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# NICU Services for Preterm Babies: Experiences of Aghem Women of Northwest Cameroon

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# Walden University

**College of Health Professions** 

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Deudonne Kum Amuam

has been found to be complete and satisfactory in all respects, and that any and all revisions required by the review committee have been made.

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> > Walden University 2022

#### Abstract

NICU Services for Preterm Babies: Experiences of Aghem Women of Northwest

Cameroon

by

Deudonne Kum Amuam

MSc, Catholic University of Central Africa-Cameroon, 2010

BMLS, University of Buea-Cameroon, 2001

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Services

Walden University

May 2022

#### Abstract

The experiences of women with health care services continue to be a challenge for health care workers in providing quality care. Women's poor impressions of health care services in sub-Saharan Africa stems from the negative behavior of health care workers during the provision of care to mothers and their preterm babies. The lack of data on women's experience with health care services in Cameroon was the problem this study addressed. The study's purpose was to understand Aghem women's experience with health services provided for their preterm babies in the neonatal intensive care unit (NICU) and how they perceived that their experience with health care services provided to their preterm babies influenced their preterm babies' healthcare outcomes. Swanson's caring theory was a guide for data collection and analysis. A qualitative approach was used, and data was collected through in-depth interviews with 10 Aghem women who had experienced health care services for their preterm babies in a NICU in Cameroon. The results showed that health care workers demonstrated the five tenets of Swanson's caring process including knowing the mothers of preterm babies, spending time with them, teaching, and helping them to maintain hope during the care process. However, many aspects of the caring process challenged mothers' experiences, including health care workers' reluctance to provide health care and their contentious interactions with mothers of preterm babies. The results and recommendations from this study may help inform health stakeholders about the problem and design strategies to improve women's experiences with health care services and the health outcome of preterm babies in Cameroon.

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#### Dedication

I dedicate this dissertation to my lovely wife Mildrate Amuam for love before, during, and certainly after the dissertation journey. I also saved the dissertation to my children; Faris Amuam, Treasure Amuam, Princess-Unity Amuam, Marvel Amuam-Senior, and Cherish Amuam for their continuous support; just being by my side gave me the impetus to move on. Special recognition goes to my mother, Juliana Amuam, who held my hand to school at the beginning of my academic journey more than thirty years ago.

Lastly, I thank my entire family for the moral support, including my grandmother, Regina Ekei Amuam, who could still relate to her preterm birth experience in the late 1940s.

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#### Chapter 1: Introduction to the Study

Preterm babies may require the services of a neonatal intensive care unit (NICU) to improve their health outcomes. Preterm birth is among the top causes of mortality in children under 5 years worldwide (Hug et al., 2019; Liu et al., 2016; Ndombo et al., 2017). Globally, an estimated 15 million babies are born prematurely (delivery before 37 completed weeks of gestation) every year, giving a ratio of more than one in 10 babies of the total number of births (Gondwe et al., 2016). Of the 15 million babies born prematurely globally, most of them are found in South Asia and sub-Saharan Africa and contribute to about 50% of neonatal morbidity and mortality in developing countries (Shapiro-Mendoza et al., 2016; Wagura et al., 2018). Each year, approximately 1 million children under the age of 5 die due to preterm birth complications (Liu et al., 2016). Complications of preterm birth may vary from severe infections to lasting disabilities and death. For Cameroon and other countries in sub-Saharan Africa, neonatal and infant mortality rates remain alarming (Lawn et al., 2014).

In Cameroon, infant mortality rates due to preterm birth vary between 30.1% and 69% (Chiabi et al., 2013; Ndombo et al., 2017; Nlend et al., 2016) among hospitalized infants. The observed high mortality rates in Cameroon point to a need to further investigate the health services received by the preterm babies in the NICU. The problem of neonatal mortality persists in Cameroon (Ndombo et al., 2017), and studies have identified the importance of helping mothers of preterm babies to clarify their needs and values to improve their care experience and the health outcome of preterm babies in the NICU (Lundqvist et al., 2019; Ndombo et al., 2017). The Aghems are among the people

who make up one of the five ethnic groups inhabiting the grass field region of Northwest Cameroon. Being a member of the Aghem people and aware of preterm birth-related infant mortality problem, I decided to choose this topic and population.

#### **Problem Statement**

Improving women's experience with health services for preterm birth seems to drive hospital care and improve preterm babies' survival chances and health outcomes. According to Kahabuka et al. (2012) and Jonas et al. (2017), the negative behavior and attitude of health care workers in developing countries affect women's experience with health care services offered to both women and their babies. African women's experience with prenatal and postnatal services is challenged by the performance and attitude of health care workers (Haile-Miriam et al., 2012; Mohale et al., 2017). Many studies have identified the importance of exploring the experiences of mothers of preterm babies with NICU services to improve the quality of care and outcome of preterm babies in the NICU (e.g., Beattie et al., 2015; Lavallée et al., 2019; Liu et al., 2016; Lundqvist et al., 2019; Petty et al., 2019). These findings point to a need to investigate further mothers' experience with health services received by their preterm babies in the NICU in Africa and Cameroon.

Globally, researchers and health care leaders are increasingly interested in understanding the care experience among parents of preterm babies in the NICU. Earlier studies revealed that positive parents' experiences with postnatal health care services positively impact neonatal care (Jones et al., 2012). However, in developing countries, most of the studies focus on parents' perception of preterm birth. Very few studies focus on parents' experience with health care services (Gondwe et al., 2016). Mothers are significant stakeholders in neonatal care (Beattie et al., 2015). Mother's health care experience is inextricably linked to their newborn baby'shealth and survival (Liu et al., 2016). According to Beattie et al. (2015), Liu et al. (2016), and Mohale et al. (2017), understanding mothers' experience with preterm care can lead to ways to improve their experience and the welfare of preterm infants. Moreover, Abeasi and Emelife (2020), Kalhor et al. (2016), and Yang et al. (2019) recommended the consideration of mothers' experience with the care of the newborn as an effort to prevent long-term hospitalization of preterm infants and reduce associated consequences.

According to Jonas et al. (2017), women in sub-Saharan Africa reported poor health care service experience due to healthcare workers' negative behavior and attitude during health service delivery to the women and their babies. Jonas et al. recommended that further studies be conducted in other countries in sub-Saharan Africa to make conclusive and generalizable findings of women's experiences with health care services. There is a lack of information about women's experience in Cameroon with NICU services for preterm babies. Earlier studies of preterm birth in Cameroon focused on risk factors associated with preterm birth (Chiabi et al., 2013), determination of hospital neonatal mortality rates (Ndombo et al., 2017), and the effect of antiretroviral therapy on occurrences of preterm birth (Nlend et al., 2016). According to Ndombo et al. (2017), preterm birth is the main reason for admissions in the NICU in Cameroon. To my knowledge, very little information was available regarding the mothers' experience of NICU health services provided to their preterm babies. The study's findings hopefully lead to an understanding of the experiences of Aghem women with NICU services. The results might inform better strategies to improve care delivery for preterm babies while in the NICU in Cameroon. Improvement in the delivery of care by health providers might lead to an improved experience of mothers with health services and subsequently lead to improved health outcomes of the preterm infants.

#### Nature of the Study

The nature of this study was qualitative research in which a phenomenological approach was used. In-depth interviews were used to explore Aghem women's experiences with NICU services for preterm babies. Moustakas (1994) recommended interviews with open-ended questions to elicit views and opinion from participants. Descriptions and themes were developed from the data to make meaning of the experiences of Aghem women of Northwest Cameroon with health care services provided to their preterm babies in the NICU.

#### **Research Questions**

RQ1: What are the experiences of Aghem women of North West Cameroon with health care services provided to their preterm babies in the NICU?

RQ2: How do Aghem women perceive that their experience with health care services provided to their preterm babies in the NICU influences the health care outcome for the babies?

#### **Research Objectives**

My primary objective with this study was to understand the experiences of Aghem mothers of preterm babies with health care services provided to their preterm babies. These mothers were asked open-ended questions about their experience with health services provided for their preterm babies in the NICU. The open-ended questions were intended to allow the women to provide in-depth information about their experiences.

#### **Purpose of the Study**

The study's purpose was to understand how Aghem women of Northwest Cameroon experienced health services provided for their preterm babies in the NICU and how they perceived that their experience with health care services provided to their preterm babies in the NICU influenced the health care outcome of the babies. I explored mothers' views of preterm babies' health care services, regarding their encounter with health care workers who provided health services for preterm babies during hospitalization in the NICU. The study's findings helped to inform an understanding of the experience of Aghem women with NICU services and ways to improve women's experiences and preterm babies' health care outcomes.

#### **Theoretical Framework**

The theoretical base for this study was Swanson's (1991) caring theory. Swanson's caring theory was proposed to understand the process of caring and health services delivery through participants' lived experiences. Swanson's caring theory was used to improve a patient's or family's experience of a healthcare encounter (Cook & Peden, 2017; Welch & Fournier, 2018). Swanson used the theory to generate five categories of the caring and health service delivery processes: (a) knowing, (b) being with, (c) doing for, (d) enabling, and (e) maintaining belief. I used Swanson's caring theory to explore

and understand mothers' experiences with NICU services provided to their babies. The five categories of the caring process helped to guide questionnaire designing and data analysis. These categories helped me to understand women's experiences with care and informed strategies to improve the Aghem women's experiences with the care of preterm infants in NICU. Researchers have used Swanson caring theory for different objectives: (a) to understand nursing care for women experiencing birth (Nurse et al., 2019), (b) to understand the perception of care and support mothers received from clinicians during breastfeeding initiation (Westmoreland & Wojnar, 2019), (c) to investigate the relationship between caring nurse behavior and primiparous maternal confidence (Mott, 2016), and (d) to understand parents' experiences of their interaction with care providers (Kavanaugh et al., 2015).

#### **Operational Definitions**

To provide a better understanding of this study, the following terms were defined. *Extremely preterm*: Birth that occurs before 28 completed weeks of gestational age.

*Late preterm birth*: Birth that occurs between 34 and 37 completed weeks of gestational age

*Moderately preterm*: Birth that occurs between 32 and 34 completed weeks of gestational age.

*Preterm birth*: Birth occurs before 37 completed weeks of gestational age (Liu et al., 2016).

*Very preterm*: Birth that occurs between 28 and 32 completed weeks of gestational age.

#### Assumptions

I made three assumptions in this study. One assumption was the availability of participants for the study. I assumed that I was going to get the required number of participants for the study. Another assumption was that the participants provided accurate and honest responses about their experiences with health services provided for their preterm babies in the NICU in Cameroon. Also, I assumed that the participants were in a state of mind to respond without any influence from health providers or other issues.

#### **Limitations and Challenges**

This study was limited to a sample size of 10 Aghem women of Northwest Cameroon. The purposeful selection of only a small number of study participants might have introduced a limitation in the generalization and transferability of the results. To address the issue with sample size, Moustakas (1994) proposed the idea of saturation and an estimated sample of 10 for a phenomenological approach. Thus, I used a sample size of 10.

Offering money as an incentive to participants was another limitation. Participants could have participated in the study just for the money benefit. They might not have provided genuine answers to the interview questions. To address this limitation, I used the institutional review board (IRB)-approved amount of 10dollars (\$10) for this study's participants' compensation. Also, I explained to participants that the study's findings could eventually benefit the community in ways such as informing strategies to improve

women's experiences with health care services provided for their preterm babies and preterm babies' health outcomes.

A challenge resulted from interviews conducted in Pidgin English. Translation across languages can hardly be entirely accurate. The meaning of some phrases might be lost during translation to and from English. To address this challenge, I translated the data. I am a native speaker of Pidgin English, and have also completed postgraduate health care courses within the United States and Cameroon. These experiences, therefore, gave me a solid understanding of both languages and cultural nuances.

