mosques or their religious



gatherings in their diagrams. However, during the interviews, the Muslim participants also talked about their reliance on Islamic beliefs in order to cope with the loss, as seen below:

I used to feel depressed whenever I think of the experience, but on many occasions, I still have reasons to thank God because I am better off than a barren woman (SK4)

I finally accepted that after all, I have given birth to male and female children. If I did not have any child, I would have been more devastated. Despite everything, I am grateful to God (SK1)

My nephew told me that the same God that made it possible for me to get pregnant in the first instance will do another one... I eventually accepted that God gives and takes away as He pleases (SK18)

This suggests that religious beliefs of the participants, regardless of whether they are Christians or Muslims complemented the cultural idea of grief resolution in stillbirth bereavement because the participants' quotes reflected their acceptance of the situation through a process of gratitude to God. However, while religion was helpful to almost all the participants' in dealing with the loss, religion also powerfully influenced the participants' adoption of health-seeking behaviour as many of them believed that seeking support or help was not worth it. This is because of the belief that the occurrence of stillbirth was ordained by God and nothing could have been done to prevent it from happening. As an illustration, when the participants were asked whether they sought any form of help outside their family or if they requested an autopsy, they gave the following reasons for not seeking help:

I did not seek support help from anybody, I just accepted that that is how God destined it to be (SK15)

I think it is when stillbirth becomes recurrent that it deserves both medical and indigenous interventions. But when it is just once off, there is no cause for alarm, it is a common thing in our community (SK2)

Only God knows why it happened, and we don't have a right to question why it happened the way it did (SK5)

In summary, the participants adhered strictly to their religious beliefs, and this seemed to be helpful for their acceptance of the loss and as well as their resilience. However, religious and cultural

beliefs also appeared to play a role in preventing the participants from seeking support for stillbirth. This was surprising because, at the end of each interview, the only question that most of them seemed to be very interested in was related to strategies for achieving successful pregnancies in future pregnancies and how to achieve fertility. One would have thought that they would have sought answers to some of their burning issues from healthcare institutions.

## **5.4 Material support makes a difference**

This third category was presented to illustrate the socio-economic interactions that transpired between the participants and their support networks after stillbirth. This is the only category with two sub-categories (people give less if a baby is stillborn and people still help in limited ways) and this reflects the limited material support that mothers received after stillbirth, even though many of them were worse off financially after stillbirth. This category was different from the earlier categories because it centres around the concrete assistance that the participants received after stillbirth. It also highlights that mothers of stillborn babies received far lesser support than women with a liveborn infant and some of the factors that influence this social disadvantage for mothers were also highlighted.

### **5.4.1 People give less if a baby is stillborn**

In order to understand the kinds of support that mothers received after stillbirth, participants were asked to list what they received from people after stillbirth. In the image presented below, one of the participants (SK17) illustrated the difference between what she received when she had a live birth versus when she had a stillbirth.

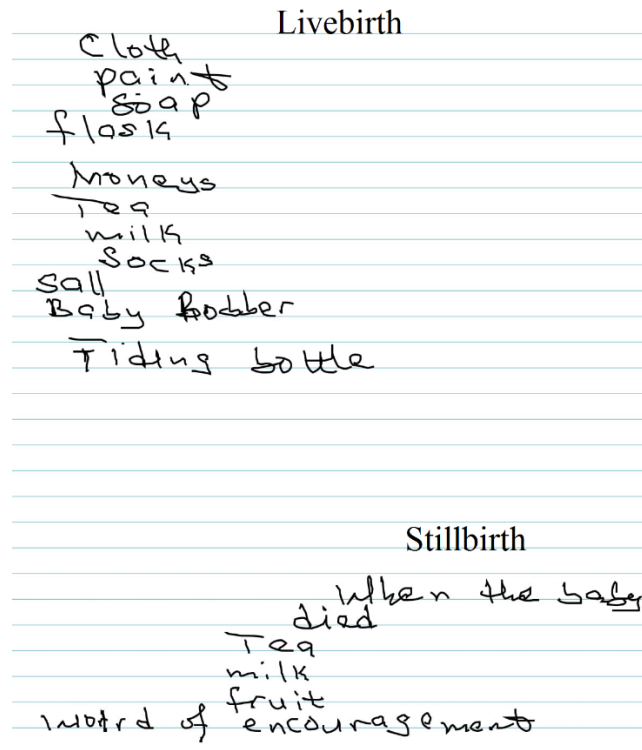


Figure 33: Participant (SK17) makes a distinction between stillbirth and livebirth

The diagram above is representative of the nature of the material support that most of the participants received after stillbirth, and this underscores the perception that women with stillbirth have lesser needs than women with a livebirth. Fruits and beverages are intentionally given and culturally acceptable because it symbolises the recognition and priority for physical recovery over other types of recoveries such as emotional or psychological. When the participants talked about the obvious difference between the socioeconomic support that they received when they had a livebirth versus stillbirth, they explained that their inability to bring forth a live baby discredited them from the rights to material support, as described below:

People don't give anything, but people who are very close to you may give milk, tea, fruits for your recovery (SK16)

Since there is no child, there can never be gifts. People give gifts because of the child, and when there is no child, there is no gift. It is as simple as that (SK13)

I only expected people to say sorry, God will bless you with another child. It is wrong to expect anything from anybody when your child dies (SK1)

However, while some of the participants believed that “giving a mother of a stillborn baby any gift or material support is *“culturally inappropriate”* (SK2) and that *“receiving a gift won’t make the mother feel better”* (SK3), many of the participants were in financial jeopardy after stillbirth and this made their adjustment to the loss even more difficult. Apart from those that incurred huge debt because of surgical interventions needed for childbirth, having a stillbirth in most cases required unplanned expenditure because in many instances, women often require scans to confirm the loss, and many of them detailed how they stayed longer in the hospital because of slow labour progress, as described below:

if the baby was a normal delivery and we did not have to spend so much, maybe it would have been better... my husband was under a lot of pressure because of how much money he spent, and he became very impatient and insensitive (SK16)

I was in the hospital for three days, but the nurses just kept saying "you need to relax; it will come on its own" .... they rarely come to my side, except I call them... but throughout the whole time, I was secretly praying and hoping that I won’t need surgery (SK12)

Because of the resources that went into the childbirth itself, some of the participants cannot even afford to rest and recover, as described in the following examples:

There was no time to recover, I started working almost immediately because I simply cannot afford to take time off work (SK20)

... my ex-husband was so irresponsible that I had to start work immediately after discharge even when I was supposed to be resting (SK14)

During the focus group discussion, there was consensus among the participants that having a stillbirth magnifies the socioeconomic disadvantages of mothers because *“most people do not give anything or render anything that is really impactful”* (FGD) and as a result, the focus group participants believe that the socioeconomic disadvantage of stillbirth ought to be recognised by the government. Their arguments for this position was based on the government support that exists for widows, where widows can access funds and acquire skills through various skills and loans acquisition programmes both at the local and national levels. These social safety programmes are part of social welfare initiatives because of the government's recognition that spousal death can result in socioeconomic disempowerment and the participants described this below:

There are many financial programs for the widows, and I think the government should also have one for mothers of stillborn babies so that whenever this happens, we can easily access these programmes to protect ourselves because some of us cannot rely on our family for support (FGD)

There was a woman who was held in the hospital for several months due to inability to pay her hospital bills and this woman had to be sleeping on the floor. So, there should be some social programmes for stillbirth (FGD)

The government and those close to the woman need to support when things like this happen because the woman may not have the means to support herself after the loss... In my own case, there was nothing to eat in the house (FGD)

The importance of having someone who can support financially, especially when the childbirth requires C-Section or prolonged stay in the hospital is crucial because most medical facilities in Nigeria do not provide treatment when payment obligations have not been met by the participants. In rare circumstances, if medical professionals treat a patient out of compassion to save the life of the individual, the patient may be held in the hospital for as long as possible until the hospital bills are paid. This means that even though participants were devastated by the loss of the baby itself, they were also wary that lack of financial support could have plunged them into more crisis and this explains why some individuals in the diagrams were only there because of the financial support provided. As an illustration, in the diagram below, the participant awarded three lines for her husband, suggesting he was a strong source of support.

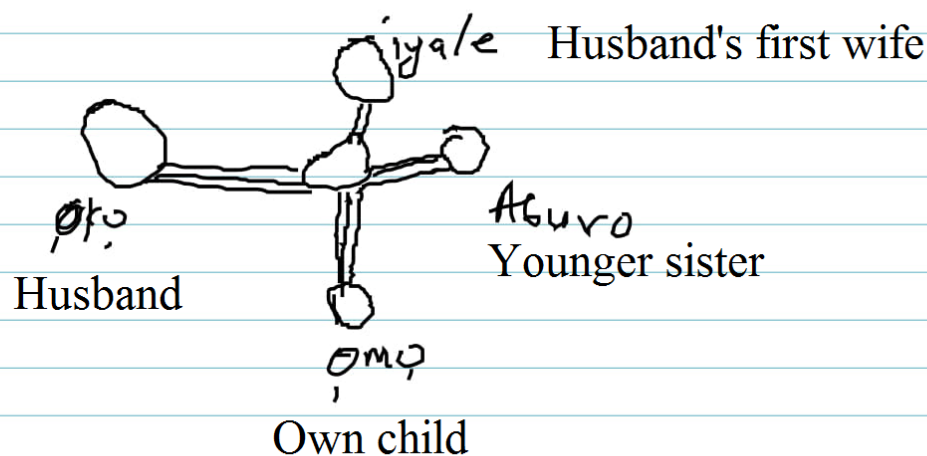


Figure 34: Participant (SK16) included her spouse because of the financial support provided

The reason for the three lines that was given to the husband was explained in a very short sentence by the participant where she described that “*he [husband] was the one that paid all the hospital bills and I know he must have gone through a lot to get such amount of money within a short notice*” (SK16). However, apart from the financial support, the husband was missing in all other domains of support and in fact, he was the most insensitive person to the participant. The participant explained that when she told her husband that she was not yet ready to resume work, the husband asked “*ki lo se e ti ko se eni kan ri*”, meaning do you think your situation is exclusive to you?” (SK16). This suggested to the participant that she does not deserve any special treatment, care or attention just because she had a stillbirth. The participant said she felt that the husband would have just moved on if she had died with the baby. But despite what appeared as a very blunt and insensitive attitude from the husband, the husband was not only included as a source of support but a solid source of support. This suggests that it is essential to understand why participants choose to add certain people as a source of support in their diagrams.

#### 5.4.2 People still help in limited ways

Since there were limited exchanges of material support due to cultural and social expectations, the only alternative way for people to support mothers of stillborn babies is through the provision of domestic help, which in this study centred around assistance with household chores, as described below:

She [friend] was really there for me. She did my laundry, brought meals, prayed for me and visited with her family (SK17)

My husband's first wife ensured that all my personal cares were attended to. She did all the cooking and kept the house organised during her brief stay (SK16)

My friends also visited to check how I was doing, and they also asked what they can help with. Some cleaned the house, some did laundry, and others just sat with me (SK11)

Although much of the support provided by people was restricted to domestic help as indicated above, this form of assistance was still handy for the participants because as people assist with household chores, participants had more time to focus on grieving. Also, as domestic help demands the physical presence of friends and family, there was also an additional opportunity for socialisation with the sympathisers. This is important because the immediate period after stillbirth required participants to stay in-doors for some time and it was essential to retain social ties, as described below:

Whenever they [neighbours] notice that I was alone, they will quickly come to my room and encourage me to go outside and be with other people (SK5)

Some of my friends made it a point of duty to sit with me to grieve, and they also took care of my other children because I was not strong enough to do any stressful work (SK14)

Some of my very close friends that knew about it tried to take me along for outings, just to divert my attention from the grief (SK17)

As previously highlighted, only a few of the participants received any form of financial support as described below:

The support of my in-laws was also very helpful because they also contributed towards the payment of the hospital bills and they also visited (SK16)

People took care of me. Some gave money, some made sure I had food to eat, and some were just supportive (SK4)

With only just a few of the participants receiving any form of material support, it seemed that mother of stillborn babies were not recognised as needing material support. However, people, especially friends and neighbours still helped in meaningful ways that met some needs of the participants.

## 5.5 Health professionals neither help nor support

This category highlights how health professionals failed women on multiple levels, and this was discussed under three sub-categories, which are: breaking the bad news, losing faith in the competencies of health professionals and opportunities for improvement in bereavement support. Although the role of health professionals in the experience of stillbirth was not the focus of the study, one of the unexpected findings in this research was the poor interactions and encounters that the participants had with health professionals. Health professionals were poorly represented as a source of support, and this was consistent across the three datasets. The participants produced 20 images of those that supported them after stillbirth, and although a total of 88 entities were identified as providing support, only one of those entities was a member of the medical team (nurse). This means that only one participant found the actions of health professionals supportive in the study, as shown in the diagram below and she described that *"she [nurse] came to my side and counselled me to take heart. She was the first person who made the situation lighter in my heart"* (SK11).

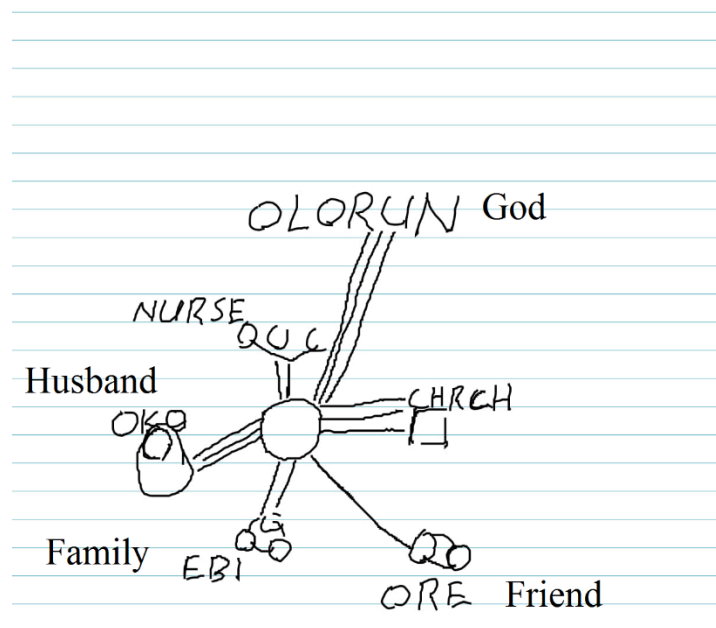


Figure 35: Participant illustrate the support she received from a health professional

The low representation of health professionals in this study was surprising because 19 of the participants had their babies in health facilities and almost all of them spoke of attending antenatal classes. During the interviews, the participants detailed poor and unprofessional treatment that



they received in the hands of health professionals and this has reduced their levels of trust in health professionals.

### **5.5.1 Breaking the bad news**

Health professionals engaged in acts of deceit, lies and false reassurance to avoid being the one to break the bad news and when participants finally knew of the loss, they felt heart-broken because the health professionals whom they have held in the highest regard excluded them from something that primarily concerned them. The Yoruba people will say 'aki fa'ri leyin olo'ri' which literally means you do not shave the head of an individual in his or her absence. In other words, before anyone should know about the diagnosis of stillbirth, the first person to tell is the mother of the stillborn infant because the issue primarily concerns her. In the worst-case scenario, the woman must be present with others when the news is being broken. This means that in the traditional sense, the health professionals that excluded mothers of stillborn babies during the breaking of the news violated the basic traditional ethical principle of autonomy and by the participants' own account, this is one of the worst parts of the experience of having a stillborn:

During the scan, the doctor's body language suggested that something was wrong, but he said nothing to us. Later, he called my husband to the side, told him the baby had died and instructed him not to tell me... From the time I started suspecting that the baby had died till when I finally delivered was three days and those three days were the most dreadful experience of my life because I feared something terrible could happen to me as well (SK20)

No one, in particular, disclosed the news to me. It was my mother-in-law who accompanied me to the hospital that the nurses disclosed the news to. I overheard her [mother-in-law] talking to other relatives just outside my window that her grandchild did not make it (SK3)

Other participants who heard the news directly from the health professionals narrated that the experience was dehumanising, blunt and raw, and they described this below:

The doctor just said in front of everyone, "madam, you see that child inside you is no longer useful. We don't need it anymore. You should worry about your own survival and forget about the child" (SK18)

At first, I did not even know the baby had died as I was asking for the baby persistently, but I was told I needed to be transfused with blood. When we were leaving the hospital, and the bill was being paid, I asked for my child again, and that was when my ex-boyfriend's mother told me the baby did not survive. The nurse then said "it is better you take it easy; otherwise, you may react to the transfused blood and anything can happen to you (SK6)

By being dishonest and insensitive about stillbirth diagnosis, health professionals made the experience harder for the participants because it robbed them of the opportunity to physically and emotionally prepare for the birth. One of the participants said the labour experience was more difficult as the health professionals made it seem obvious that they were doing her a favour by taking delivery of a dead baby. She narrated that the nurse said to her "*open your legs wide and push or do you want to end up like your baby?*" (SK18). It seemed that health professionals treat women who are labouring to deliver stillborn babies differently because every communication that ought to allay the fears of the woman, while also preparing them for the birth itself was withheld from them. One participant described this below:

What made it harder was that there was no communication from the nurses on what to expect. No one was telling us how the labour was going to be like. If we had support during the labour, we could have been more prepared... We did not know what was coming (SK12)

Although nearly all the participants had their babies in the hospital, most do not have a concrete experience of what their babies looked like. Most of the participants had a vague memory of their encounter with their baby, as described below:

I did not hear her cry. She was taken away immediately after she was delivered. When I asked for her to be given to me, the nurse allayed my fear that my baby was okay and that there was nothing to be worried about... I was blindsided throughout the whole process (SK13)

The nurse asked me "what would you do with it [the body of the stillborn infant] if we hand it over to you? It is not normal, it is not right, you will not like it (SK5)

From the accounts of the participants, health care professionals are simply replicating the same treatment that mothers would have been exposed to if the stillbirth happened in the community. The treatment that the health professionals gave the participants was even worse than having a home birth because if the baby was born at home, the woman would know almost immediately that the baby had passed away. But in the case of women in this study, health professionals not only deceived participants into thinking that their babies were alright, but they also gave false reassurances which made it even more difficult for mothers to process the loss when they eventually knew.

### **5.5.2 Losing faith in the health professionals' competencies**

Women in this study were not given the kind of bereavement care that they would have loved to have. Although health professionals did all they could to deprive women the opportunities to make memories of their experience through either holding the baby, seeing or even having an honest communication about the loss, it seemed that if women are supported, they may be more likely to see their babies. As an illustration, some of the participants said:

Every woman wants to know what came out of her body. That is why I sneaked to where the child was kept, just to see for myself (SK5)

I would have wished to carry and see him, I suffered too much during the pregnancy not to see him (SK12)

I wished to see what I had carried for nine months, but they [nurses] did not give me a chance (SK9)

Some of the participants' detailed alarming ways the baby's body was presented to their husbands in the following quotes below:

The child was handed to my husband in a plastic bag, but because he was more concerned about my welfare, he brought the baby home with us... but since I knew the child was somewhere in the kitchen, I was eager to look at him, and I went in search of the bag till I found it... He was not dressed; he was curled up in the foetal position with blood all over him (SK10)

I thought they could have at least buried him with one of the dresses we brought for him, but they returned all the clothes without touching them. The nurses said there was no need to dress him (SK2)

Because of the disrespectful ways that some of the participants received their babies, one of the participants asked, "*why do doctors and nurses behave like they are not humans?*" (SK10) when a baby die. This suggests that the participants want empathetic health professionals and one participant said, "*just a little conversation about the situation and what to expect would have made a huge difference in my experience*" (SK10). The participants have no confidence in the health professionals' ability to provide sensitive bereavement care, with many even alleging that the health professionals were complicit in the death of the baby. There are multiple cases where participants said they had communicated concerns about baby movements to health professionals and instead of taking their concerns seriously, they trivialised it. As an illustration, some of the participants narrated that:

I felt that the baby dropped down in my stomach, and immediately the pattern of the labour changed... I was no longer feeling much pain at my back. When I told the nurse, she said "but I just checked you now, you are not the only patient here" (SK20)

I noticed that he kept moving for a long period and that was unusual. But the following day, he did not move at all. When I told the nurse, she told me she thinks the baby was resting after moving so much the previous day, but she never checked me. She was so wrong... I should have been properly checked (SK11)

But instead of the nurses to own up to their mistakes, they put blame on the women for not being persistent enough in their requests to get the baby checked. As a result, some participants believed that health professionals have a penchant for shifting the blame on patients when things go wrong, and one of them described that "*everyone here knows how nurses operate. When something bad happens, they shift the blame to the patient*" (SK20). Another participant (SK14) added that she has been advised to stop going to the hospital where she had her most recent stillbirth, explaining that "*people said they kill babies in that hospital, don't go there again*".