Additionally, I needed to obtain ethical clearance from the Faculty of Health Science Review Board (FHSRB) of the University of Buea in Cameroon before posting flyers and collecting data in the study's community. I also asked permission from church and hospital administrations before the flyers were posted and interviews were conducted at these places. Knowing that the approval process might take a long time and cause a delay in the study, I applied for the ethical clearance 3months before I intended to start data collection. Moreover, the FHSRB of the University of Buea was accredited for studies all over the Cameroon national territory. The approval process was relatively faster than other IRBs in Cameroon.

My experience as a researcher might have been part of the limitations of the study. At the initial research stage, I avoided discrepant data by establishing a basic and simple standard operating procedure that was easy for participants to follow. I also double-checked every step of the data collection process to ensure that it was at the level of the participant's understanding. The research committee constituted part of the available resources used to ensure data was collected and coded accurately.

My personal bias might have influenced the processes of qualitative data collection and analysis. Moreover, the collected data required interpretation and value judgment which my bias could have influenced by applying my experience. According to Merriam and Tisdell (2016), conducting a pilot study is an appropriate means to eliminate flaws related to data collection. Thus, conducting a pilot study ensured that the process of data collection had no flaws. Using reflexivity and bracketing helped to avoid bias in the analysis and interpretation of data. Creswell and Creswell (2018) noted that researchers reduce their personal bias by reflecting on how their experiences and background may shape their understanding of data and by putting aside these experiences so that they do not override the importance of the content of the study.

Moreover, the period of 1 year might have been too long for some women to remember their hospital experience. I might not have obtained a certain level of in-depth experience from some women with health care services provided to their preterm babies in the NICU. However, the inclusion criteria included a preterm birth experience within the last 3-6 months. I did not extend this period to 1 year as all participants had experienced preterm birth within the last 3-6 months to the interview. Maintaining confidentiality might also be a challenge. To address this challenge, I used a variety of ways to conduct the interviews, with each way suitable to ensure absolute confidentiality. I also ensured a private area in the community where no other person could overhear the interview. Phone interviews were scheduled with participants at their convenience and at a time and place where they could talk without interruption from any other person.

To overcome biases that might influence the study's validity, reliability, credibility, and accuracy, existing literature was explored to build a coherent justification of the themes that emerged from the collected data. In addition, triangulation and a detailed description of the processes of data collection, analysis, and interpretation were used. These strategies contributed to proving the validity and accuracy of findings (Moustakas, 1994). According to Moustakas (1994), overcoming the biases ensures that research results represent the views and opinions of the participants.

#### **Scope and Delimitations**

The scope of this study was limited to the understanding of the experiences of Aghem women with NICU services for preterm babies. The data were collected from women who have had their preterm babies admitted to the NICU in Cameroon within the last year. A purposeful sample of participants was selected based on having an experience with health services provided for their preterm babies and willingness to participate in the study after understanding the purpose and procedure of the study, which I had explained to the participants.

Since the study's goal focused on Aghem women's experiences with preterm babies' health care services in the NICU in Cameroon, an in-depth description of the study was an essential component of the research. It could contribute potential knowledge about the phenomenon in the community. The generalization of this qualitative study may require replication of the study and an assessment of more respondents. However, future researchers may not have access to the same respondents and may not obtain the same results from other respondents. Therefore, transferability was limited in this study.

#### Significance of the Study

The study provided an understanding of the experience of Aghem women with health services provided for their preterm infants in the NICU. Additionally, patient experience contributes significantly to developing better strategies to improve the quality of health care services (World Health Organization [WHO], 2017). This study implies that understanding the experience of Aghem women with NICU services would stimulate health professionals to focus on improving patient experience and possibly lead to improved health outcomes of these preterm infants. The study adds to the pool of knowledge on the issues of preterm care from the perspective of the Aghem women of Northwest Cameroon. Increasing the pool of knowledge may empower health care providers to affect a positive social change by improving mothers' experience with health services provided for their preterm infants in the NICU.

#### **Summary and Transition**

Preterm birth tends to add a burden to the family, health professionals, and the entire society. Preterm birth potentially affects an infant's health and educational performance later in life (Kelly, 2016; Lilliecreutz et al., 2016). In addition, preterm birth is associated with an economic burden in society (Adu-Bonsaffoh et al., 2020). The health and financial burdens of preterm birth are reflected, in part, by the type and amount of health services used by preterm infants. Two significant ways to curb the impact of preterm birth are prevention and management of preterm babies (Ley et al., 2019). According to Ley et al. (2019), preventive strategies focus on the improvement of the prenatal services women receive as pregnant women. In contrast, the management of preterm babies aims to improve the health outcome of the babies and reduce neonatal mortality.

Mothers' experience with the health services provided for their preterm babies during hospitalization in the NICU tends to influence the health outcome of the babies. Researchers have indicated favorable results with improved mother's experience with health services provided for their preterm babies in the NICU (Beattie et al., 2015; Lavallée et al., 2019; Liu et al., 2016; Lundqvist, Weis, & Sivberg, 2019; Petty et al., 2019). However, very little is known about the experience of NICU services for preterm babies among Aghem women of Northwest Cameroon. In the next chapter, Chapter 2, I present a review of the literature, followed by Chapter 3, the Methodology and Research design in which the procedure for this study is described. Add information on Chapter 4 and Chapter 5.

#### Chapter 2: Literature Review

The study's purpose was to understand how Aghem women of Northwest Cameroon, experienced health services provided for their preterm babies in the NICU and how they perceived that their experience with health care services provided to their preterm babies in the NICU influenced the health care outcome of the babies. Preterm birth is a significant public health problem, especially in sub-Saharan Africa, including Cameroon. According to Haile-Mariam et al. (2012) and Mohale et al. (2017), the experiences of sub-Saharan African women with health care services lend ways to health care workers to improve the health services provided for preterm babies. As a result, I focused on understanding the experiences of Aghem women to shed more light on the topic in Cameroon.

This literature review is organized into six major topics (literature search strategy, challenges of preterm birth, health services for preterm babies in the NICU, mother's experience with health care services, and theoretical framework. Finally, this chapter concludes with a summary of literature review results, bringing out significant themes, the gap in the literature, and a brief description of how this study bridges the gap.

#### **Literature Search Strategy**

Online academic databases were used to search for this review. The search terms include the following keywords: *NICU services for preterm babies, NICU experiences among women, preterm delivery in Cameroon, hospital care of preterm infants, challenges in the NICU, preterm baby outcomes, and NICU health care services.* 

Thoreau, and Walden University library databases were used to select articles relating to NICU services for preterm babies: Women's experiences.

Other databases used included Dissertations and Theses @ Walden University, ProQuest Central, ProQuest Dissertations & Theses Global, Medline, PsycINFO, PubMed, Google Scholar, ScienceDirect, Public Health, Health & Medical Collection, and Nursing and Allied Health. In some cases, I introduced the words such as *developing countries, sub-Saharan Africa, and Cameroon* in the search terms to narrow the search to Cameron. Other literature was identified using articles from the bibliographies of previous studies and doctoral dissertations on preterm birth. The journals accessed included Advances in Nursing Science, Archives of Pediatrics, Clinical Nursing, Fetal and Neonatal Medicine Maternal and Child Health, Palliative and Supportive Care, Pediatrics, Pediatric Health Care, and Neonatal Nursing. Others were Lancet, Lancet (ScienceDirect), Lancet Global Health, International Journal of Population Research, African Journal on Reproductive Health, Maternal Research and Treatment, Reproductive Health, and the BMC Pregnancy and Childbirth. Also accessed were BMC Health Policy, BMS Pediatric, Lancet Health Policy, Asian Journal of Nursing Education Pregnancy and Childbirth, Health and Social Behavior, Health Services, and Research.

The literature review included websites of credible health care organizations. Websites of WHO and United Nations Children's Fund (UNICEF) were used to obtain further details about recommendations and best practices involved in the care for preterm birth. Only papers published in peer-reviewed journals or information from reputable sources were selected for inclusion in the literature review. However, the literature search yielded relatively few papers published on this study's topic within the last 5 years. As a result, I expanded the search to include articles published within the previous 9 years.

#### **Challenges of Preterm Birth**

Preterm birth is considered a significant public health problem worldwide (Chawanpaiboon et al., 2019). Recent studies have shown an increase in the rate of preterm birth. In the United States, the rates declined between 2007 and 2014 but have steadily risen since 2015, reaching about 10% in 2018 (Centers for Disease Control and Prevention [CDC], 2018). The increased use of advanced technology and experts to assist childbirth in developed countries seemed to account for the observed rise in the preterm birth rate in the United States (Mahwasane et al., 2020). With a less advanced technology when compared to developed countries, low-and middle-income countries (LMICs) have recorded more significant impacts of preterm birth (Chawanpaiboon et al., 2019). In 2017, an estimated 2.5 million newborns died during the neonatal period, with approximately 7,000 deaths per day globally (Desalew et al., 2020). Developing countries experienced 98% of neonatal deaths, with a more significant burden in sub-Saharan Africa (Desalew et al., 2020). The burden of neonatal mortality rate in Sub-Saharan Africa remains high, with an average rate of 41 per 1,000 live births in contrast with an average rate of four per 1,000 live births in developed countries (Lawn et al., 2014). The disproportionate higher impact in LMICs compared to high-income countries (HICs) was attributed to increased health care costs, long-term infant morbidity, and high perinatal mortality in sub-Saharan Africa (Adu-Bonsaffoh et al., 2020). Like other sub-Saharan African countries, Cameroon faced a similar burden of preterm birth with a neonatal

mortality rate of 21 per 1,000 live births (UNICEF, WHO, WORLD BANK GROUP, UN-DESA Population Division, 2015). Preterm birth accounts for most neonatal deaths.

Many studies revealed preterm birth as one of the most prevalent causes of neonatal mortality by neonatal infection, birth asphyxia, and malformation (e.g., Desalew et al., 2020; Lawn et al., 2014; Ndombo et al., 2017; Peige et al., 2016). Preterm birth is second to pneumonia as the cause of mortality among children of 5 years and below (Liu et al., 2016; WHO, 2015). Furthermore, preterm birth is the single most important direct cause of low birth weight and death within the first month of life (Liu et al., 2016; WHO, 2015). In Cameroon, neonatal and infant mortality rates remain persistently high. With the impact of preterm birth on neonatal mortality, the WHO, UNICEF, over 43 governments, 23 global organizations, and more than 2,000 individuals, implemented the Every Newborn Action Plan (ENAP) to reduce neonatal deaths and stillbirths to 10 per 1,000 births by 2035 (WHO& UNICEF, 2014). The objectives of ENAP included improving the quality of maternal and newborn care and harnessing the power of parents, families and communities (Akseer et al., 2015; WHO & UNICEF, 2014). The focus on parents to improve the health outcome of newborns led to the interest in understanding mothers' experiences with health care services for preterm babies.

In a study by Nlend et al. (2016), infant mortality rates in a hospital in Cameroon varied between 47% and 37% in the Period 1 (1998. 1999, and 2004) and Period 2 (2010 and 2013) respectively for low-birth-weight (LBW) infants (>1000g and <1500g). Throughout the study periods, the mortality rate remained very high (95%) among very-low-birth-weight (VLBW) infants (<1000g). The results showed that Cameroon was far from attaining the recommendation of Millennium Development Goals Number 4 (MDG4) of lowering infant mortality rates by two-thirds in 2015 (Akseer et al., 2015; UNICEF, WHO, WORLD BANK GROUP, UN-DESA Population Division, 2015). The decline in infant mortality rates also remained slow in Malawi who had met the MDG4 and the following sub-Saharan African countries, Eritrea, Ethiopia, Liberia, Madagascar, Mozambique, Niger, Rwanda, Uganda, and Tanzania (Kawaza et al., 2020). The persistent preterm birth-related infant mortality indicates the need for continuous efforts in sub-Saharan Africa to curb the effects of preterm birth, which remains a public health problem and takes a toll on health care costs.