### 5.5.3 Opportunities for improvement in bereavement support

With everything that the participants have expressed through the diagrams, interviews and focus group, the central questions in the focus group discussion was to allow the participants to suggest ways of minimising the impact of stillbirth on them and for them to suggest how they would like to be supported. The participants suggested three areas where improvement can be made to ensure delivery of care that meets their bereavement needs. The first intervention that participants believed can positively impact on their experience of the loss is the need to know the details about the death of the baby, so that they can ascertain whether the baby really died and what lead to the death of the baby. This need for this intervention was expressed in the quotes below:

It is more painful when you cannot attribute the death of your child to any cause and you are left with speculations and assumptions (FGD)

The government should do their best on what causes stillbirth and how it can be prevented and controlled. Doing this I believe will help women to adjust to the loss (FGD)

The nurses and doctors must be able to discuss things like why it happened so that we won't repeat the same mistake in subsequent pregnancies. Prevention is better than cure (FGD)

Lack of honest conversations about the cause of death, especially when the majority of the babies died in the hospital means participants found it difficult to believe that the baby died. Only two of the participants [SK5 and SK10] satisfied their curiosity about the death of the baby by sneaking to where the baby was kept, and both described the experience as emotionally fulfilling because it actually assisted them in accepting that the baby was truly dead. One of the participants who went in search of the baby in the kitchen where he was kept in a plastic bag described the moment she met her child:

I took him out of the plastic, every part of his body was well formed, the head, his feet... I was just standing there with him, hoping for a miracle and telling him, why do you have to leave me, I really wanted you... I was holding on to him till my husband came to take him away... I was happy that I had that moment with him because his death became real to me and it was easier for me to let it go because I saw it with my own eyes that he was dead (SK10).

Although just two of the participants saw their babies, the positive experience that they made of it suggests that the Yoruba culture can adapt to allow women to obtain the kind of support that they would like to receive after stillbirth.

Secondly, the participants expressed a strong desire for counselling services for stillbirth loss. Participants believed that tailored individual counselling services for mothers of stillborn babies will encourage those affected to seek help, and this is described in the quotes below:

The same way there is an emphasis on antenatal care, there must be an emphasis on post-stillbirth care. The government can introduce programs that would make it possible for women to seek counselling after stillbirth (FGD)

As I was saying, if our government can have a laid down program that includes counselling services for people that have experienced stillbirth, it will be good because it will encourage people to seek help. This is because it is not all of us that get support from our families and some of us don't even have our relatives around us (FGD)

My advice is that we should forget our government. It would have been better if there are non-governmental organisations that can sensitise us during the pregnancy period about the dangers signs to watch for. The pre-knowledge about how to achieve a good pregnancy outcome is essential to prevent guilt (FGD)

The participants' desire for counselling services was not surprising considering that not all of them derived adequate support from their social circle. In line with the cultural value of continuity, the participants wanted a robust counselling services that will not only attend to the emotional aspect of the loss but that which can also assist them in becoming better prepared for subsequent pregnancies.

The third intervention recommended in the focus group is that health professionals need to be trained to provide the kind of care that meets the needs of mothers and this was expressed in the following quotes:

Nurses should be prepared and well equipped with the necessary knowledge about stillbirth because most of these problems come from nurses at the hospital. My baby was alive when we got to the clinic, and I was shocked when I was told the baby died (FGD)

People take information from health professionals seriously. The advice from home may not resonate with some of us until we hear it directly from the health professionals (FGD)

The medical professionals should not restrict their care to the medical aspect alone. They need to know how to give counselling, show empathy and say words of encouragement because the pain of stillbirth is not a physical pain that requires just medical treatment (FGD)

The participants' experience suggest that health professionals can improve bereavement outcomes for participants by being empathetic, respectful and by being active players in the bereavement process. This means health professional cannot afford to take the back seat during stillbirth diagnosis and they need to question their practice concerning the dominant perception that all women do not want to see their babies or have conversations about it. During the focus group discussion, the participants also reiterated that they would not like to be associated with interventions that require them to be part of a stillbirth support group because of the shame and stigma surrounding stillbirth. A participant in the focus group said “*ki ni idunu elewon ton so ago mo 'wo*” (FGD), which literally means that someone sentenced to life imprisonment should have nothing to be happy about. In other words, being part of a social support group is like being happy over what one should be sad over. Membership of a stillbirth support group is therefore likely to socially alienate the mother of a stillborn baby from those who would normally be sympathetic to her loss. Although some of the participants expressed that they had the need to talk to people and ask burning questions when the loss happened, they were too ashamed to go public with their concerns. One of them described that “*I did not join any Facebook forum about pregnancy and child loss because I was worried someone that knows me would see my posts*” (FGD). Likewise, there seemed to be some sentiment that home visitations by other mothers of stillborn babies that are previously unknown to the mother before the stillbirth incident may also not be an ideal way to provide support, and this is discussed in the quotes below:

No one would want a stranger to come and visit her in the house to talk about stillbirth. That is why a counselling unit will be a great idea (FGD)

I don't think speaking to another mother of a stillborn baby would have made any difference because I believe her own scenario might be different from mine. I had a problem with my boyfriend, and the whole family was against me. It is difficult for anyone to relate to what I went through (SK12)

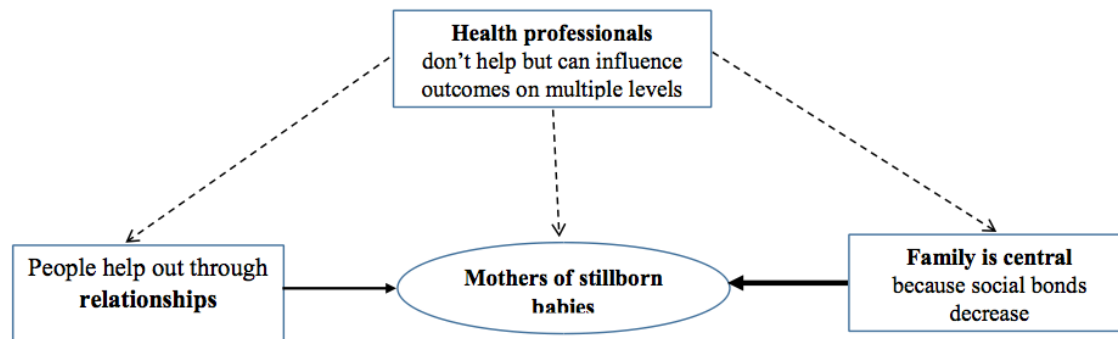
This means that bereavement care for Yoruba women needs to be individualised, institutionalised and driven by health professionals, as many participants do not want to be associated with the label of ‘stillbirth’. The bereavement needs of the participants and how it can be met therefore requires consideration of many factors and levels of care at the personal, interpersonal and societal levels to deliver effective bereavement care. Because of the difficult social terrains that mothers of stillborn babies had to negotiate to grieve in culturally acceptable ways, the following quote was explicitly chosen to end the findings of the study, as it captures what it means to be a mother of a stillborn baby in a Yoruba community:

Grieving as a mother whose child passed away is very tricky and challenging. On the one hand, you cannot move on too quickly because people expect a lengthy and genuine portrayal of soberness from you... your conduct should convince people that you were truly and deeply pained by the loss. On the other hand, you also cannot dwell on it for too long, because people expect you to be grateful for your own life... So, grieving a stillborn child is like a performance, the timing of your re-entrance into the society, the way you carry yourself and your countenance must genuinely reflect your sadness but also your gratitude... Performing this role is hard (SK13).

## **5.6 The outcome space: Seeking a positive pathway for stillbirth bereavement**

From the data presented above, an outcome space, which is a diagrammatic representation of the understanding of the roles of social capital in the participants’ experience of stillbirth was derived and presented in figure 36 below:





*Figure 36: The outcome space*

The outcome space above is a map of relations between the categories of description that represents the collective understanding of the roles that social capital played in the participants' experience of stillbirth. The outcome space revealed that the family played central supportive roles after stillbirth and the reason for this was because of the decrease in social bonds, as well as the unique position and advantage of the family in being physically present during the crisis. Through the participants' relationships with others, they gained spiritual support, some material support such as assistance with chores and as well as encouragement and empathy. Although the role of health professionals was an unexpected finding in this thesis, it is such an important finding that it is powerful enough to change bereavement outcomes for mother of stillborn babies. This is because health professionals have an influence on the participants, their families, as well as the public understanding and engagement with stillbirth issue. From the participants' own account, health professionals need to be adequately prepared to provide empathetic care, while also showing an understanding of the immediate and longer-term psychosocial impact of stillbirth. This is because health professionals can assist mothers of stillborn babies to adjust to the loss through a positive pathway by preparing them to deal with the social expectations of the loss such as relationship changes, decrease in social bonds and the expectation that people may give less after stillbirth.

## 5.7 Summary

Four main categories of description that represent the role of social capital in the participants' experience of stillbirth was presented in this chapter. These categories are: relationships change,

relationships matter, material support help and health professionals neither help nor support. These categories were logically presented to give an idea of how the social networks of the participants reacted to the loss of their babies. The outcome space was presented to highlight the connections between the categories, and it emphasised that the family was the central supportive figure for the participants and that relationships matter for the participants. However, the health professionals have an enormous opportunity to influence the stillbirth bereavement outcomes for the participants because of their unique position in the community. The next chapter presents a summary of the findings, implications of the findings, the contributions of the study to phenomenography and social capital theory and the recommendations for nursing practice, future research and health policy.

## **Chapter 6: Discussion and conclusions**

### **6.1 Introduction**

The chapter presents the discussion of the findings of this study. The purpose of this study was to understand the role of social capital in Yoruba women's experience of stillbirth. To this end, the previous chapter provided a detailed account of what the research discovered with respect to the role of social capital in the experience of stillbirth for these Yoruba women. This chapter is organised to first provide a summary of the findings, and then goes on to present the implications of these findings which were derived from reflecting on these findings alongside current understandings espoused in the literature and which therefore make a contribution to how support for mothers of stillborn babies may be understood and improved not only in Nigeria but globally. There are three key areas that are revealed. These are: (1) relationships, and all the benefits that they bring, get smaller, but become more intense; (2) culture really matters in terms of how stillbirth grief is expressed and supported; and (3) there is a real deficit of kind, compassionate and skilled nursing/midwifery care for these mothers and their families. This chapter also includes a discussion on the contribution that this study made to phenomenography and social capital theory. In conclusion, there was a list of recommendations for nursing education and practice, for future research and for health policy.

### **6.2 Summary of the findings**

This study aimed to understand the role of social capital in Yoruba women's experience of stillbirth. To achieve this aim, four objectives were laid out, which were to: identify the social networks of mothers of stillborn babies; examine mother's description of received support; understand the bereavement needs of mothers and to bring attention to social capital analysis. The findings of the study yielded four broad categories and 11 sub-categories which helped in fulfilling the study aim and objectives. The first category of description was about the changes that happened to mothers' social relationships after stillbirth and this was reflected in the three sub-categories which revealed that mother's experienced stillbirth in diverse ways, but that a decline in their social bonds is what led to the emergence of the family as the main support network for stillbirth grief. The second category of description, which was about the value of social relationships was presented to illustrate that even though mothers experienced a decline in their social bonds, it is their relationships with others that made them receive empathy and encouragement, advice to

move on and spiritual support and these were the three sub-categories. The third category was presented to illustrate that even though material support makes a difference after stillbirth, mothers have little of such support. This category was presented in two sub-categories that illustrated that people give less if a baby is stillborn and that the limited support that mothers received were confined to domestic chores, which did not reflect their need for material support. In the fourth and final category, it was shown that health professionals neither help nor support and this was illustrated in three sub-categories that exposed the failure of health professionals during the breaking of the news and their inability to provide the kind of care that mothers wanted. These led to lack of trust in health professionals' competencies and also prompted mothers into identifying changes such as better communication about the cause of death, the need for bereavement counselling for mothers of stillborn babies and the need for training for health professionals that can be implemented for better bereavement care.

Some of these findings mirrored what has been reported in the literature. As an illustration, some studies have reported that mothers suffer relationship loss after stillbirth (Cacciatore, 2007; Cacciatore et al., 2008; de Montigny et al., 1999; Hazen, 2003) and others have also revealed that family is the most important support for mothers of stillborn babies (Obi et al., 2009; Cacciatore et al., 2009; Raitio et al., 2015). The findings of this study also supported other studies that reported that women mostly receive support in form of sympathy, companionship, listening and encouragement (Allahdadian et al., 2014; Sutan & Miskam, 2012; Tseng et al., 2014), but less material support (Kiguli et al., 2015; Malacrida, 1999). This study also added to the growing evidence in the literature that continues to demonstrate the substandard care that mothers receive after stillbirth in the hands of health professionals (Adebayo et al., 2018; Mills et al., 2016; Modiba and Nolte, 2007). However, while the findings of this study confirmed what has been reported elsewhere, the ways through which Yoruba culture and the contextual social conditions of the setting interacted to force changes in the participants social relationships differs from other studies. This means the findings take on a different dimension due to contextual realities and as a result, the next section discusses the implications of these findings.

## **6.3 Implications of the findings**

### **6.3.1 Relationships and all the benefits that they bring get smaller but more intense**

The social support that mothers of stillborn babies received in this study was from a few individuals, mostly family members. By losing the support of informal networks such as friends, neighbours, and colleagues, and the absence of formal support, the participants were forced into relying on the family. While it is a good thing that mothers maintained or strengthened their relationships with family members, this finding needs to be placed within the broader context of the Yoruba culture. Saki community, like any other Yoruba communities, operates on the premise of communalism (Jegede, 2009) and this means the extent to which the family can help is dependent on the resources that they can get from the community. As an illustration, the function of burial ceremonies for good deaths in Yoruba culture is to reconnect the bereaved family with relatives, friends and the broader community so that they can obtain necessary support needed to cope with the loss. This means the family receives their support from the wider community and that is how they can effectively support the bereaved mother. From this perspective, one can argue that stillbirth bereavement led to the isolation of the family unit because the strong social and cultural norms put constraints on what the family can access from the community. Likewise, the need for support and the obligations placed on the limited family members who were available to provide support may not be practical in the long-term because family members may not be able to stay off work to be with the bereaved mother for a prolonged period. Thus, even though the community frames stillbirth as the problem of the individual mother, the inability of family members to fulfil the intense need for support will eventually lead to cracks in family relationships, as experienced by some women in this study.

Networks are built and developed in reaction to a threat, and while the participants in this study mobilised the support of their family members, the threat of stillbirth did not result in the formation of any new social networks, even among those who did not have the support of their family. Other studies (Cacciatore et al., 2009; Chung & Reed, 20017; Haws et al., 2010) have also confirmed that the isolation of women after stillbirth have encouraged stronger bonds with family members and others have found that loss of social networks have pushed mothers into seeking alternative forms of support beyond the family (Cacciatore, 2007; Inati et al., 2018; Kelly & Trinidad, 2012). The reason why women in this study did not form new networks or access any support beyond the

home can be attributed to the absence of formal and informal support outside the family. However, it also reinforced that the community was not the basis of social capital for mothers in this study and this hurt the ability of the family to be a reliable source of support. Bruegel (2005) has argued that social capital is not about adhering to one's family values, but rather, it is about the connectedness and shared values formed across many different groups. Thus, even though the sense of shared identity that mothers formed with their families unify them, it dissociates them from the wider community.

The lack of social capital at the community level undermined the ability of the family to generate the kind of support that will benefit the mother in the long term. This means that even though the participants of this study received social capital from their families and few close friends for survival, it does not imply they have the power to alter the broader context where the real threat exists. While acknowledging the limitations of family-only social capital, some (Bruegel, 2005; Ferlander, 2007; Portes, 1998; Putnam, 2000) have suggested that it can be a stepping stone to change. But with the family also isolated, it may be difficult for Yoruba women to achieve any change by relying solely on their family. This suggests that the family-only support has limitations in the context of this study, because despite been a powerful source of encouragement, empathy and companionship, this form of support did not connect mothers with other services or support. Thus, the support that the participants in this study did not receive might be as important as the support they received and also signalled the precarious situations that mothers without the support of the family will face after stillbirth.

The emergence of the family as an important source of support in both resource-poor contexts like Nigeria and high-income contexts where strong formal and informal stillbirth bereavement support exist, suggests that family support is very important to mothers. One reason for this may be because of the strong sense of reciprocity and moral obligation that the mother may have built with family members before the incident. While the support of the family only, may not be sufficient in both the short and long term, as demonstrated in this study, it is important to identify how the presence or the absence of family networks can impact bereavement outcomes. This is important because of the conflicting research findings regarding the impact of certain social networks after stillbirth. As an illustration, some studies have reported that the support of the family was the only form of support that minimised the risk of anxiety and depression after stillbirth (Cacciatore et al., 2009;

Obi et al., 2009), while others have said it is the support of friends (Chung & Reed, 2017; Sutan et al., 2010). These conflicting findings suggest that in stillbirth bereavement, mothers of stillborn babies may have a broadened definition of family, which might include people outside the traditional definition of family. As such, it is important to understand an individual mother's definition of a family and what support means for them. For instance, one of the reasons why mothers who were interviewed in this study abandoned certain relationships was because of lack of support or inadequate support. The high expectation that mothers have in certain individuals might mean that their relationships with such individuals transcend friendships or casual relationships. These kinds of relationships need to be defined because their presence or absence can negatively impact bereavement outcomes. Even within the context of this study, some individuals like boyfriends, who are not traditionally included as members of the family, had significant negative impact on the bereavement experience because of their lack of support. This blurring of the lines between relationships that mothers have with others, needs to be taken into consideration when caring for mothers of stillborn babies.

### **6.3.2 Culture really matters in terms of how grief is expressed and supported**

The findings of this study provided an insight into the cultural perspective of stillbirth among Yoruba women in Nigeria, by introducing how the Yoruba culture shaped mothers experience of stillbirth. The experience of the mothers in this study which included an absence of funeral ceremonies, memory making, body viewing and socialisation among sympathisers revealed the categorisation of stillbirth as a bad and insignificant death in Yoruba culture. None of the women in this study was given a chance to see their stillborn infants. Those who saw their babies did so on their own volition by defying the odds. The separation of the stillborn infants from their mothers immediately after birth was done to remove the woman from the experience of stillbirth. As a result, mothers do not have any tangible experience of the baby and the only experience they hold on to is that of the chaos surrounding the death.

The separation of the mother from the baby, as well as preventing mothers from knowing the details about the child's burial fits both the cultural beliefs that stillborn babies are not meant to live and that the child would not have benefitted the mother in any way if he or she had lived. Yoruba culture believes that the stillborn infant is possessed with an evil spirit and the mother must do everything possible to separate herself from the child. This is the main reason why mothers

are denied any memory-making opportunities because it goes against the acceptable way of grieving, which is to sever ties with the child. The absence of rituals is therefore designed to help mothers cope with the loss. Although women believed that it is impossible to forget the loss, the goal is to try and live as if the loss never happened. This is because holding on to it is believed to be unhelpful in the cultural sense. From this perspective, holding remembrances for a stillborn baby is not a culturally appropriate way to support Yoruba mothers of stillborn babies, and this is a sharp contrast to other contexts where remembrances are seen as a form of compassionate care (Kelley & Trinidad, 2012; Yamakazi, 2010).

Stillbirth grief is placed lowest on the scale of grief in Yoruba culture, and this is buttressed by the 'pot and water' ideology, where the death of the pregnant woman is the real tragedy and not that of the stillborn infant. This explains why women in this study balanced their pain with deep gratitude for their own lives, and one way of showing a sense of gratitude is by detaching oneself from the child that has died. As a result, keeping of memorabilia, mementoes or talking about the experience does not reflect the mother's readiness to heal from the loss. It has been reported in other studies that women value the preservation of the memory of stillborn babies by keeping memorabilia such as photographs, footprint or any other tangible item as a form of remembrance (Gravensteen et al., 2013; Sun et al., 2014). Some cultures in Japan (Yamakazi, 2010) and Taiwan (Tseng et al., 2014) also encourage rituals because of the belief in the continued existence of the stillborn infant. Other studies have also reported that keeping memorabilia or observing some forms of rituals help mothers and their social networks in acknowledging the loss (Erlandsson et al., 2013; Lindgren et al., 2014). This is however not the case in Yoruba culture, as the women in this study find the idea of keeping memories in the form of memorabilia not only strange but also unnecessary and counterproductive to the grief resolution that they were pursuing. From the Yoruba ontology, the only thing that can fill the void left by the stillborn child is another child, and this explains why there was so much emphasis on having another child. Thus, having memorabilia is unhelpful at the intrapersonal and interpersonal level because it does not allow discourse about the loss. This is because in Yoruba culture, a woman cannot be a mother to a dead child and a woman will never count a stillborn infant among her children.

As far as the community is concerned, the stillborn infant is not a child, and this is why the words 'child' and 'mother' are not part of the greetings for mothers of stillborn babies. Thus, a Yoruba



woman is likely to pick offence if anyone tries to attach ‘personhood’ to the stillborn child. This might explain why Yoruba women find the idea of support groups strange because apart from having little memories of the baby itself, conversations that bring the dead back to life is a clear sign of pathologic grief, which will attract a stiffer penalty of stigma from the community. Thus, the cultural explanations and ideological beliefs about stillbirth emphasised the embrace of attitudes and values that demotivate people from joining a stillbirth support group. This may, therefore, explain why women preferred individual counselling session to support group. Unlike in other contexts where the acknowledgement of the stillborn child is a sign of sensitive and respectful care (Blood & Cacciatore, 2014; Hazen, 2003), what Yoruba mothers want is an acknowledgement of the efforts that went into trying to achieve motherhood. This means a mother is more likely to appreciate conversations about the pregnancy itself, how the labour started, how she learnt about the death, and her plans for subsequent pregnancies, than conversations about the child that died. These conversations can help women derive meaning because it allows them to reflect on what they could have done differently, and this is a big step towards the acceptance of the loss.