Health care cost for preterm babies is higher than the cost of care for term infants and increase with the level of care and decreasing infant gestational age (Zainalet et al., 2019). The study findings demonstrated that two-thirds of admission cost per infant was contributed by NICU-specific overhead (Zainalet et al., 2019). Furthermore, mortality rates were higher among extremely preterm infants than their late-term counterparts (Karnati et al., 2020). The higher impact of extremely preterm care may explain the focus on this category of preterm birth.

Other studies showed that late preterm babies have more extended hospital stays, higher readmissions, and higher morbidity and mortality rates at one year when compared to term-born infants (e.g., Karnati et al., 2020; Zainal et al., 2019). Preterm birth was also associated with increased unpaid time off, higher debts, and financial worry among parents of preterm infants (Lakshmanan et al., 2017). The increased number of days preterm infants spent in the hospital and their frequent readmissions contributed to a

higher cost of health care for preterm infants than for term-born infants. Higher morbidity rates further augmented the cost of care among preterm infants.

Immediately after birth, survivors of preterm birth face some difficulties adapting to postuterus life due to the immaturity of many organs (Mahwasane et al., 2020; Heringhaus et al., 2013). These difficulties are more pronounced with decreasing gestational age of the preterm baby. Extremely preterm babies (born before 28 completed weeks of gestation) often experience disabilities that may persist through childhood, including learning disabilities; and visual and hearing problems (Kelly & Li, 2019; Soleimani, Zaheri, & Abdi, 2014). Another study showed that about 20.6% of extremely preterm infants developed a certain degree of motor or cognitive delay at approximately 2 years of age (Pascal et al., 2018). Compared to term-born survivors, there is poorer health-related quality of life among extremely preterm birth survivors from their early teens through their mid-30s (Saigal et al., 2016). Add summary and synthesis throughout the paragraph to balance out the use of information from the literature with your own analysis.

Morbidity and mortality rates are higher among extremely preterm and very preterm infants than among moderate and late preterm infants. Preterm birth-related respiratory distress syndrome (RDS) was found to constitute a higher morbidity rate (15%) in moderately preterm infants than in late preterm infants (3.2%; Mahwasane et al., 2020). The findings also showed 61.4% and 22.5% mortality rates, respectively, among severely preterm babies and moderately preterm babies (Mahwasane et al., 2020). As a result, most studies focus on extremely preterm birth. However, late preterm infants account for a majority (>75%) of preterm birth and are at higher risks of readmission and medical complications when compared to term-born infants (Karnati et al., 2020; Thygesen et al., 2016). From these results, extremely preterm birth, very preterm birth, moderately preterm birth, or late preterm birth require extra health care, leading to a financial burden to the families, the health system, and society. The results also indicated the importance of including late preterm birth in the study of preterm birth. For this reason, I incorporated preterm birth of all gestational ages in this study.

Another challenge of preterm birth in sub-Saharan Africa is limited research on the issue in sub-Saharan African countries. The scarcity of high-quality preterm birth research deprived health care providers and other stakeholders of the tools to improve health care services for preterm birth (Adu-Bonsaffoh et al., 2020). As a solution, Adu-Bonsafoh et al.(2020) recommended more research in local life realities on preterm birth. Thus, I focused on the experiences of Aghem women with health care services for their preterm babies. Hopefully, the findings will generate local evidence-based realities that can improve health services and health outcomes of preterm babies in Cameroon.

#### Health Services for Preterm Babies in the NICU

Preterm birth survivors tend to require health care services beyond those required by term-born babies, and the amount of type of health care services provided for preterm babies indicate, in part, the economic burden and health status of preterm babies (Zainal et al., 2019). According to Lavallée et al. (2019) and Steyn et al. (2017), the health services provided for preterm babies in the NICU favor normal development of the fetus during the postnatal period. Due to the unusual early exposure to the external environment (Lavallée et al., 2019) preterm babies require enhanced medical and nursing services (Kelly & Li, 2019). These services may include the provision of warmth, feeding support, use of safe oxygen, and infection control (Mahwasane et al., 2020). Enhanced nursing and medical services support immature organs like the lungs, the brain, and the skin. Preterm babies are sometimes placed on oximeters and incubators to enhance the lungs by taking in oxygen and the brain and skin to maintain body temperature, respectively (Heringhaus et al., 2013; Mahwasane et al., 2020). The enhanced nursing and medical services resulted from remarkable efforts in the developing science and technology to improve care for preterm babies (Liu et al., 2016).

Specialized equipment is limited in number or completely unavailable in sub-Saharan Africa, including Cameroon. Several studies have highlighted insufficient resources such as heaters, incubators, pulse oximeters, Ambu Bags, oxygen apparatus, trained staff, oxygen supply, and lack of antibiotics. These insufficiencies are significant challenges in providing health care services in sub-Saharan Africa (Heringhaus et al., 2013; Kadia et al., 2020; Mahwasane et al., 2020). Casper and Kuhn (2017) and Kahabuka et al. (2012) reported insufficiency in providing health services for preterm babies even with the availability of specialized equipment. According to Wei et al. (2018), the best health care service practices go beyond the diagnosis and treatment of physical illnesses and include care for the heart and soul. The results of these studies indicated that the challenges of health care services for preterm babies go beyond the availability and affordability of specialized equipment.

Developmental care interventions (DCI) are often required to improve preterm baby overall physical, cognitive, social, and emotional development (Lavallée et al., 2019). These interventions may include rehabilitation (physical, speech, or occupational therapies) and individualized learning. Improving DCI services in NICU has shown a significant increase from 56.6% to 70.9% in survival rate without morbidity among preterm infants (Lee et al., 2020). The engagement of the preterm baby's mother and family is a major determining factor for the success of developmental care interventions in the NICU (Lavallée et al., 2019). The mothers play an essential role in providing care in the NICU, including thermal care and nutritional support. Similarly, Kalhor et al. (2016) recommended the involvement of parents in the care of the newborn as an effort to prevent hospitalization of preterm infants and reduce associated consequences. These findings indicated the importance of improving mothers' experiences with health care services for their newborn. The findings further justified the purpose of this study to understand mother's experience with health care services provided for their preterm babies.

#### **Mothers' Experience With Health Care Services**

Mothers' experience with the health care services provided for their preterm babies stands out as an essential factor to improve health care services and health outcomes of preterm babies (Beattie et al., 2015; Lavallée et al., 2019; Liu et al., 2016; Lundqvist et al., 2019; Petty et al., 2019). Investigating parents' experiences with health care services provide valuable information to improve the quality of health care services (Karisalmi et al., 2020). The mother's health is closely linked to that of the baby and efforts geared towards improving the wellbeing of mothers will help improve the baby's health outcome (Liu et al., 2016; Sylvia et al., 2013). Carter et al. (2018) posited that the interaction between mothers and health care workers influenced the mother's reflection of the actual health care process. According to Beattie et al. (2015), Lavallée et al. (2019), Lawn et al. (2016), Lundqvist et al. (2019), and Petty et al. (2019), information gathered from the experiences of mothers with health services for preterm babies can be used in designing strategies to improve the quality of care and health outcome of the babies. WHO (2017) reported higher chances of improvement in health services when a significant consideration is taken to ensure the participation of the target population in the design and assessment of health service delivery. Responsive and acceptable preterm care services from the hospital to preterm infants and their mothers could be developed from understanding women's lived experiences regarding the services provided in the NICU (WHO, 2017). Because a history of preterm birth was a significant predictive factor of subsequent preterm births, understanding women's experiences with NICU services helped optimize the care of subsequent preterm births (Glover & Manuck, 2018; Oyston & Groom, 2018). Mothers, therefore, play a significant role in neonatal care (Beattie et al., 2015). Understanding mothers' experiences with health services provided an opportunity to ameliorate the care and welfare of the newborn (Liu et al., 2016). Ireland et al. (2019) stated that understanding parents' experiences can help to facilitate parents' adaption in the neonatal environment and their infants' wellbeing. Another study highlighted that mothers' ability to assist in detecting illness and improving clinical outcomes of the care for their babies could be enhanced by understanding mothers'

experience with health care services (Mbwele et al., 2013). These findings from previous studies further illustrate the importance of this study to potentially improve mothers' health care experience and preterm babies' health outcome.

Parents' health care experience is increasingly used to determine the quality of health care services (Faraz et al., 2014). Several studies highlighted varying mothers' experiences and the importance of these experiences in improving infants' health outcomes. Lundqvist et al. (2019) and Ndombo et al. (2017) highlighted the importance of helping mothers of preterm babies to clarify their needs and values to improve the care and outcome of preterm babies in the NICU. The mothers' needs and values could be easily explained and understood when they express their healthcare services experiences.

A study by Degni et al. (2014) stressed the importance of understanding women's experiences with health care services to improve health care services and help in the sociocultural integration of women. Degni et al. considered women's experience of health care services to adopt a culturally competent health care service. Women's experiences with health care services may help both the women and healthcare workers better understand health care services and perform their roles as crucial stakeholders of the health care system.

In another study, Lomotey et al. (2019) highlighted that the mothers of preterm babies have emotional experiences when their preterm babies are in the NICU in part by their sense of guilt and fear of the baby's health outcome. These findings are consistent with earlier studies by Aagard et al. (2015), Ionio et al. (2016), and Linda et al. (2018), indicating that mothers are often surprised by the event of preterm birth, leaving them in stressful conditions. The awareness of the emotional state of the women might have led to the suggestion of additional support for these women, including emotional support (Carter et al., 2018; Russell et al., 2014; Wei et al., 2018; Widding et al., 2019).

Studies about mothers' experience of health care services reported varying results. Mothers of preterm babies expressed emotional difficulties related to their separation from their babies, their share of the same hospital ward with mothers of term-born babies (Linda et al., 2018). Other participants reported positive experiences with health care workers who treated them with respect and dignity (Linda et al., 2018). Participating mothers used the words competence, altruism, responsible, and empathy (CARE) to characterize the attitude of health care workers (Wei et al., 2018). Other studies described the overall experience during the birthing and postnatal periods as disrespectful and discriminating (McLemore et al., 2018). Mothers varying experiences also indicated that the role of nonclinical factors, like treatment received from health care staff, cannot be overemphasized to ensure a positive patient experience with health care services (Fernandez-Perez et al., 2019). The different experiences among mothers further support the relevance of local evidence-based research findings to adapt health services to consumers. This study therefore contributed to the available knowledge to improve mothers' experiences with health care services for their preterm babies.

The behavior of health care workers is increasingly known as a significant challenge in improving mothers' experiences with health care services (Haile-Mariam, 2012). According to Ekström and Thorstensson (2013), the perception and understanding of parents with health care during childbearing are influenced by the attitudes and support of health care workers. Ekström and Thorstensson (2013) highlighted the importance of training health care workers to improve their professional attitude and the quality of care for the child and parents. Other studies have identified other challenges, including poor attitudes among health service providers towards preterm infants and their parents (Heringhaus et al., 2013; Kahabuka et al., 2012). Kahabuka noted that a welcoming environment, a supportive and empathetic health staff were among other important factors to improve the quality of health care services and outcomes of preterm babies. Building from these results, health care services can be more relevant to the consumers if consideration is given to the people's experiences with the health care services (Kahabuka et al., 2012). Heringhaus et al. (2013) pointed out the importance of training doctors and nurses in communication skills to meet parents' emotional needs and the baby's health outcome in the NICU. Giving mothers of preterm babies a chance to describe their experiences with health care services provided for their preterm babies may lead to a better understanding of the challenges associated with the attitudes of health care workers. Furthermore, understanding mothers' experiences with health care services can lend to the design of strategies to improve mothers' experiences and the health outcomes of preterm babies.