Women in this study expressed the desire to see the child out of curiosity, and this suggests that in the future, Yoruba women may have a tangible experience of their babies that they can talk about. While this finding is a sign that no culture stays the same, the main reason why the women in this study wanted to see their babies was to satisfy their conscience that the baby indeed died. Unlike in the past where the words of a traditional birth attendant mean absolute truth and will never arouse any doubt or foul play about the survival of the child, healthcare professionals continue to be in the news for unethical conduct. As an illustration, as recent as this year, the whole country was shocked to wake up to the news that two nurses were apprehended for deceiving a woman into believing that she had a stillborn, only to later found out that the child was not stillborn. One of the online News outlets that carried the story narrated that

Two nurses have been arrested for allegedly selling a woman’s baby and deceiving her that she had a stillbirth... The suspects were alleged to have told the baby’s parents that it died and they buried the stillborn to save the family the trauma... Trouble started after the woman’s family insisted on seeing the body, but the nurses could not provide it, claiming that the baby’s head was bad (Igbonwelundu, 2019, p. 1).

As poorly as this scandal reflects on the healthcare system, it also highlights the desperation that Nigerian women will go through to have a child and why lack of opportunities for viewing of the body of stillborn babies by the mother and her family may be abetting unethical practices by unscrupulous health professionals. However, while more women are now expressing the need to see their stillborn infant, the purpose of this is to satisfy the fact memory that the death did occur and not to recount the experience. This is because, from the Yoruba worldview, there must be a severance of the bond between what has been lost (stillbirth infant) and the restoration that the woman is trying to achieve through another pregnancy. But to leave the memory behind, the woman must be certain that the baby really died and this is expressed in the popular Yoruba saying that ‘omo eni ku san ju omo eni sonu’, meaning that it is better for someone’s child to die than to be missing. Scandals about swapping and selling of babies that are now becoming common in the healthcare system are unlikely with home births and could explain why women would previously accept the baby’s death without having to see the body. Women without the opportunities of confirming the death and where family members were not given the body would, therefore, seek help for a logical explanation about the cause of death and the strategies to achieve successful pregnancies in the future, but not about the experience itself. This may be different for women in other contexts or cultures where validation of the existence of the baby is an important part of successful grieving and counselling.

There is a clear indication in this study that the Yoruba death taboo, which forbids a woman from knowing the gravesite of her own child still holds steady, as women in this study expressed no desire to be part of any burial arrangements or even to have knowledge of the gravesite of the stillborn infant. The cultural norm against burial arrangements for stillborn babies may be due to the high prevalence of stillbirth in Nigeria as a whole. With the widespread prevalence of stillbirth and the low economic status of mothers who are most impacted by stillbirth, the need for burial ceremonies could add undue hardship for mothers who might have been impoverished by pregnancy and childbirth. Some of the women in this study have experienced stillbirth on multiple occasions, and while this alone is seen as a form of shame and maternal incompetency, it may be impractical for mothers to organise burials that would match the status of ‘good’ deaths. As such, the cultural norm that treats stillbirth grief as insignificant may be protective and realistic to the socioeconomic conditions of this Yoruba community and also means that stillbirth may move up in the hierarchy of grief if it occurs less frequently. This research has really highlighted that notions

of grief and loss have strong cultural frameworks. The challenge is to provide care in this context that is both respectful of current cultural norms yet manages to respond compassionately and actively to what is a shared human experience.

Based on the findings of this study, I would agree with other scholars that the value of seeing the body of the stillborn infant is valuable regardless of the context in which the mother finds herself. However, this study adds that seeing the baby may mean different things to different women. For some women, it is about memory making, while for some, it is about confirmation of the death. As such, things like seeing or holding the stillborn baby will have personal, social or cultural dimensions and this means the individual needs of the mother and her family must be considered within the context of the loss. It is important for those caring for mothers of stillborn babies to realise that while culture may mean how things are seen to work in certain places, culture, in the context of stillbirth may mean all behaviours that may or may not improve support for mothers. As such, while there is a tendency to use the cultural frame of the individual mother affected by stillbirth as a premise for culturally-competent care, those working with mothers of stillborn babies may also need to recognise that their own behaviours, guidelines and utterances are part of what mothers interpret as the cultural context of their grief.

Although demonstrating awareness of a mother's cultural beliefs in relation to stillbirth may promote trust, this does not mean one is necessarily culturally competent to provide care for that woman. As such, there is a need to move beyond what culture prescribes for a mother after stillbirth, to conversations about what the individual mother feel about the way things work within the context of the loss. With increasing globalisation, more women from collectivist societies like Nigeria are finding themselves in individualistic societies. But because culture itself is constantly evolving, one may contribute negatively to how a mother would experience stillbirth by assuming that the best care would be the care that fits the cultural frame within which a mother identifies. It is much more complex than that. This study indicates that, given the importance of culture and the consequences of cultural issues, those working with mothers of stillborn babies need to understand that culture serves both as a critical tool to communicate and collaborate and as a lens through which to provide individualised and culturally competent care.

### **6.3.3 There is a real deficit of kind, compassionate, and skilled nursing care**

There is increasing awareness in the Saki community and as well as other parts of Nigeria that childbirth is safer when attended by health professionals. Thus, there are increasing numbers of women giving birth in healthcare facilities, and this is also mirrored in this study as 19 out of the 20 participants delivered their stillborn infants in healthcare facilities. With more women achieving successful birth outcomes in healthcare facilities, the traditional model of childbirth is slowly being replaced by the medical model of childbirth and this has also contributed to a slow deconstruction of the traditional narrative where pregnancy outcome is seen as something due to chance or where stillbirth is seen as a form of evil spirit. Thus, unlike before, where a stillbirth was explained as a child that did not want to live, many women now know that a child can die from many causes such as prolonged labour, cord around the neck or malposition. The medical version of the cause of stillbirth is not only logical for women but also resonates with women who do not want to live with the thought that they are being targeted by the evil spirit of an 'Abiku' child. As a result, women and their families are increasingly putting their trust and faith in the conventional healthcare system, and women who fail to deliver at the hospital or misses antenatal care may be blamed for negligence by others in the community.

The shocking lack of compassionate care from health professionals that was exposed in this study is comparable to what Kutu and Ilesanmi (2011) reported from their study among Yoruba women, where only three out of 45 mothers of stillborn babies considered the healthcare system as supportive after stillbirth. The failure of the health professionals to provide women with an acceptable level of care means that the women in this study were doubly disenfranchised because they are unable to derive meaning for their losses from the same healthcare system that has encouraged them to abandon their indigenous traditional childbirth practices. This means women are left with no strong framework to process their grief because the traditional framework has been portrayed as inadequate for childbirth practices. The void created by the inability of the health professionals to have an honest and compassionate conversation with mothers about the death did not only lead to the erosion of trust but also means the healthcare system failed to reward the trust that women have in their ability to provide decent and compassionate care.

The incompetence of health professionals in meeting the bereavement needs of the mothers through lies, false assurances, and insensitive comments made readjustment more difficult for

these women. Similar to other studies (Alladdadian et al., 2016; Kelley & Trinidad, 2012; Modiba & Nolte, 2007), women in this study wanted to experience the human and emotive aspect of medical care that recognises their journey towards motherhood, and that can accommodate the emotion surrounding the loss of a valuable entity. This study adds to the growing number of international studies about the substandard care that women receive at the hands of health professionals after stillbirth (Adebayo et al., 2018; Brierley-Jones et al., 2014; Gopichandran et al., 2018; Kelly & Trinidad, 2012; Sereshti et al., 2016). However, this finding is worrisome in the context of this study because health professionals are aware that the patriarchal nature of Yoruba societies have created a situation where having children is widely seen as a viable way for women to gain access to power, resources and inheritance. The value of children for women is apparent in the customary laws of Nigeria, and this is reflected in Olueze's (2004, p. 136) interpretation of inheritance law in Nigeria:

In most cultural jurisdictions in Nigeria (particularly the Ibo, Yoruba, Benin and Urhobo), the wife or widow of a deceased does not come within the meaning of the term 'member of the family'... The right of a widow to reside in her deceased husband's house [is] by virtue of her children's interest.

This means that a woman can lose everything that she has worked for all her life, just because she does not have children. However, while this study exposed the social context within which interactions occur between health professionals and mothers of stillborn babies, it is worrisome that the knowledge that the health professionals have about the context did not translate to compassionate and empathetic care. This suggests that the care provided by health professionals did not reflect the cultural realities of stillbirth loss and the impact it has on the woman. The implication of this is that health professionals who are supposed to be patient advocates are also contributing to their disempowerment. The finding of this study, therefore, paints a grim picture of the current ability of health professionals in Nigeria to provide culturally safe and competent care for mothers of stillborn babies. But while it is unfortunate that health professionals' knowledge of the cultural context did not benefit mothers of stillborn babies, this finding may also signal health professionals burnout and compassion fatigue due to the prevalence of the issue. The bluntness and indifference of health professionals to the suffering of the women in this study may

be an indication of burnout, but may also reflect the inadequacy of the nursing and midwifery curriculum, which is still heavily reliant on sometimes irrelevant and outdated Western concepts.

#### **6.4 Contribution to phenomenography**

This study contributes to the methodology of phenomenography by being the first study to apply phenomenography to the issue of stillbirth. One of the advantages of employing phenomenography for this study was the natural fit between the epistemological assumptions of phenomenography and the theoretical ideas of social capital. Phenomenography studies the interrelationship between the individual and the experience in order to identify how individuals conceive various aspects of their reality (Marton, 1986). The interrelationship between stillbirth phenomenon and the women who experienced it are the people who made the participants experienced stillbirth the way they did. As an example, an unmarried woman who had a terrible experience because of a lack of partner support had such experience because of the actions of the spouse. As a result, approaching this study from the phenomenographic viewpoint assisted in focusing the study to capture the relationships that made women experience stillbirth the way they did and also allowed the findings to reflect the context of the experience. Thus, phenomenography allowed the findings of the study to reflect the role of social relationships in the experience of stillbirth in Saki.

Likewise, the need to present the findings of a phenomenographic findings through an outcome space, a distinct feature of phenomenographic methodology means that the data analysis was not only rigorous but also involved repeated analysis before the relationships between the categories were derived. In this study, the outcome space was presented to illustrate that the family was the most important source of support and that the support that social relationships made available for mothers in this study was limited. Even though the healthcare system was not supportive, its potential to transform the outcome of stillbirth bereavement was highlighted by placing it over the participants, the family and the social networks of the participants. Thus, the outcome space assisted in articulating and communicating the key findings of the research in a logical way. Because phenomenographic outcome space involves the interrelationships between the key concepts in the findings, Marton (1981, p. 180) has argued that phenomenography allows the communication of both the “conceptual and the experiential” (Marton, 1981, p. 180) aspect of the lived experience of stillbirth from a Yoruba perspective. Concerning the outcome space, Marton (1981, p. 194) argued that it is “*generalizable between situations*” and this is another strength of

phenomenography because similar studies with populations of mothers of stillborn babies whose sociocultural environment is similar to that of Yoruba people should be able to replicate the outcome space derived in this study. This means that the findings of phenomenographic research may have better transferability than other qualitative approaches because the outcome space provides a basis for comparison with other studies.