Most of the studies on mothers' experiences in the NICU are based on mothers' expectations of caring for their preterm babies in the NICU. The studies have focused on dimensions related to emotional support to parents (Linda et al., 2017), parents' needs (Amorim et al., 2019), and social and financial support (Todd et al., 2019). These studies focused on the qualitative assessment of the care for preterm babies in the NICU from the

mother's perspective. Mothers' expectations of the care for their preterm baby in the NICU may vary with parental characteristics (e.g., age, educational level, marital status, income, previous experience in the NICU), infant's health, and the environment of the NICU (Amorim et al., 2019). Investigating mothers' experiences with health care services goes beyond what mothers expect of the health care services.

A focus on mothers' expectations or needs with the care for their preterm babies in the NICU may limit the outcome to their satisfaction with the expected care. Kumah (2019) highlighted a gap between parents' expected care and the care parents are provided. A satisfaction survey was used to collect data from mothers about their views of the difference between their expected care and the care they experienced (Beattie et al., 2015). According to Beattie et al. (2015), patients often overrate their satisfaction with health care services, thus limiting the validity and usefulness of satisfaction. Unlike patient satisfaction, patient experience focuses on what happens to the patients during the encounter with health care staff (Lam et al., 2019). As a result, Beattie et al. (2015) recommended using patient experience to inform strategies to improve health services and patient experience of these services. This study was aimed at understanding mothers' experiences may increase the likelihood of using mothers' voices to improve their experiences and the health services for their preterm babies.

#### **Theoretical Framework**

Swanson's caring theory was developed by Swanson (Nurse-Clarke et al., 2019). According to Swanson (1991), caring for patients aims to contribute to the patient's biopsychosocial and spiritual wellbeing. Swanson developed the caring theory using series of work with mothers experiencing a miscarriage, parents and healthcare providers in a neonatal intensive care unit, and socially at-risk mothers (Nurse-Clarke et al., 2019). Five tenets make up Swanson's caring theory, including knowing, being with, doing for, enabling, and maintaining belief (Swanson, 1991). According to Swanson (1991), these tenets describe categories of the caring processes.

Nurse-Clarke et al. (2019) described the Swanson categories of caring processes as follows:

• Knowing: Communicating with the patient to understand the event and the meaning from the patient's perspective.

• Being with: Spending extra time with the patient to let them know they are not alone.

• Doing for: Anticipating the patient's needs and acting to meet these needs while comforting and protecting their dignity.

• Enabling: Providing information in stages so that patients can easily understand and control the difficult moment.

• Maintaining belief: Enhancing the patient's confidence and optimism for a better future.

These categories of the caring processes are non-linear and can help understand and analyze mothers' experiences with health care services received (Nurse-Clarke et al., 2019).

In this study, Swanson's caring theory is applied as follows:

• Knowing: What mothers think about health workers' efforts to consider mothers' opinions in the management options of the preterm babies.

• Being with: What mothers think about health workers' efforts to spend more time with them during their babies' stay in the NICU.

• Doing for: What mothers think about health workers' efforts to do for mothers what they cannot do during their babies' stay in the NICU.

• Enabling: What mothers think about health workers' efforts to guide the mothers and preterm infants during hospitalization in the NICU.

• Maintaining belief: What mothers think about health workers' efforts to help mothers be optimistic throughout caring in the NICU.

Swanson's caring theory guided the development of the interview questions and the analysis of the responses.

Many studies used Swanson's caring theory to analyze the caring processes. Nurse-Clarke et al. (2019) used Swanson's caring theory to determine the extent to which labor and delivery nurses use the tenets of the theory to care for women whose babies were stillborn. In this study, Nurse-Clarke et al. (2019) used the five categories of the caring processes described in Swanson's theory to conduct a secondary analysis of a qualitative interview of 20 labor and delivery nurses. The findings revealed that nursing care for women experiencing a stillbirth included all five categories of Swanson's caring theory (knowing, doing for, being with, enabling, and maintaining belief). The tenets of Swanson's caring theory can therefore be used as a guide to caring for women experiencing stillbirth (Nurse-Clarke et al., 2019). According to Nurse-Clarke et al., Swanson's caring theory can be used to enhance the wellbeing of bereaved mothers and the relationship between nurses and patients. However, the study was limited to an analysis of secondary qualitative data. Therefore, the study could not bring out additional in-depth data regarding Swanson's caring theory. In addition, the study analyzed the experience of care for bereaved mothers from the nurse's perspective. For this study, primary data were collected from mothers of preterm babies. Hopefully, the analysis will generate more in-depth data that resonate with the five tenets of Swanson's caring theory.

Kavanaugh et al. (2015) applied Swanson's caring theory to describe how parents with the risks of delivering extremely preterm babies interpreted their interpersonal interaction with the health care providers. Kavanaugh et al. used Swanson's caring theory to analyze previously collected data from 54 parents (40 mothers and 14 fathers). The study's findings demonstrated that parents' expectations of caring included the five categories of the caring processes as described in Swanson's caring theory. The expectations of parents resonated with the 5 tenets of Swanson's caring theory as follows: (a) maintaining belief: health care workers were expected to encourage parents to respect and believe in their capacity to make the best decisions for their family; (b) knowing: health care workers were expected to understand parents' experiences and their endless efforts protecting their infant; (c) being with: health care workers were expected to engage with the parents both physically and emotionally; (d) enabling: health care workers were expected provide information including available possibilities to the parents; and (e) doing for: health care workers were expected to help parents navigate the system and also create an environment for them to make decisions (Kavanaugh et al.,

2015). According to Kavanaugh et al., the use of Swanson's caring theory to understand parents' prenatal caring expectations guarantees a deeper insight. It aligns their expectations with the palliative care movement. Both Nurse-Clarke et al. (2019) and Kavanaugh et al. (2015) applied Swanson's caring theory on secondary analysis. Unlike Kavanaugh et al., whose data was from parents with the risks of delivering extremely preterm babies, the data used by Nurse-Clarke et al. was from labor and delivery nurses. My study included an analysis of primary data from mothers of preterm babies.

In another study, Swanson's caring theory was applied to understand how nurse caring behaviors correlate with primiparous maternal confidence (Mott, 2016). The data for this study were collected from 104 primiparous mothers. Using descriptive statistics, a correlation was demonstrated between four of Swanson's concepts and maternal confidence and between nurse caring behaviors and maternal confidence. Swanson's concept of doing for did not show a significant relationship with maternal confidence. The study demonstrated the use of Swanson's caring theory to inform nurses of the importance of the nurse-patient relationship to promote maternal confidence among primiparous mothers. The study by Mott (2016) indirectly indicated other ways to improve the wellbeing of mothers and their newborns by increasing maternal confidence. Kavanaugh et al. (2015) and Nurse-Clarke et al.(2019) applied Swanson's caring theory in qualitative data. Contrarily, Mott (2016) quantitatively tested Swanson's caring theory to measure the relationship between nurse caring behavior and maternal confidence among primiparous mothers. Westmoreland and Wojnar (2019) used Swanson's caring theory to explore mothers' perceptions of care and support received from clinicians during breastfeeding initiation. Westmoreland and Wojnar conducted a secondary data analysis from a prior phenomenological inquiry of 11 mothers' meanings of early feeding experiences.

Two major themes were identified in the study (The Acts of Caring and The Lapses in Caring). These themes summarized women's experiences of care received from clinicians during the initiation of breastfeeding. The study further illustrated the utility of Swanson's caring theory to understand mothers' experiences with health care professionals' caregiving act. Westmoreland and Wojnar (2019) also used Swanson's caring theory to understand which professional acts the women perceived as caring.

Similar to Kavanaugh et al. (2015) and Nurse-Clarke et al.(2019), the study by Westmoreland and Wojnar (2019) was a secondary analysis of qualitative data. As in the study by Mott (2016) in which Swanson's caring theory was shown to improve maternal confidence potentially, Westmoreland and Wojnar (2019) showed that Swanson theory might help build trusting women-clinician relationships and women's confidence in meeting their breastfeeding goals. Trusting mother-clinician relationships and improved women's confidence may also improve mothers' experience with health care services. The study by Westmoreland and Wojnar (2019) further demonstrated the relevance of Swanson's caring theory in understanding mothers' experiences of health care services.

#### Summary

The challenges of preterm birth negatively impact the family, community, health care professionals, and the entire society. Furthermore, preterm birth disproportionately

affects low-and-middle-income countries compared with high-income countries (Desalew et al., 2020; Lawn et al., 2014). A remarkable effort has been recorded regarding science and equipment development to improve care for preterm babies (Liu et al., 2016). To support this effort, another focus is directed to DCI to improve the preterm baby's overall physical, cognitive, social, and emotional development (Lavallée et al., 2019). Mothers of preterm babies play an essential role in the process of DCI (Kalhor et al., 2016).

Many studies have shown how mothers' experiences with health care services can help to improve the health outcome of a newborn, including that of a preterm baby (Beattie et al., 2015; Carter et al., 2018; Ireland et al., 2019; Karisalmi et al., 2020; Lavallée et al., 2019; Liu et al., 2016; Lundqvist et al., 2019; Petty et al., 2019). Mothers' experiences vary from one study to another, pointing to the need for local evidence-based research findings to adequately adapt health services to a particular community (Adu-Bonsaffoh et al., 2020).

Recurrent challenges associated with mothers' experiences with health care services included health care workers' behavior (Ekström & Thorstensson, 2013; Haile-Miriam, 2012; Heringhaus et al., 2013; Kahabuka et al., 2012; Mohale et al., 2017). Many studies have used Swanson's caring theory to better understand mothers' experiences with health care services (Kavanaugh et al., 2015; Mott, 2016; Nurse et al., 2019; Westmoreland & Wojnar, 2019). The five tenets of Swanson's caring theory have been used to analyze data on mothers' perception, experience, and satisfaction with the caring processes.

The gap identified in the literature included; the lack of data on mothers' experience with healthcare services for their preterm in the NICU. Most of the studies focused on parents' perception of preterm birth. The current study adds to the few studies that addressed mothers' phenomenological experiences with health care services for their preterm babies. Unlike the current study, previous studies had a different research purpose, study population and were conducted in other geographical locations. One study described the lived experiences of mothers with preterm babies at a Mother and Baby Unit (MBU) of a tertiary hospital (Lomotey et al., 2019). Another study explored the views of health care service providers and policy-makers about preterm infants' care in health facilities and the existence of any policy protocol documents guiding the delivery of care to these infants (Gondwe et al. (2016). Kavanaugh et al. (2015) described how parents at risk of delivering their infants before 26 weeks gestation interpreted the quality of their interpersonal interactions with healthcare providers. Mbwele et al. (2013) assessed mothers' experiences, perception, and satisfaction of neonatal care in the Kilimanjaro region of Tanzania hospitals.

From the perspective of the women, the absence of quality data on Aghem women's experience with health care services for their preterm babies might continue to limit the needed information by health care providers to improve mothers' experiences with health care services. This study, hopefully, addressed the gap in the literature on the topic in North West, Cameroon. The next chapter presents details of the design and the methodology of the current study.

#### Chapter 3: Research Method

The study's purpose was to understand how Aghem women of Northwest Cameroon, experienced health services provided for their preterm babies in the NICU and how they perceived that their experience with health care services provided to their preterm babies in the NICU influenced the health care outcome for the babies. This study was designed to serve as a baseline to improve women's experiences with healthcare services provided for their preterm babies and improve their health outcomes in Cameroon. The study involved qualitative research in which a phenomenological approach was used. Moustakas (1994) indicated several qualitative research approaches used by qualitative researchers in social and health sciences, including phenomenology, narrative, case study, ethnography, and ground theory.

According to Creswell and Creswell (2018) and Moustakas (1994), a phenomenological approach helps identify the meaning attached to human experiences of a particular phenomenon from the perspective of individual participants. I used in-depth interviews to obtain in-depth information from Aghem women about the phenomenon.

In this chapter, I presented a description of the methodology, participants, research questions, and the role of the researcher. Also discussed were research tools and instruments and a pilot study. The later part of the chapter included a detailed presentation of the procedures for recruitment of participants, data collection and analysis, and discussions regarding trustworthiness and ethical concerns.