However, the focus of phenomenography and phenomenographic interviewing technique is *“neither on the person, nor on the theme, but rather on how the theme appears to, or is experienced by the person being interviewed”* (Bruce, 1994, p. 50). As a result, the strength of phenomenographic interview approach is that it allows the capturing of the relational aspect of the experience of stillbirth and this means it assisted in understanding how mothers perceived the roles of others in their experiences. This means the findings of this study did not reveal the mothers’ *“reflective attitude”* (Richardson, 1999, p. 61) nor *“the mental processes of the respondent”* (Bruce, 1994, p. 49). As an illustration, mothers in this study talked about mothers-in-law, ex-boyfriends, health professionals and so many others that let them down or that supported them, but they spoke less of their own personal experience. As a result, researchers who are interested in the feminist critique of phenomena, and as well as power imbalances in relationships may find the result of phenomenographic research less useful because phenomenography focuses less on the person who is experiencing a phenomenon. So, while the social norms that led to the loss of relationships, and prevented women from forming social connections outside of their family can be framed as an issue of a power imbalance between women and the wider community, this aspect of the experience was not reflected in the findings. The lack of attention to power imbalances in social capital research and theory, especially when the research involves women have been the basis for the feminist critique of social capital theory.

In retrospect, having recruited participants into a phenomenographic study, I realised that it is important for the researcher not to use the current circumstances of the participants as a yardstick of variation. Rather the participants' circumstances during the experience itself may be the source of differences. The lenses that the mothers of stillborn babies were using to analyse and discuss their experience reflect the situation that they were at that period of their lives which did not necessarily reflect their current circumstances. As such, selecting participants based on their current features may not lead to the uncovering of the full range of differences. While I based my

purposeful sample strategy on differences in parity, marital status, socioeconomic situation and even age, I did not consider that the participants would describe their experiences based on their situations somewhere between 36 or 6 months ago. As an illustration, some of the participants who experienced stillbirth negatively because of lack of material support were in a better financial position during the time of their interviews. Because social norms are against the exchange of gifts in stillbirth bereavement, the issue of material support will not be an issue for mothers who are well off when they suffered stillbirth. Thus, the strong need for material support that emerged in this study may be silent if the sample mostly consisted of mothers with high socioeconomic status. As a result of this, it is possible that not all the differences in the experience of stillbirth was captured in this study. Hence, even though Marton (1988) described the goal of phenomenography as seeking for and capturing the totality of the different ways that a phenomenon is experienced, I am unable to make that claim based on the sample and the context of this study.

Looking back to the research process, I realised that the context (Saki) in which the experience took place had some implications for the methodology. Although the participants differ in some ways, the fact that they experienced the loss within the same context means the variation uncovered in this study may still be limited. As an example, no number of children can be too much for a Yoruba woman because of their cultural value of continuity. This means that the cultural context has imposed a kind of framework on how the participants perceived the experience, and this may even produce similarities instead of differences. This means that when using phenomenography to study a contextually-bound experience, finding the differences will depend on the kind of evidence that the researcher is looking for in the data when trying to describe it. As a result, the phenomenographer must realise that a phenomenon may vary from concrete to abstract. As an illustration, the two women who have had hysterectomies alongside stillbirth had a concrete experience of double tragedy (loss of a child and reproductive ability), but how they were supported can be described as an abstract experience because one of them even said people did not even acknowledge loss because of the complications that followed.

Phenomenography's position on relationality, which prioritises the experience more than the individual was difficult for me during this analysis. I found it hard during my analysis to think of my transcripts as a collection of experiences and not the individuals who provided the experience. This is even more important because one has to interpret the experiences instead of just



summarising them. So, even though phenomenography focusses on the experience and not the individual, I did not believe that one can understand the experience in isolation to the person with the experience, especially when one is dealing with an issue like stillbirth which is highly personal and sensitive to the mothers. In this study, I took an empathic stance, and I used my knowledge of the participants and the context of the experience to paint a real picture of the participant's experience of stillbirth. As a result, healthcare researchers may experience tension between the philosophical position of nursing and midwifery which is premised on caring for the individual experiencing a phenomenon and the epistemological position of phenomenography which is focused on the experience itself. This dichotomy between the caring philosophy of nursing and the epistemological assumptions of phenomenography may explain why phenomenography has been more used in educational settings.

Also, despite that a range of possible data sources such as observations, drawings and products of work such as buildings have been used to collect data in phenomenographic studies (Marton, 1988), interviews are the most likely to generate the differences in experiences because of its interactive nature. Focus groups are not commonly used in phenomenography because it does not give the interviewer the flexibility to constantly check on the meanings being attributed by the participants (Bruce, 1994), making it less likely to generate differences in experience. In this study, the focus group did not have the interactive element of the phenomenographic interview because the purpose of the focus group was aimed at the participants' collective idea of how better bereavement care can be provided. Also, the focus group discussion was also self-driven by the participants, and there was no opportunity to probe or follow up on the responses of the individual participants. This means that the differences in the conceptions of experience that were presented in this study were elicited at the level of the interviews and drawing narratives, even though the whole dataset was analysed as a whole. There is little information about how differences can be discovered from focus group data and other methods like observations, and it is important for phenomenographers to address such methodological issues so that phenomenography can evolve to accommodate data from varying methods. This can enhance the robustness of phenomenographic findings and as well as rigour in phenomenographical methods.

## **6.5 Contribution to theory**

This study is the first to apply the theory of social capital to stillbirth bereavement, and the findings of this study contribute to the understanding of social capital theory. The theory of social capital was helpful in identifying the type of social connections that women used in dealing with the problem of stillbirth and also allowed an understanding of how lack of reciprocity and trust in social relationships can collapse and transform the social networks of mothers of stillborn babies. Even though women in this study derived only limited resources from their social relationships, the findings of this study still confirmed that access to social resources is dependent on social ties. However, the utility of social capital theory would need to be re-considered in highly cultural contexts where social conditions stifle the ability of individuals to form of social capital. In this study, one of the obstacles to effective mobilisation of resources was the social sanctions and norms against stillbirth, and these sanctions are what made mothers depend entirely on family ties. The reliance on family social networks undermined the central idea of social capital because it prevented women's access to resources at the community level. As a result, social norms and reliance on the family was a barrier to social inclusion and instead of the issue of stillbirth to unite the community, it created a divide between the family and the community.

While this disadvantage of social capital is context-specific to the setting where this study was conducted, the question now is how mothers of stillborn babies can overcome the adverse effects of social capital. This question is important because the strong connections and bonds that women formed with their families cannot influence change and influence at the community level. Coleman (1995) have extensively discussed the potentials of cultural capital and cultural ideology as capable of helping minorities and disadvantaged populations to negotiate their marginalities. From the perspective of Coleman (1995), cultural ideologies encourage people to act in the best interest of others. Indeed, even in Saki community, many associations, clubs, vigilantes and women groups have been formed because of cultural ideologies and some peculiar challenges. As an example, there are many associations, and support groups for widows and these groups of women have successfully fought the customary laws that disentitle women from inheritance. Using both cultural capital and legal avenues, women are now securing rights to inheritance, power and position that they previously did not have access to.

However, this is not the case for stillbirth grief, and the reason why the social norms are so powerful in the case of stillbirth is the value attached to motherhood and stillbirth's ability to make women feel a sense of personal failure. Also, the assumption that the child can be replaced has created the belief that the solution to the problem is to get pregnant again. This approach to grief resolution effectively makes the problem of stillbirth a personal issue and not a community issue. As a result, the understanding of social capital and how women can benefit from it cannot yield any fruitful debate without first understanding the social norms that are perpetuating the disadvantages that women face after stillbirth. From the perspective of this study, social capital is only an aspect in the varying sociocultural process that is shaping the experience of stillbirth and cannot be a solution to the problem because of lack of community engagement with the issue. While the finding of this study may generate debate on social capital building between the mothers and the community, it also points to the contextual limitation of social capital theory. While joining a stillbirth support group or having access to bereavement counselling have been identified with better bereavement outcomes in western countries (Cacciatore et al., 2009; Inati et al., 2018; Kelly & Trinidad, 2012), Putnam and Coleman's ideas of social capital are silent on those individuals who are excluded from accessing resources because of certain norms. As an illustration, women in this study said they would access counselling services if it were available, but this was not possible because it was not there. As a result, the idea of social capital in the context of African populations may need to be broadened or re-conceptualised to reflect the realities and constraints of these contexts and as well as identifying family networks as a real form of social capital.

The findings of this study also signal some of the implications of social capital as a theory of social relationships. As an illustration, Putnam made a distinction between bonding (family relationships) and bridging (formal relationships). In the classic research of Coleman (1988), a group of parents and teachers whose children were attending the same private school were conceptualised as bonding social capital because of the sense of community and norms that made them relate with each other as members of a family. However, while the distinction between the forms of social capital may seem straightforward theoretically, its application in research is not straightforward. This is because the construct of social relationships itself is hard to define. Apart from being dynamic, social relationships are also context-dependent, and this suggests that the meanings that people attach to their relationships are not static. As an illustration, if I had not asked the participants to define their social networks based on whether they are family, friends, colleagues,

it is possible that the participants might have conflated formal and informal relationships. This is even more relevant in the context of Nigeria, where social cohesion and communalism means it is not unusual for an individual to refer to a friend or colleague as a family. With this fluidity in the meanings that people attach to their social relationships, conceptualising social capital based on types or forms such as bonding or bridging is unlikely to yield any useful debate, and this might explain the conflicting findings about the impact of social capital on health and wellbeing.

Thus, the use of constructs such as trust and reciprocity may be more realistic ways of engaging in the social capital debate, especially in communities with deep-rooted cultural beliefs and norms. In retrospect, the findings of this study and analysis of data were more straight forward because cultural norms prevented mothers from forming new relationships and also, there was no formal or informal support like support groups available in the context. As such, the heavy reliance on the family was easier to recognise and conceptualise. If support such as counselling or support groups were to be available, I would have been faced with fitting several types of relationships, both conventional and unconventional into either bonding and bridging and this may have ended up leading to findings that failed to reflect the realities of the participants. So, for instance, if a participant sees a colleague as a family member and the colleague is coded as a family, then one would have lost the debate on the essence of social capital which is based on relationships with people outside the home.