#### Methodology

According to Moustakas (1994), a qualitative phenomenology study focused more on getting the depth than getting the breadth of the participants' experiences. Moustakas also noted that there is no standard sample size in qualitative studies. From a review of contemporary studies, Creswell and Creswell (2018) suggested a sample size ranging from three to 10 for a phenomenological study. From this information, a sample size of between eight and 10 was sufficient to obtain appropriate data for the study (see Burkholder et al., 2016). Burkholder et al. (2016) further argued that more in-depth and richer interview data is collected with fewer participants than with a more significant number of participants. According to Burkholder et al., a smaller sample size may be appropriate for a qualitative phenomenological study because the analysis of a larger sample can be more labor intensive, costly, timeconsuming, and does not necessarily provide more insight. Because sampling in a qualitative study involves more researcher engagement with participants than just increasing the number of participants (Burkholder et al., 2016), I was able to prolong the length of contact with participants. Asking followup questions also contributed to giving participants enough time to reflect and respond to each question. These two strategies might have helped the participants feel comfortable and provided a free flow of in-depth information.

# **Participants**

Every region in Cameroon currently has at least a NICU where health care workers care for preterm babies and other neonates. The NICU's goals are to control infection, monitor the preterm infants during feeding, help the babies gain weight and warmth, and provide oxygen when needed (Ndombo et al., 2017). During the infant's hospitalization in the NICU, mothers of preterm babies either stay in their homes or take up a room within the hospital with the NICU. Health care workers usually give mothers a schedule to meet with their babies, breastfeed, pick up prescriptions, or attend to other requests like providing clothing for the preterm baby.

The mothers of these preterm babies made up the population from which participants were recruited for the study. A combination of purposeful and snowball sampling strategies was used to recruit participants. The purposeful sampling strategy helped in recruiting initial participants from the population of the study. The first part of the purposeful sampling included verification of the inclusion criteria for the study. The snowball sampling facilitated the recruitment of additional participants using referrals from initial participants.

To gain participation, I posted flyers (see Appendix D and E) in churches and hospitals after getting permission from the administration of these institutions. I also posted flyers in the community. To be included in the study, the women were at least 18 years of age, had had their preterm birth (less than 37 weeks of gestational age) experience in a hospital in Cameroon within 1year before the time of the interview, must be of Aghem origin (having one or both parents from Aghem) and speak English or Pidgin English (Creole). I obtained written or verbal informed consent from those who volunteered to participate in the study. In-depth interviews were conducted from a purposeful sample of 10respondents. Interviews were conducted using various methods, including face-to-face, video conferencing, and phone interviews with participants who fulfilled all the inclusion criteria.

# **Research Questions**

Using a qualitative phenomenological design to understand women's experiences with health care services, I posed the following research questions:

RQ1: What are the experiences of Aghem women of Northwest Cameroon with health care services provided for their preterm babies in the NICU?

RQ2: How do Aghem women perceive that their experience with health care services provided for their preterm babies in the NICU influences the health outcome for the babies?

# The Role of the Researcher

I took full responsibility to plan and execute the study, including identifying study sites, recruiting participants, interviewing participants, audio recording participants' responses, and securing and analyzing data. Observing participants' body language and taking notes as they respond to interview questions was also included in data collection and analysis.

My personal bias might have influenced the processes of qualitative data collection and analysis. The collected data required interpretation and value judgment which my bias could easily influence by applying the researcher's experience of the phenomenon. I used reflexivity and bracketing to reduce bias in the analysis and interpretation of data. Creswell and Creswell (2018) recommended that the researcher identify and describe (a) past experiences with the research problem or participants or site and (b) how these experiences shape the researcher's interpretations. I was born in the Northwest region of Cameroon where he attended high school. I attended university studies in Cameroon's Southwest and Center regions and the United States of America. I had no preexisting relationship with Aghem women who have experienced preterm birth. Still, I reached out to sites and potential participants through phone calls, writing, or inperson to build this relationship before beginning data collection.

Memos were written during the process of data collection and analysis processes. According to Creswell and Creswell (2018), memos help guide the researcher in generating codes and themes. Reflecting on personal experiences and writing memos during the research process helped me be aware of personal bias and avoid undue data interpretation. Tracking reactions and thoughts and acknowledging them throughout the research helped me from being judgmental and prevented my personal bias from negatively impacting data collection and analysis.

#### Instrumentation

I used the informed consent form, the individual in-depth interview with a separate section to collect participants' sociodemographic information, and a voice recorder for data collection. The individual in-depth interviews included open-ended questions about women's experiences with health care services for their preterm infants in the NICU. Included in the interview questions were specific questions that drew out data to answer RQ1 and 2. (See Appendices B & C).

Also, the semistructured interview guide favored an informal setting encouraging participants and I to interact as the participants responded to interview questions freely.

Other advantages of using semistructured interviews included (a) that it permitted me to maintain control over the direction of the interview and the participant to maintain control over the information provided, and (b) they helped me obtain adequate and rich data by delving deep into particular questions that suited the comfort of the participant and researcher alike.

The section on participant's sociodemographic information included the place of origin, place of birth, age, marital status, level of school education, number of experiences of preterm birth, number of years from the most recent experience of preterm birth, religious denomination, family income, and employment (See Appendix A).

Voice recorders were used to capture data from participants. All participants were required to sign the informed consent form before responding to face-to-face interview questions. Consent was obtained via audio recording for participants who took part in the phone or video interview

#### **Procedures for Pilot Studies**

Before using the interview questions to collect data for the study, the questions were tested for relevance, validity, and cultural acceptability. I conducted a pilot study by selecting two Cameroonian women who had experiences with health care services for preterm babies in the NICU in Cameroon. These women had the same inclusion criteria as the actual participants and they responded to the same interview questions designed for mothers of preterm babies in the actual study. Eligible and consented women for the pilot study chose to be interviewed in person at their convenient location or on a phone call. The questions were administered in English, and participants were offered a \$10 gift card (5000frs) each for their time and participation.

The pilot study helped me to verify participants' understanding of the interview questions and the relevance of interview questions to the study's purpose. The procedure informed me about revising the interview questions and improving clarity to ensure that the participants understood and readily answered the questions. The time to complete the interview was recorded, permitting me to determine whether the time was reasonable for participants' participation during the interview. I did not include data from the pilot study in the main study.

# **Procedures for Recruitment, Participation, and Data Collection**

To recruit participants, flyers containing information about the research process, participant eligibility criteria, and researcher's contact information were made available in the hospitals and in the community where the study was conducted. Women who had experiences with health care services for preterm babies in the NICU and who volunteered to participate in the study were contacted to explain the study to them and verify their eligibility to participate. Participant referral was used to recruit additional participants. Other participants were recruited from the pool of women who, after reading the flyers, reached out expressing their willingness to participate in the study.

After contacting potential participants, screening questions were used to ensure that only eligible participants were interviewed. The screening questions involved verifying if the participant was Aghem, at least 18 years old, and had experienced health care services for preterm babies in the NICU within the last year. Women considered

very sick, deaf, and unable to provide informed consent were excluded from the study. Other exclusion criteria included having a preterm baby in the hospital at the time of the interview, refusing to sign the informed consent form, and refusing to have the interview audiotaped. The participant chose a venue in the hospital or in a nearby neutral location to ensure that no other person listened to the interview other than the interviewee and the interviewer. Written or verbal informed consent was obtained from each eligible participant and the participants were informed about their right to exit the study at any time they deemed necessary. Participants were also informed of the confidentiality of their responses and the approximate duration of the interview. Participants' permission to record the interview was also obtained. The interview was conducted in either English or Pidgin English, depending on the participant's convenience and choice. The interview questions focused on 1) the experiences of Aghem women with health care services provided for their preterm babies from the perspective of the mothers of preterm babies, and 2) how Aghem women perceive that their experience with health care services provided for their preterm babies in the NICU influences the health outcome of the babies. Voice recorders were used to record the interviews and created a firsthand account in the participants' language. Each participant was offered five thousand francs (5,000fCFA), approximately ten US dollars (\$10) for transportation, and their time to participate in the study.

#### **Data Analysis Plan**

The data analysis started after the interview process was over. Following Hycners's (1985) guidelines regarding data analysis, the first step involved a word

verbatim transcription of audiotapes of the in-depth interviews. Transcripts of interviews conducted in Pidgin English were translated to English. The researcher then read through the participants' responses repeatedly to make a general sense of each participant's responses. The coding process followed this step. Units of meaning were delineated from words or phrases that were judged to illuminate the researched phenomenon; women's experiences with health care services provided for their preterm babies in the NICU. Nvivo qualitative analysis (QDA) software was used to code, group, and sort the data. The Nvivo software was chosen because of its auto coding properties, which rendered data analysis easier and faster than hand-coding. Also, Nvivo is among the recommended most user-friendly QDA software for analyzing unstructured or qualitative data such as interviews and open-ended survey responses (Predictive Analysis Today, 2016). According to Hycner (1985), the weight and chronology of events can lead to a difference in the actual meaning of two similar units of meaning. Therefore, considerations were given to literal content, the frequency at which the meaning was mentioned, and how the meaning was stated to extract units of relevant meaning, scrutinize, and eliminate redundant units. The relevant units of meaning were then categorized into themes by clustering together the units of meaning into themes that make the basis of the study. Hycner (1985) and Creswell and Creswell (2018) emphasized the importance of the iterative nature of the data analysis process. The researcher went back and forth to the list of relevant units of meaning to derive themes of appropriate meaning to the study. The iterative data analysis process also helped the researcher modify and

validate the themes elicited from the data. A summary incorporating all the themes was developed to give a holistic context of each interview.

A composite summary of all the interviews was written, bringing out general, shared, and unique themes with the context from which the themes emerged. Creswell and Creswell (2018) indicated three ways of coding 1) from data collected from participants, 2) from predetermined codes based on the theory being used, and 3) from a combination of emerging codes and predetermined codes. Creswell and Creswell also noted that predetermined codes are shared in common in the health sciences. Because the themes made the basis of the study, the results, therefore, appeared as themes based on the experiences of Aghem women with health care services provided to their preterm babies, emphasizing the use of Swanson's caring theory.

#### Validity and Reliability

The trustworthiness of a phenomenological study is demonstrated by its validity and credibility (Moustakas, 1994). To demonstrate that the method I used was appropriate to achieve the accurate and actual value of the study, the researcher consciously bracketed himself to understand the phenomenon from the participants' perspective. Audio recording of the interviews added to the validity of the findings. Other ways to achieve the validity and credibility of the study included providing details of the procedures for data collection and analysis and a detailed and thick description of the findings. A detailed description of different study aspects added to the validity of the findings (Moustakas, 1994). The researcher also used triangulation by exploring other data sources and existing literature to justify themes. Presenting a detailed narrative of the time I spent in the field interacting with participants to understand the phenomenon lent credibility to the findings. Moustakas (1994) noted that findings' accuracy or validity increases with researchers' increasing experiences with participants. Having the research committee review, ask questions, and approve the research tools also added validity to the findings.

To ensure reliability, the researcher double-checked some research processes to determine consistency in the approaches. Transcripts were reviewed for mistakes that might have occurred during transcription. The researcher wrote memos and continuously moved back to the collected data and themes, comparing the data with the themes. The iterative approach helped verify the consistency of findings and permitted other researchers to follow the procedure (Moustakas, 1994). Pre-testing the interview questions was another means to check the reliability of the study. Interviewing was piloted prior to its use in the actual study. At the end of each interview, participants were allowed to validate the accuracy of their statements so that reliability was maintained.