## **6.6 Recommendations**

### **6.6.1 Recommendation for nursing practice and education**

This study provides some insights for nurses and midwives who are seeking to provide culturally safe and competent care for mothers of stillborn babies. There are current discussions and efforts between the International Stillbirth Alliance (ISA) and the WHO on a soon to be released consensus document on the Global Bereavement Care Package for stillbirth (de Bernis et al., 2016; Shakespeare et al., 2019). This Global Bereavement Care Package is a set of recommendations for health care professionals working with women. I contributed to the consensus document through completion of surveys and membership of the Stillbirth Advocacy Working Group, which is a working group of the ISA. As such, these recommendations proposed in this study can contribute

to the global understanding of stillbirth bereavement. The following recommendations are proposed for nursing practice and education:

- Health professionals working in cross-cultural settings need to be aware of the subtle cultural differences about stillbirth and its implication for the expression of grief and what supportive care will look like for the particular mother.
- Health professionals need to explore strategies of harnessing the strength of the family when dealing with women from collectivist communities, as that may be the only form of support available to them.
- Health professionals must incorporate reflexivity into their practice so that they can be more aware of how their behaviours, comments, and gestures can contribute either negatively or positively to the bereavement outcome after stillbirth.
- There is no better time for nursing educators to pay attention to nursing and midwifery curriculum and address the neglect of cultural realities of stillbirth bereavement.
- The curriculum of nursing and midwifery need to incorporate family-centred approaches to bereavement care, and this can only be achieved by focusing on the partnership with mothers and their families and through the promotion of empathetic models of practice.
- The curriculum of nursing and midwifery should be flexible enough to accommodate the changing needs of mothers, while also promoting skills necessary for translation of research to practice as a means of providing robust health education during pregnancy and after stillbirth.
- Health professionals need competency in developing comprehensive care plans that acknowledge the cultural and religious beliefs of mothers and harnessing this to build the resilience of mothers.
- Unmarried women, those with recurrent stillbirth and those expressing shame should be identified as having additional risk factors for poor bereavement outcomes.

#### **6.6.2 Recommendations for future research**

- Since it is believed that the outcome space of phenomenographic research can be replicated in similar contexts, it would be interesting if similar studies with other ethnic groups in Nigeria and elsewhere can replicate the outcome space derived in this study. The

replicability or non-replicability of the outcome space of this research will benefit the methodology of phenomenography.

- Future studies should explore burnout and compassion fatigue among childbirth professionals in Nigeria.
- Future studies should consider family-related approaches to research by including not only the mothers of stillborn babies but also their families.
- Future studies may also want to consider whether the social networks of mothers recover from the impact of stillbirth over time.
- The social milieu of stillbirth bereavement will still need to continue to be the subject of research so that knowledge of the factors magnifying disadvantages for mothers can be identified.

#### **6.6.3 Recommendations for health policy**

- Policymakers should consider establishing and incorporating counselling services as part of prenatal and postnatal services.
- There is a need to develop bereavement protocol and policies that can guide health professionals with regards to communication, care and counselling mothers of stillborn babies.
- There is a need to roll-out in-service bereavement training for childbirth professionals in Nigeria.
- There is a need for support and debrief services for health professionals working in areas impacted by high perinatal mortality.
- Policy makers and stakeholders must continue to explore culturally-appropriate avenues through which resources to cope with stillbirth reach mothers.

#### **6.7 Conclusion of the study**

The findings of this study demonstrate that culture makes an important contribution to our understanding of the experience of stillbirth. In this study, I addressed the question of whether the application of social capital theory to stillbirth grief could contribute to our understanding of stillbirth in specific cultural contexts, such as Nigeria's Yoruba women. The findings indicate that culture is not only related to how women experience stillbirth, but also how they are supported.

Apart from the social capital implications of stillbirth loss which manifested as a decline in social bonds, and limited support, cultural norms and values appear to explain the willingness of participants to engage with support and the kind of support that they will find useful. The findings of this thesis are significant for the global stillbirth agenda with regards to the provision of a package of bereavement care because the success of bereavement care will depend on its ability to deal with the social and cultural dimensions of stillbirth which vary from one context to another. The global burden of stillbirth is still enormous and is likely to remain a significant problem for generations. Developing countries such as those in Africa are the most affected. This study has further confirmed the importance of family relationships, has identified the critical but very complex place that culture plays in how stillbirth is understood and managed and highlighted the lack of skilled, compassionate and sensitive care from health professionals. Mothers of stillborn babies, and their husbands, and their families deserve better care and support.

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## Appendices

### Appendix 1: University's Ethics Committee Approval



Phone 0-4-463 5480  
Email susan.corbett@vuw.ac.nz

## MEMORANDUM

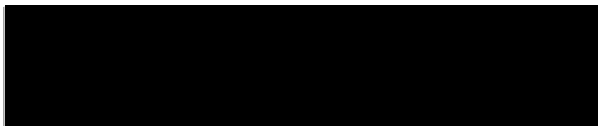
TO	Tosin Popoola
COPY TO	Dr Kathy Holloway
FROM	AProf Susan Corbett, Convener, Human Ethics Committee
DATE	21 October 2016
PAGES	1
SUBJECT	<b>Ethics Approval: 23450</b> SOCIAL CAPITAL AND WOMEN AFFECTED BY STILLBIRTH IN NIGERIA: A PHENOMENOGRAPHIC STUDY

Thank you for your application for ethical approval, which has now been considered by the Standing Committee of the Human Ethics Committee.

Your application has been approved from the above date and this approval continues until 31 December 2018. If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with the research.

Kind regards



Susan Corbett  
Convener, Victoria University Human Ethics Committee

## Appendix 2: Local Ethics Approval



# BAPTIST MEDICAL CENTRE

**P.MB. 43, SAKI.  
OYO STATE, NIGERIA.**

Tel: 08027278375, 08059498328, 08059498357

E-mail: [bmcsaki@yahoo.com](mailto:bmcsaki@yahoo.com)

29, August 2016

Our Ref: \_\_\_\_\_ Your Ref: \_\_\_\_\_ Date \_\_\_\_\_

**Mr. Tosin popoola**  
Graduate School of Nursing,  
Victoria University of Wellington,  
Wellington, New Zealand.

*Dear Mr. Popoola,*

### APPROVAL OF RESEARCH PROPOSAL

This is to convey approval of the Ethical review committee of the above named institution for your study titled: Social Capital and women affected by stillbirth in Nigeria: A Phenomenographic study.

The committee expects that you abide by the content of the proposal as approved and that you update the committee on the progress of the study.

Wishing you success in your endeavour.

*Yours faithfully*

  
**DR. T O. OJEBODE, FWACP (FM)**  
*For Ethical Review committee,  
BMC, Saki*

Baptist Hospital, School of Midwifery, Nursing Training Programme, School of Medical Laboratory Technology.  
G.M.P. Training Programme, Nursery/Primary and Secondary Schools.

Motto: "In as much as ye have done it unto one of the least of these my brethren, ye have done it unto me" Matt. 26:40

## Appendix 3: Information sheet for interviews



### **Shifts in social support: A phenomenographic study of Nigeran women who have had a stillborn**

#### **INFORMATION SHEET FOR INTERVIEWS**

Thank you for your interest in this project. Please read the following information before making a decision on participating.

#### **Who am I?**

My name is Tosin Popoola, and I am a PhD student in Nursing at the Graduate School of Nursing, Midwifery & Health, at Victoria University of Wellington in New Zealand. This research project is a work towards my PhD *thesis*.

#### **What is the aim of the project?**

Experiencing the loss of an unborn child (stillbirth) is a significant loss and I sympathise with you. In this project I am hoping to better understand the role that other people in your life (friends, family and colleagues) played in your response to your loss. My goal is to use the information provided by you to contribute to a more realistic policy to support women experiencing stillbirth in Nigeria. This research has been approved by the Victoria University of Wellington Human Ethics Committee (approval number: 23450) and the Ethical Committee of Baptist Medical Centre Saki.

#### **How can you help?**

I plan to talk with 20 women about their experiences of stillbirth. Each conversation will take place in your home or a place that we choose, at a time that is convenient for both of us. Your travel costs will be reimbursed if you have to travel to the place of interview. We will talk for about an hour and a half, during which you will be invited to draw and discuss the experience of your loss. You are free to speak either Yoruba or English. I will record and transcribe the interview and send the transcription to you if you wish to receive a copy. I will be happy to discuss any changes you may wish to make. You will be required to sign a consent form for participation.

You can stop the interview at any time, without giving a reason. You can withdraw from the study by contacting me at any point before \_\_\_\_\_. If you withdraw, the information you provided will be destroyed or returned to you.

I also plan to run discussions with the interviewed women in groups. You can choose to take part in the interview and not the group, but you cannot take part in the group if you are not part of the individual interviews. A separate information sheet about the group will be given to you if you are interested.

At the end of the interview, you will be given a Love Stone as an appreciation for your time and in remembrance of your child. The Heart was donated by the Stillbirth and the Neonatal Death Society of New Zealand (SANDS) as a message of support for you. You will also be offered refreshments (snacks and soft drinks).

### **Benefits and risks of being a participant**

The possible benefits of taking part in the study include talking through the experiences you have had and the impact that it has on your life.

However, talking about your loss may upset you and create distressing feelings. If this happens, the interview will be stopped, and you may choose to withdraw from the study, reschedule the interview or take a break. If you need to talk to someone about this immediately, a psychologist has been arranged to talk to you at no cost. His name is **Dr Tobi Victor**. His phone number is +[REDACTED]. You may also wish to consider consulting your General Practitioner (GP) for additional support.

### **What will happen to the information you give?**

Your conversations with me are strictly confidential and your details will be protected with a pseudonym (false name). Only my supervisors and I will read the notes and transcript of the interview. The interview transcripts, summaries and any recordings will be kept securely and destroyed 5 years after the research ends.

### **What will the project produce?**

The information from my research will be used in my *PhD dissertation, conference presentations and journal articles*.

### **If you accept this invitation, what are your rights as a research participant?**

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the interview;
- withdraw from the study before \_\_\_\_\_;
- ask any questions about the study at any time;
- receive a copy of your interview recording;
- read over and comment on a written summary of your interview;
- agree on another name for me to use rather than your real name;
- be able to read any reports of this research by emailing the researcher to request a copy.

### **If you have any questions or problems, who can you contact?**

#### **Student:**

Tosin Popoola  
[REDACTED]

#### **Supervisor:**

Dr Joan Skinner  
Graduate School of Nursing, Midwifery & Health  
+ [REDACTED]  
[REDACTED]

### **Human Ethics Committee information**

If you have any concerns about the ethical conduct of the research you may contact the Victoria University HEC Convener: Associate Professor Susan Corbett at [susan.corbett@vuw.ac.nz](mailto:susan.corbett@vuw.ac.nz) or [REDACTED].