#### **Ethical Procedures**

Before the data collection process, I applied to the IRB of Walden University for approval of the study (Walden University's approval number: 06-28-21-0744724). Ethical clearance was also secured from the Faculty of Health Science Review Board (FHSRB) of the University of Buea in Cameroon before posting flyers and collecting data in the community for the study. I also obtained permission from church and hospital administrations before posting flyers and conducting interviews at these places. Potential participants were provided a comprehensive explanation of the purpose, benefits, and implications of the study. Those who were willing to participate were given enough time and choice to schedule for participation. The participants were also explained the voluntary nature of their participation and their rights to withdraw from the study when they deemed necessary.

Also, every participant willingly signed the informed consent form before face-toface data collection. For phone or video interviews, verbal consent was obtained from participants before participating in the study. Every effort was made to limit the disruption of participants' activities and the physical setting of the venue where interviews were conducted. This effort was made partly by allowing participants to schedule the interview at their convenience. Interviews were conducted in a language that participants found comfortable, and a little reward was offered to all participants for their time and participation.

Pseudonyms were used to represent participants to ensure the anonymity of participants. Participants were allowed to choose their pseudonyms. The identification of participants by readers was no longer possible after concealing participants' personal information during data collection. The researcher conducted the interviews to prevent another person from identifying the participants with their corresponding responses.

The collected data were safely stored and protected from any manipulation by any other person. Data were stored electronically with a password on the computer. The researcher used a lockbox and two electronic flash drives to protect data and securely transport the data from Cameroon to the United States. Voice recorders and transcripts were stored in a lockbox in the room, and I was the only one who had access to the lockbox. Regarding Walden university's requirements, the original data was stored to be destroyed after five years.

At the end of the study, participants were offered five thousand francs (approximately \$10) to compensate for their transportation and time.

#### Summary

In this chapter, I described the plan of the study. I also provided details of the study's conduct to understand the experiences of Aghem women with health care services provided for their preterm babies in the NICU. I described participants' recruitment process, including posting study flyers in the communities where the study was conducted. Also, the consent process was described, including a written or verbal informed consent collection from women who volunteered to participate in the study. I used a qualitative research approach to conduct in-depth interviews with ten Aghem women who had had preterm birth experience in a NICU in Cameroon. Voice recorders were used to capture the interviews. I transcribed all the interviews and also translated interviews conducted in Pidgin English to English. The use of Nvivo qualitative data analysis software and data analysis processes were described, including considerations of the researcher's biases. I also described measures taken to ensure the validity and reliability of the findings. The chapter ended with a discussion of ethical considerations and ways to avoid ethical issues.

#### Chapter 4: Results

The study's purpose was to understand how Aghem women of North West, Cameroon, experience health services provided for their preterm babies in the NICU and how they perceive that their experience with health care services provided to their preterm babies in the NICU influences the health care outcome for the babies. To meet the purpose, the researcher conducted interviews with Aghem women about their experiences with the healthcare services provided for their preterm babies. The research questions that guided the study were the following:

RQ1: What are the experiences of Aghem women of Northwest, Cameroon with health care services provided to their preterm babies in the NICU?

RQ2: How do Aghem women perceive that their experience with health care services provided to their preterm babies in the NICU influences the health care outcome for the babies?

In this chapter, I presented and described the pilot study, study setting, and study results. I also provided a detailed analysis of the data collected using the open-ended interview questions for mothers of preterm babies.

#### **Pilot Study**

After the approval of the proposal, I pretested the study tools with two women recruited from the Northwest region of Cameroon. I discussed the study with the women, explained the study's purpose to them, and also obtained verbal consent. One of the women (aged 36 years) had previously given birth to premature twin babies. The other woman (aged 47 years) had experienced preterm birth when her younger sister gave birth to a preterm baby. The interviews were conducted over the phone while the women were in their homes in Yaoundé-Cameroon. This process was helpful to identify if any issue existed regarding participants' understanding of interview questions. Although I made no significant changes to the interview question guide after the pilot study, the process helped me to better adjust the estimated interview time. Data collected from the pilot study were not used in the main study.

#### **Study Setting**

I conducted the study in Cameroon within June and July 2021. In-person interviews were conducted in a neutral place in Yaoundé, including the church area and the stadium. I ensured that no other person listened to the interview except the interviewee and the interviewer. Before phone interviews were conducted, I advised each respondent to be in a place with little or no interruption. The respondents chose either a place away from their house or home where they could freely talk about their experiences and I was in a quiet hotel room. I informed each participant when the recording was to begin before putting on the voice recorder. Recording began with the consent process and ended with my thanking the participant for participating in the interview. I had another phone for a backup voice recorder.

## **Demographics**

#### **Participants' Sociodemographic Characteristics**

In total, 10 women participated in the in-depth interviews. The ages of participants ranged from 21 to 37 years, with a median age of 28 years. All the participants had attained at least a secondary school level of education. Participants were assigned the following pseudonyms to maintain anonymity: Participant 1 (Angela), Participant 2 (Becky), Participant 3 (Caro), Participant 4 (Dela), Participant 5 (Eva), Participant 6 (Fibi), Participant 7 (Grace), Participant 8 (Hope), Participant 9 (Ivy), and Participant 10 (Joy). Table 1shows the sociodemographic data of the participants in this study.

Four women experienced extreme preterm birth, four experienced very preterm birth, and two experienced moderately preterm birth. Three women gave birth to twin preterm babies, and four participants lost their babies during their health care service experience. Table 2 shows other variables to describe the participants in this study.

# Table 1

Participant	Age	Marital status	Educational Status
Angela	34	Married	University
Becky	24	Single	University
Caro	25	Single	Secondary
Dela	27	Married	Secondary
Eva	23	Married	Secondary
Fibi	37	Married	Secondary
Grace	32	Married	Secondary
Hope	29	Married	Secondary
Ivy	21	Single	Secondary
Joy	31	Married	Secondary

Participants' Sociodemographic Data

# Table 2

Variable	Number	Percentage
Place of residence		
Wum	3	30%
Bamenda	2	20%
Yaoundé	3	30%
Others	2	20%
Marital Status		
Single	3	30%
Married	7	70%
Divorced/Widowed	0	0%
Delivery facility		
Referral Hospital	1	10%
District/Regional hospital	5	50%
Health Centre	2	20%
Clinic	2	20%
Type of preterm (gestational age in weeks)		
Extremely preterm (<28)	4	40%
Very preterm (=>28<32)	4	40%
Moderate preterm (=>32<34)	2	20%
Late preterm $(=>34<37)$	0	0%
Number of babies born per woman		
Number of women who gave birth to one	7	70%
child		
Number of women who gave birth to twins	3	30%
Child alive/lost		
Number of women whose child/children were	6	60%
alive during health care service		
Number of women who lost their child/children	4	40%
during health care service		

Other Variables Used to Describe the Study Participants

#### **Data Collection**

Approximately 2 months before my arrival in Cameroon, an application for ethics approval was submitted to the University of Buea-Cameroon. Flyers that indicated the research process and eligibility criteria for participants were prepared and distributed in the community after final IRB approval. The consent forms were marked to indicate those for in-person consent and those for verbal consent. Consent forms were also presented in English and Pidgin English. Participants' demographic information was also collected. The demographics further helped to confirm participants' eligibility, which the participants could determine from the information in the flyers. I obtained either written or verbal consent from each participant.

I had a purposeful sample of 10 participants for this study. The inclusion criteria for the participants were (a) being a native of Aghem, (b) at least 18 years old, and (c) having experienced health care services for preterm babies in the NICU in Cameroon within the last 1 year. The exclusion criteria included (a) women who were very sick, deaf, and unable to provide informed consent; (b) having a preterm baby in the hospital at the time of the interview; (c) refusing to sign the informed consent form; and (d) refusing to have the interview audiotaped.

With the participant's permission, I used the voice recorder to capture the interview in addition to notetaking. The interview was recorded in English or Pidgin English. Each interview lasted for about 30 minutes. Two interviews were completed per day. The recordings were later transcribed, and I compared the recordings with the transcripts. I noticed missing data in the interview conducted with Participant 6 (Fibi), re-

contacted Fibi, and completed the missing data. Transcripts in Pidgin English were later translated into English.

# **Data Analysis**

Data analysis included a series of steps. On the first, I read over the entire transcripts and listened to the recorded interviews. This step served the purpose of giving myself an overview of the data. The next step involved reviewing field notes, searching for words or phrases that stood out. Data were then imported into Nvivo 12 software and organized in tables with the aid of the software to reveal characteristics and variables. After importing the 10 interviews into Nvivo, each interview represented an internal source. Doubleclicking on a source opened a detailed view of the source content. I highlighted portions of the source content found to be particularly important and rightclicked on the highlighted content to create new codes or attach the highlighted content to previously created codes. I identified the highlighted contents by labeling them with words or short phrases. I returned to other portions of the source content and repeated the coding process, including highlighting, rightclicking, and labeling. Then I conducted the coding process on each internal source.

Furthermore, codes reflecting a particular pattern and similarities were grouped into categories. Categories were grouped into themes, bringing out more meaning from the data. Apart from using commonalities to cluster codes and categories into themes, some categories and themes were constructed from my direct observation of the data. As part of the data collection instrument, the researcher can construct themes directly from the data (Hycner, 1985). More so, the research questions guided the development of these categories and themes. I refined the themes further, organized them, and analyzed them using Hycner's (1985) phenomenological analysis of interview data. Also, patterns and comparisons were explored among the themes using matrices and queries created on the explore tool of the Nvivo (2020 release) software.

Twelve hierarchical themes, including eleven main themes and one subtheme, were created from pre-existing and emerging themes.

# **Study Results**

The study's results are presented below in two sections; Aghem women's experiences with health care services provided to their preterm babies in the NICU and Aghem women's perception of how their health care experience influenced the preterm babies' health outcomes.

In the analysis of the experiences of Aghem women with health care services provided to their preterm babies, nine themes frequently emerged. Five of the nine themes were predetermined from the Swanson caring theory and generated using deductive coding. These predetermined themes were knowing, being with, doing for, enabling, and maintaining belief.

Four additional themes constantly emerged from this analysis, including unpreparedness, surprise, confrontation, and frustration. From the women's description of their experiences with health care services provided to their preterm babies in the NICU, the nine themes were incredibly related and overlapping. The women's experiences were generally positive, characterized by the care provided for both the women and their babies. The elements of care as expressed in the participants' responses cut across the nine themes and are presented separately below:

#### Theme 1: Health Care Workers Knew the Women

This data indicated that health care workers (HCWs) recognized and considered the opinion and situations of participants when making decisions regarding the care provided to the preterm babies. Many women reported that the HCWs knew them and explained to them the baby's treatment. Some women said the HCWs called them by their names, while others reported that HCWs asked about their issues that were not visible when someone looked at them. The interview question below was asked to get data for this theme

#### Interview Question1

An analysis of participants' responses to this interview question showed that all the participants experienced a cordial and respectful relationship with the health care workers while they were in the hospital. Because HCWs knew the women, this might have helped the women to freely express their curiosity, asking questions to understand more about preterm birth. The following response from Dela supports this analysis:

I later became friends with the nurses. I was so curious, asking questions to the nurses. I made the nurses my friends and we were actually friends. I think my ability to speak both French and English facilitated the relation.

The women interacted with HCWs using multiple languages. These women made efforts to create a cordial interaction with the HCWs to facilitate a smooth navigation of the hospital system during hospitalization.

# **Interview Question 2**

An analysis of participants' responses to this interview question revealed further that HCWs knew the women. The HCWs reminded the women about their medical problems and explained the solutions before treatment was applied. This approach might have made the women feel closer to HCWS and think HCW consider their situations before treatment. Below are sample participants' responses to support the analysis:

Angela:

The nurses could call me by my name and would also check on the mark on my stomach. It was very dark spot like a burn. The mark was hidden under my clothes but they will still check on it. Even after going for antenatal clinic sessions, they still recognized me.

Becky said

Oh yes, they recognized me because they could call me by my name. Oh yes, yes especially when they were treating the baby for yellow fever. I was satisfied because the discussion was really good. They told me how they were going to do to treat the baby of yellow fever.