Or you can contact Dr Theophilus Ojebode at [theosegun@yahoo.com](mailto:theosegun@yahoo.com) or + [REDACTED],  
Chair of the Ethical Committee of Baptist Medical Centre Saki.

If you need to talk to the Psychologist (Dr Tobi Victor), please contact him at + [REDACTED].

## Appendix 4: Consent form for interviews



### Consent for interviews

#### **Shifts in social capital: A phenomenographic study of Nigerian mothers who have had a stillborn**

Principal Investigator: Tosin Popoola, PhD student at the Graduate School of Nursing, Midwifery & Health, Victoria University of Wellington.

---

*I have read the Information Sheet about this research project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.*

*I understand that:*

- My participation in the study is voluntary;
- I would be required to talk about my past experience of losing an unborn child;
- I am free to withdraw from the project at any time, without any consequence, and I can withdraw the information provided up to \_\_\_\_\_ after the interview;
- I consent to my interview being audiotaped;
- I can request to have the tape recorder turned off at any time during the interview;
- Any raw data on which the results of the project depend will be kept in secure storage for five years, after which it will be destroyed;
- I will not be paid for my involvement in this project, but reimbursement for travel costs will be given;
- The results of the study will be published but my anonymity will be maintained, and any personal information will remain confidential.

Please indicate if you would:

- like a copy of the transcript of your interview: Yes ☐ No ☐
- like a summary of your interview: Yes ☐ No ☐
- like to receive a copy of the final report and have added my email address below. Yes ☐ No ☐

I \_\_\_\_\_ (full name) hereby consent to take part in this study.

Signature \_\_\_\_\_

Date \_\_\_\_\_

E-mail address for final report: \_\_\_\_\_



## Appendix 5: Interview consent in Yoruba



### Yoruba Consent for interviews

#### Shifts in social support: A phenomenographic study of Nigerian women who have had a stillborn

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**Oniwadi:** Oruko mi ni *Tosin Popoola* mo je dokita akeko ninu agbebi ni Victoria University of Wellington. Ise agbese yii jemo eto nipa eko mi.

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Mo ti ka awon Information di nipa iwadi yi ise agbese ki o si ye ohun ti o je nipa. Gbogbo awon ibeere mi ti a ti si dahun te mi lorun. O ye mi wipe mo le bere fun alaye ki alaye ni akoko ki akoko iwadi yi.

O ye mi wipe:

- Ikopa ninu iwadi ti inumiwa;
- Emi yoo wa ni ti a beere lati soro nipa mi tele oyun ti yorisi ni aisi omo mi pelu awon awadi;
- Mo ni ominira lati ku ro ninu iwadi yi akoko ki akoko to ba wunmi lai si wahala kan kan. Oye mi wipe mo le gba ohun ti mo ba ti so pada titi di ojo \_\_\_\_\_;
- mo gba pe ero amohun ka oro ti mob a so;
- mo ti le beere lati ni awon teepu agbohunsile wa ni pipa ni eyikeyi akoko nigba ti lodo;
- eyikeyi aise data lori eyi ti awon esi ti ise agbese dale yoo wa ni pa ni aabo ipamo fun odun marun, lehin ti o ti yoo wa ni parun;
- Mo ti yoo wa ko le san fun mi ilowosi ninu ise agbese yi, sugbon sisan pada fun irin-ajo owo yoo ao fifun;
- awon esi ti iwadi yoo wa ni atejade sugbon mi aidanimoyoo yoo wa ni muduro, ati eyikeyi alaye ti ara eni yoo wa nibe asiri.

E jowo e fihan ti e ba fe:

- bi a daako ti awon tiransikiripiti ti re lodo: Yes ☐ No ☐
- bi a ni soki ti re lodo: Yes ☐ No ☐
- fe lati gba a daako ti awon ik iroyin ki o si ti fi kun mi adiresi imeeli below. Yes ☐ No ☐

I \_\_\_\_\_ (oruko) gba lati kopa ninu iwadi yi..

Ibuwo lu \_\_\_\_\_

Ibuwo lu \_\_\_\_\_

Addresi e-meeli fun adako iroyin: \_\_\_\_\_

## Appendix 6: Focus group consent form



### Consent for Group Discussion

#### **Shifts in social support: A phenomenographic study of Nigerian women who have had a stillborn**

Principal Investigator: Tosin Popoola, PhD student at the Graduate School of Nursing, Midwifery & Health, Victoria University of Wellington.

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*I have read the Information Sheet about this research project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.*

*I understand that:*

- My participation in the project is voluntary;
- I would be required to talk about my previous pregnancy that resulted in stillbirth and my response to it with other women;
- Focus group ground rules will be discussed and agreed upon before the group discussion commences;
- I understand that taking part in this study is voluntary (my choice) and I know that I can leave the group if I wish but anything shared up to that point will remain part of the study. I understand that withdrawing would not have any impact on my care;
- I agree to keep the identity and opinions of other group members confidential;
- I agree to have the focus group tape-recorded, so it can be transcribed after the group discussion is held. I can request to have the tape recorder turned off at any time during the group discussion;
- I am fully aware that I am not obliged to answer any question, and that I do so at my free will;
- I understand that my name will not be used in any reports or publications of the study, and the information that I provide will not be utilised in any way that will identify me;
- Any raw data on which the results of the project depend will be kept in secure storage for five years, after which it will be destroyed;
- I will not be paid for my involvement in this project, but reimbursement for travel costs will be given.

I \_\_\_\_\_ (full name) hereby consent to take part in this study.

Signature \_\_\_\_\_

Date \_\_\_\_\_

## Appendix 7: Focus group consent form in Yoruba



### Yoruba Consent for Group Discussion

#### Shifts in social support: A phenomenographic study of Nigerian women who have had a stillborn

**Oniwadi:** Oruko mi ni *Tosin Popoola* mo je dokita akeko ninu agbebi ni Victoria University of Wellington, ni New Zealand. Ise agbese yii jemo eto nipa eko mi.

Mo ti ka awon Information di nipa iwadi yi ise agbese ki o si ye ohun ti o je nipa. Gbogbo awon ibeere mi ti a ti si dahun mi itelorun. O ye mi wipe mo le bere fun alaye ki alaye ni akoko ki akoko iwadi yi.

Mo ti ni oye wipe:

- Ikopa ninu iwadi ti inumiwa;
- Emi yoo wa ni ti a beere lati soro nipa mi tele oyun ti yorisi ni iku omo mi mi esi si o pelu miiran obirin ati awon awadi;
- Mo ni ominira lati ku ro ninu iwadi yi akoko ki akoko to ba wunmi lai si wahala kan kan. Oye mi wipe mo le gab ohun ti mo ba ti so pada larin ose meta leyin oro mi toro oro;
- mo gbà pe ero amohun ka oro ti mob a so;
- mo ti le beere lati ni awon teepu agbohunsile wa ni pipa ni eyikeyi akoko nigba ti lodo;
- O ye mi pe kiko pa ninu iwadi yi je atinuwa ati pe mo mo pe emi mo le fi egbe si le ni akoko ki akoko sugbon ohun ko hun ti mo ba ti so ko ni se dapada fun mi. Tim o ba kuro ninu egbe, mi o ni ni wahala kan kan.
- Mo gba lati pa awon idanimo ati ero ti miiran egbe omọ egbe igbekele;
- Mo ti gba lati ni awon idojuko Egbe teepu-gba sile, ki o le ti wa ni didako lehin awon egbe fanfa ti wa ni waye. Mo le beere lati ni awon teepu agbohunsile wa ni pipa ni eyikeyi akoko nigba ti egbe fanfa;
- Emi li kikun mo pe mo ti n ko ro lati dahun eyikeyi ibeere, sugbon ki emi ki o se be ni mi ife;
- O ye mi pe oruko yoo wa ko le lo ni eyikeyi iroyin tabi je ti awon iwadi, ati awon alaye ti mo ti pese yoo wa ko le nlo ni eyikeyi ona ti yoo da mi;
- eyikeyi aise data lori eyi ti awon esi ti ise agbese dale yoo wa ni pa ni aabo ibi ipamo fun odun marun, lehin ti o ti yoo wa ni parun;
- emi ki wa ni san fun mi ilowosi ninu ise agbese yi, sugbon sisan pada fun irin-ajo owo yoo wa fun;

I \_\_\_\_\_ (full name) gba lati kopa ninu iwadi yi.

Ibuwoḷu \_\_\_\_\_

ojo \_\_\_\_\_

## Appendix 8: Semi-structured interview guide

INTERVIEW SCHEDULE:

PSEUDONYM: \_\_\_\_\_

INTERVIEWER: \_\_\_\_\_

### Stillbirth PhD Research

PARTICIPANT:

Format: Semi-Structured Interview

Date and Time of Interview:

Location of Interview:

Sem-structured interview guideline
1. Can you tell me about your pregnancy?
2. What was it like for you when you lost your child?
3. When you think of the experience, what comes to your mind?
4. When you think back on the loss of your baby, what are those things that you can say assisted you to deal with the situation?
5. Looking back, how well would you say you were supported by those around you? Your family, partner, friends and colleagues after the loss of your baby?

## Appendix 9: Instructions for drawing exercises

INTERVIEW SCHEDULE:

PSEUDONYM: \_\_\_\_\_

INTERVIEWER: \_\_\_\_\_

### Stillbirth PhD Research

PARTICIPANT:

Format: Instructions for drawings

Date and Time of Interview:

Location of Interview:

Drawing instructions
<p>Instructions for drawing of relationships</p> <ol style="list-style-type: none"><li>1. I would like you to draw an image of yourself.</li><li>2. I would like you to add images of people (friends, neighbours, partner, extended families) that comes to mind when you think of the loss of your child.</li><li>3. I would like you to add images of any social and environmental systems (hospital, church, mosque, midwife/nurse/doctor, school, work, child support agency) that played either positive or negative roles in your experience of loss.</li><li>4. Please connect yourself to the images that you have drawn using lines or arrows. Up to three lines for each person/system may be drawn, depending on the importance of that person/system to the participant.</li><li>5. If you did not lose your baby to stillbirth, what would your image of relationship to these people/system be?</li></ol>
<p>The researcher then asked about the meaning of the drawing and expanded the responses with what was seen in the images, what was missing and any discrepancies with interview data were clarified</p>

## Appendix 10: Focus group question

INTERVIEW SCHEDULE:

PSEUDONYM: \_\_\_\_\_

INTERVIEWER: \_\_\_\_\_

### **Stillbirth PhD Research**

PARTICIPANT:

Format: Semi-Structured Interview

Date and Time of Interview:

Location of Interview:

#### **Focus group question**

How do you think we can best support a mother of a stillborn baby from your own experience?