Eva: "I made them to know me as I didn't understand the French language. They fondly referred to me as the Anglophone. When I needed something, and I went to them they will say she is the Anglophone"

All 10 of the women indicated that the HCWs called them by their names, explained treatment to them, asked their opinion, and talked about their specific cases.

# Theme 2: Health Care Workers Were Being With and Spending Time With the Women

Most of the participants acknowledged that HCWs spent time with them. The participants expressed satisfaction when they explained how they spent time with HCWs. The HCWs conducted a variety of activities while spending time with the mothers of preterm babies. Participants' responses to the following interview question provided data for theme 2:

## **Interview Question 3**

The data analysis showed that HCWs spent time with the women. Most of the time, participants knew when HCWs were to come to meet them, how much time HCWs were to spend with them, and what they were to say. Participants seemed to plan the time they spent with HCWs. During this time, they expressed their worries about their preterm babies' health and asked questions. Overall, the participants were satisfied with the time HCWs spent with them. In support of this analysis, the following participants' responses to the above interview question were included:

#### Angela stated that

They nurses and doctors were coming every day in the morning to take care of the baby and myself... When the doctors called round, she will spend about 30 minutes talking with me only. I asked her what the cause of preterm birth was. She explained to me what's going on with the baby and provided answers to my questions. I was satisfied because the doctor explained to me certain things that I didn't know. She explained the possible cause of my muscles cramp and the mark

on my stomach, saying that the cramps and mark on my stomach will disappear with time. She said that the baby came along with the muscles cramp, she explained to me... The nurses checked the baby's temperature and weight. There was little interaction with the nurses compared with the time spent with the doctor...Unlike in the other hospital the doctor could come to me to explain certain things.

Caro: "The nurse was with me consoling me after the second baby passed (died). I think the nurse did her best because she could not do more than what she did to me".

Fibi stated

Every morning they came and control his weight...Usually in the morning, the professor and I used to have some devotion time, talking about the baby, the premature baby. He told me why I should be encouraged because many have gotten babies with the same conditions and the babies did not survive...I was satisfied with the time because the devotion was taking place during my free time, it was not the time for me to go take care of the baby. It was the right time for the professor and I to discuss. I was happy because he encouraged me.

Grace:

The pediatrician was coming every Sunday and every Friday...every time she comes, she will call all the mothers to where the babies were. She will crosscheck, examine all the babies. Any problem she will tell you that your child is having this problem. She will prescribe for you to buy. The women described various activities that were ongoing during the time they spent with HCs in the hospital. These activities included taking baby's weight, prescribing, explaining treatment options, and consoling mothers.

# Theme 3: Many Women Were Taught, Empowered, and Enabled by The HCWs

Mothers described the efforts made by HCWs to guide the mothers and their babies during their stay in the hospital. The mothers indicated that the HCWs taught them to care for the babies and maintain their hygiene. Some mothers reported that they learned how to give medications to the babies and to feed them with breast milk through a pipe.

# **Interview Question 5**

In analyzing women's responses to the above question, all the women stated that they learned something during their interaction with the HCWs. The women felt that their experience in the NICU was enriched with additional knowledge of preterm birth, the care for preterm babies, including infection prevention, provision of warmth, and feeding of the preterm baby. Participants confirmed they understood and knew how to administer the preterm baby's medicine. They also learned about exclusive breastfeeding, kangaroo methods, especially the importance of these methods for preterm babies. Participants' responses that supported theme three and the analysis included the following:

## Angela:

They explained to me that the baby's weight was still not good and that I had to stay on until the child has a certain weight...Teaching us what we have to do and what we don't have to do...So my experience there was not that bad. I can say my interaction with them was very good...They introduced me to the water therapy method where they asked me to drop just pure water on the baby's belly button until the navel will drop off.

Dela:

They taught us about the kangaroo method, exclusive breastfeeding, our appropriate eating so as to produce enough breast milk, avoiding others from carrying the baby, also limiting the number times the father of the baby should carry the baby...They taught us about personal hygiene.

Fibi:

Yes, how to wash, breastfeed the baby...So they taught me how to feed the baby using the pipe. They also showed me how to facilitate food to go down the baby's stomach. I had to pat the baby on the back so the food can go down.

Grace:

The Pediatrician told us not to touch the baby with our hands. That you may send your hand and... the child will contract germs. So we cannot send our hands...in the incubator... She was just advising us that we should not touch our babies without disinfecting our hands. That we should limit the baby's contact with people other than the mother or the father of the child. So no visitor was entering there to meet the baby.

In addition to the reports regarding the guidance and teachings the HCWs provided to mothers of preterm babies, some mothers indicated that they also received guidance from other mothers of preterm babies who were in the hospital. Eva: "All I learned there I copied from my neighbors in the hospital or from my experience".

The women described the various skill sets that the learned from HCWs during their stay in the hospital, including medication administration, breastfeeding through pipe, infection prevention, kangaroo methods and water therapy.

# Theme 4: HCWs Helped the Mothers in Doing Certain Things for the Mothers

The women indicated that the health care workers helped them do what they could not do by themselves. One woman reported that the HCWs helped to bathe her. Other ways included buying food for the mothers, taking the baby to the radiology department, sorting out expensive medications, and offering baby diapers.

# Interview Question 4

Participants' responses to this interview question provided data that aligned with theme 4. The data analysis showed that HCWs could go beyond their duty to assist the women. The women indicated that the HCWs helped them do what they usually were supposed to do by themselves. The HCWs helped the women in providing primary health care, including financial and transportation services. The participants' responses supporting theme four and the analysis included:

#### Becky:

We needed some medicine to apply on the baby's body as part of the treatment for the yellow fever...They provided me with the medicine to treat the baby... We paid 50% only of the price while the hospital took care of the other 50%. Fibi: "There was a time when they requested a scan of the baby's head and I didn't know where to go for it. One nurse took the baby with her to the particular place and had the scan done".

# Hope:

Another nurse, not the one who knew me, helped me to go buy food for me from the canteen. That's was the first help I received from them after just coming out from surgery while in pains. Out of her will, the nurse bought me tea from the canteen using her money.

All the women recognized that the HCWs made efforts to help them do what they could not do by themselves. Even Ivy who did not receive any help from the HCWs to do what she could not do by herself stated "It's because I had someone to help me all the time. So they could not help me in any way because mother was there to help me with everything".

#### Theme 5: The Women Were Able to Maintain Belief and be Hopeful

The HCWs made efforts to help mothers to be optimistic during their stay at the hospital. To make the participants optimistic, the HCWs either provided care that led to positive preterm babies' health outcomes, or the HCWs referred participants to God's faithfulness. The caring activities of HCWs that instilled hope in the participants included increasing the frequency of checking the preterm babies, creating jokes, and touching the preterm babies during doctor's rounds.

# **Interview Question 6**

The analysis of participants' responses to this question showed that HCWs encouraged the women to believe in their capacity to ensure better preterm babies' health outcomes. HCWs inspired the women to be hopeful. The preterm babies' positive health outcomes, and the relaxed atmosphere, characterized by joke-making, might have been the main reasons the women were hopeful while in the hospital. The following quotes demonstrate how the HCWs helped the participants to be optimistic:

Becky:

After three days the baby developed yellow fever which was well treated and after two weeks the baby showed remarkable improvement. The baby was taken care of and the weight improved from 1.4kg to about 1.8kg. They confirmed that the baby's weight was better and we were discharged two weeks after... While the baby was in the incubator the nurses were checking on the baby like every one hour. The baby did not run the temperature any longer.

Joy: "The time that they called me in, they made jokes, they were touching the baby during the time the doctor was making rounds to check the baby. So they did make me happy"

#### **Interview Question 7**

Participants' responses to this question provided additional data for theme 5. All the women explained that they were happy during their interactions with health care workers. Their happiness might have stemmed from the positive health outcomes of their preterm babies. Maintaining good hygiene and regular treatment follow-up of preterm babies seemed to have contributed to the preterm babies' positive health outcomes. The following quotes are examples of their explanations:

Becky:

I was satisfied with the interaction with nurse because every time they came to check the baby they was something they did that made the bay to get stronger. They prescribed a medicine...Since I took the baby there in the hospital the baby did not have fever any longer, and has been growing well.

Joy: "I was fine during my stay in the hospital because the place was neat and they used to change the bed sheets frequently."

The women's optimism was increased with improving health condition of their preterm babies and the clean hospital environment.

# Subtheme 5.1: Faith in God

The health care workers also used God's name to help mothers be optimistic during their stay in the hospital. Maintaining belief resulted from two different endeavors: 1) HCWs referred participants to God's faith, and 2) participants developed faith in God by themselves. HCWs recognized and told the women that the arts of patient treatment go beyond their knowledge of medicine. HCWs often advised the women to follow treatment and believe in God for a better health outcome.

#### Interview Question 6

Analysis of participants' responses to this question showed that HCWs referred the women to God as the main healer. The following quotes from participants' responses supported the analysis and theme. Caro:

To me it was like the world was coming to an end. I also tried hard not to question God, believing that it was God's will. I left everything to God...They just consoled me saying that God knows why everything happens.

Grace:

The pediatrician told us that we should not be afraid because with God all things are possible. That even she, herself she cannot take care of the children. It is only God and she knows that God will pass through her to protect all the babies...I went and bought it (medicine) upon coming back, I looked at my child the child was no longer the way I left her. I said eeh (exclamation). Since I was just praying, I just trusted God.

In addition to the predetermined themes that were developed from the deductive coding methods, other themes emerged from the participant's responses. The themes that emerged from inductive coding methods included unpreparedness, surprise, confrontation, and frustration and are presented separately below:

#### Theme 6: HCWs Were Unprepared and Slow to Provide Health Care Services

The women explained that the HCWs were unprepared to offer the health care services. They described how the HCWs were not ready to carry the babies during the caring process. There were times that the HCWs were not appropriately dressed to take the baby into the incubator, which led to a delay in providing care to the baby.

## **Interview Question 1**

The analysis of participants' responses to this question demonstrated that the HCWs were not ready to provide health care services when the preterm babies needed them. This attitude of HCWs might have contributed to the women's poor health care experiences. Also, the delay in treatment might have led to women's distrust in health care services, lack of hope in health outcomes of preterm babies, and babies' poor health outcomes. The following quotes indicated the responses of participants supporting the analysis:

Angela:

During the delivery process the baby came unexpected, even the nurses were unprepared, they weren't putting on the appropriate dressing to assist in delivery. After delivery, the nurses kept the baby on my chest as they couldn't carry to the baby the incubator with their hands. The baby gave me a mark on my stomach as the baby came out.

Dela:

The first part is that as the baby came out I carried the baby on my chest for 3 minutes while the nurses stood watching. The nurses later carried the baby and kept the baby exposed. They didn't dress up the baby immediately until my mother complained.

The women complained about the nurse's unpreparedness to offer care to their preterm babies. The nurse's unpreparedness was demonstrated by their inappropriate dressing and the delay to keep the baby warm in the incubator.

#### Theme 7: The Women were Surprised and Unhappy

The women expressed surprise with the healthcare services they received in the hospital. In addition, the women were surprised by the way the HCWs treated them and their babies and the unexpected and untimely arrival of the babies.

#### Interview Question 8

Analysis of participants' responses to this interview question showed that the women were astonished to observe specific behaviors of the HCWs. HCWs did not treat dead bodies of preterm babies with respect; HCW quickly gave up on treatment and attention to critically ill preterm babies, abandoning them to die. These behaviors of HCWs were least expected by the women, who were very unhappy. The following quotes included the responses of the women indicating their surprise and unhappiness:

Dela:

The way the nurses treated the body of a baby who had passed (died) was surprising. They just held the baby like an object and thrashed it in a bag. It was very painful to see. Also sometimes when the baby had difficulties to breathe the nurses didn't pay much attention saying that the baby will not make it...I was surprised and it was strange to me.

Eva:

At the Acha hospital, the HCWs were very caring but the only problem was that there was no incubator and I was referred to the General hospital, it was embarrassing and surprising that the caring hospital did not have an incubator...On the contrary, in the General hospital where we were referred to, there was no care. The nurses didn't care about us.

HCWs neglected critically ill preterm babies because they assumed these babies were going to die. They did not also treat the bodies of preterm babies who died with respect. The women were surprise and unhappy with these HCW's behaviors because they expected them to be caring and respectful to their patients.

## **Theme 8: The Women Experienced Confrontations With HCWs**

The women explained that they got into arguments with the HCWs during their interaction with the HCWs. These arguments resulted from payment for healthcare services, the unacceptable behavior of HCWs, and disagreement in the choice of care between the HCWs and the women.

#### **Interview Question 1**

Analysis of participants' responses to this question showed that the women often disagreed with the HCWs, which sometimes resulted in verbal confrontations. HCWs argued with the women on healthcare-related issues. The women did not seem to believe that the HCWs mastered the needed health care services. On the one hand, the women suggested and requested certain health care services. On the other hand, HCWs refused to provide health care services just because the women requested them. These confrontations often led to the preterm baby being unattended and the women being unhappy and having poor health care service experiences. The following quote indicated a participant's response in support of the analysis:

Grace:

I saw an ant on the child's body in the incubator...And I went and called one of them (nurses) that there was an ant was on the baby's stomach. The girl, the woman (nurse) told me that the ant cannot do anything to the child. I asked her to remove the ant...The nurse told me that I cannot command her and she told me that she was not going to remove the ant. I said I was not giving her orders but that but I didn't like what I was seeing on my child. I insisted that she should remove it. It was like a problem. I went and called for another nurse.

# **Interview Question 8**

Also, the analysis of participants' responses to this question further supported theme 8. The confrontational interactions between the women and HCWs also came up when the women disputed hospital bills presented by HCWs. The women were either not satisfied with how HCWs provided health care services or suspected that the hospital bills were inflated. Since HCWs could not listen to the women that they were not trained health care professionals, the women resorted to a confrontational approach to make their points. The following quote included the responses of a woman indicating her confrontation with HCWs:

#### Grace:

The nurse asked me if I were teaching her their work. She said I was not a nurse how come I wanted to teach her nursing work. One didn't even have a voice in that hospital again... When I went and gave pressed breast milk to the nurses, they put it inside the feeding bottle. After they had fed the baby, .they...let me say half or small was left in the bottle. They did not throw it. They insisted to mix it with the artificial milk. I insisted asking them to throw the remaining breast milk. I told them that I was not buying it. Even if I was buying I asked them to throw and not mix breast milk with artificial milk. The nurses still went ahead and mixed the breast milk with the other milk and fed the baby with the mixture. To me, this was very bad.

The women frequently got into argument with HCWs during moments when the women requested health care services from the nurses and when HCWs presented hospital bills to the women. The argument and confrontation often resulted from both parties not trusting each other and the women suspecting that HCWs inflated the hospital bills.

# Theme 9: There Were Times the Women Became Bitter and Frustrated

The mothers of preterm babies were shocked, disturbed, and worried about certain aspects of their stay in the hospital and their interaction with the HCWs when these HCWs were providing health care services to the preterm babies.

#### **Interview Question 1**

The analysis of participants' responses to this interview question showed that the women were unhappy and felt helpless when interacting with the NICU's HCWs. Some aspects that likely rendered the women unhappy and helpless included poor communication on the side of HCWs, preterm babies' poor health outcome, and death. Unhappiness and frustration were possible endpoints for women whose preterm babies died during their health care service experience. Also, some women got frustrated due to a lack of adequate information or instructions on the available health care services. The following quotes are examples of participants' responses demonstrating how disturbed the participants felt:

## Caro said

The second baby stayed until about 3pm the same day, then passed (died). I still gave thanks to the lord, and decided to gather strength to live on. I wasn't really expecting this to happen to me. I was traumatized. I just left everything to God. All these happened on the 22nd of January 2021.

# Eva stated

They didn't explain to me how the process of treatment was like... They didn't tell us that the name on the paper on top of the incubator is the name you have to bear throughout your stay in the hospital. The paper on the incubator was carrying all what you had to do with the child and whether a mother could read or not did not concern the nurses...My twin babies were taken to the General hospital a day before I was discharged from the Acha hospital... No one explained to him that the babies were expected to be given a bath every day at 4am. As a man he could not do these things. Even when I went there no one showed or told me what to do. I had to figure out myself. Before having the premature twins, I had a baby before but I can't say I had ever bathed a newborn... Even if you knew what to do and you took the paper to the pharmacy, they never served you if you didn't have money at hand. Especially if you didn't speak French they would just ask you to go away...The second one (baby) was still alive and needed blood. We struggled to pay for the blood but the baby too passed (died) and they put the body in a carton paper asking us to pay before they could give us the corpse. I even begged to see the corpse and they refused that they had already hidden it... The body of first baby was kept for about 2 hours, the baby died at about 4 am and we took out the body and buried it by 10 am.

#### Interview Question 8

The analysis of participants' responses to this question showed that the women were traumatized by how the HCWs treated them. The women were overwhelmed with their financial commitments. The women felt that they had to pay for the frequent prescriptions and pay the nurses to take care of their preterm babies. They became more frustrated and bitter when they thought they had lost their preterm babies because they could not afford to meet these financial requirements. The women were seriously disturbed that the nurses refused to provide health care services to their preterm babies because they did bribe them. Women's frustration also resulted from the frequent disappearance of medication they bought for their preterm babies. The following quotes indicated participant's responses in support of the analysis:

Eva:

There was a time I saw my baby struggling when the oxygen pipe was displaced from her face. When I informed a nurse about it she asked me to arrange it. I asked myself what training I got to do that...Sometimes they sent one away if they don't understand what you say.

Grace:

What I learned there was that they needed money, even the nurse. If you wanted that they should really take good care of your child, you had to also motivate them. They were not like doing their own job. The way they treated me there I cannot lie to you...every blessed day I was crying...At times they were some parents that will not stay the night in the hospital and in the evening they will go home leaving their babies there in the hospital. And if anything happened to their baby, the nurse will come and call me saying that it was my child. The nurse will ask me to give money for them to go and buy something. Thinking that it was my child, I was giving them the money... At times they collected the medicine and sold to others if you're not motivating them, you're not giving money...They were not doing their job. We were suffering and my child died because of carelessness... The nurses treated the babies according to the status of their parents and the relationship they had with the parents of the babies. They usually bathed the children of rich people but my child since the 2 weeks that I was there...they never bathed. We spent a lot. Their problem is money. They could bring a bill of so many items asking me to go and buy. .. The day the child was to pass (die). I don't know what happened in there. When the pediatrician came, she told me that the child was fine... And my child was not having any infection...They sent me to go and buy drugs (medicines). I went and bought them, upon coming back, I looked at the child the child was no longer the way left her...The drugs I bought I asked them to give me. They went and wrote a bill forgetting that I deposited 150 thousands on our first day at hospital and 100

thousand francs 3 days after. The day that child died, another bill came out that I was unable to pay. We stayed there until my brother told them (nurses) to write the names of all the items and medicines used on the baby with their prices. That's how they could no longer come out with that 500 thousand francs bill that they claimed. The bill of 500 thousand francs was brought down to 50 thousand francs with the intervention of the owner of the hospital. We then paid the 50 thousand francs.... When they learned that you have someone who is a rich or that your husband was working somewhere, your price (bill) was also different. And when they learned that this man does not have anything, their own price (bill) was also different. That's what I experienced there... They refused that I should not enter to see the Pediatrician, asking me to go to my room. They actually refused. That Sunday I never met the pediatrician. The Pediatrician came and examined my child when I was not there. They had refused that I should not come there, saying that I've been coming there too often... On Sunday the child passed out (died),...I was really touched... So it really affected me that day, Saturday, and the following Sunday, the child passed (died).

In addition to investigating the experiences of Aghem women with health care services provided to their preterm babies in the NICU, this study also investigated how the women perceived that their experiences influence the health outcome of their preterm babies. The women responded to the above investigation by providing their opinion. Some women explained their opinions with examples, while others just presented their opinions without providing further comments. Two themes emerged from the women's responses and are presented separately below:

# Theme 10: Women's Experience With Health Care Services Influenced the Health Care Outcome of Preterm Babies

Most of the women perceived that their experience with health care services provided to their preterm babies influenced the health outcome of the babies.

# **Interview Question 10**

The analysis of participants' responses to this interview question showed that the women perceived that their health care service experience influenced the health outcomes of their preterm babies. The women seemed to have understood that other factors than equipment and human resources are crucial for a better preterm baby's health outcome. The following factors could be deduced from the quotes below that the women perceived affected preterm babies' health outcomes; adequate communication between HCWs and the women, cordial interaction between HCWs, and women's health care experience.

Dela: "Yes, the doctor's advice to us like keeping the baby warm and about nutrition actually helped to improve the health of the baby. I had no idea about these things before.

Eva: "Yes, the fact that they kept the list of requirement on top of the incubator without letting me know what it was all about could lead to a delay in providing treatment to the baby."

Joy:

They treated me well. They didn't do what could make me to vex or something that could make me to breastfeed the baby while annoyed that could affect the baby. When you (the baby's mother) are not happy and you go breastfeed the baby, the baby can refuse taking the breast or the baby won't really breastfeed as expected".

The women perceived that adequate communication with HCWs and a cordial relation with them contributed to favorable preterm baby's health outcomes.

# Theme 11: Women's Experience With Health Care Services Did Not Influence the Health Care Outcome for the Babies

The women also perceived that their experience with health care services provided to their preterm babies did not influence the health outcome of their preterm babies. The analysis showed that the women had different perceptions regarding the influence of their health care service experience on the health outcome of their preterm babies.

#### **Interview Question 10?**

The analysis of other participants' responses demonstrated that the hospital equipment was the only crucial factor influencing preterm babies' health outcomes. This perception was revealed among women who perceived that their health care service experiences did not influence the health outcome of their babies. However, the women acknowledged that their health care service experiences could affect their health outcomes but not that of their preterm babies. The women said the comments below to indicate their perceptions: Caro: "To me, only the incubator could help improve the health of the babies and sustain their lives."

Ivy: "That doesn't exist. It can only affect me and not the baby. If they (HCWs) don't greet me, it can affect me (the baby's mother) only, not the baby." The women identified hospital equipment as a major factor that influenced their preterm baby's health outcomes. They also recognized that their relation with the HCWs influenced their health care experience but not the health outcome of their babies.

### Summary

Regarding women's experience with healthcare services provided for their preterm babies, nine themes emerged from the data analysis. These themes included 1) health care workers knew the women, 2) health care workers were being with and spending time with the women, 3) many women were taught, empowered, and enabled by the HCWs, 4) HCWs helped the mothers in doing certain things for the mothers, 5) the women were able to maintain belief and be hopeful. The women also explained some negative experiences with the health care services through the following themes: 1) HCWs were unprepared and slow to provide health care services, 2) the women were surprised and unhappy, 3) the women experienced confrontations with HCWs, and 4) the women became bitter and frustrated. Two other themes emerged from the women's perception regarding the influence of health care experience on the baby's outcome. These themes included: Women's experience with health care services does influence the health care outcome of preterm babies, and women's experience with health care services does not influence the health care outcome of preterm babies. In the next chapter, I interpreted the findings, presented limitations,

recommendations, and potential impact on positive social change.

Chapter 5: Discussion, Recommendations, Implications, and Conclusions

Despite medical advances, preterm birth continues to be a public health problem worldwide. Globally, preterm birth remains among the top causes of morbidity and mortality in children under 5 years (Hug et al., 2019; Liu et al., 2016; Ndombo et al., 2017). The effects of preterm birth are unevenly distributed over the globe, with higher mortality rates in LMICs compared with high-income countries (Adu-Bonsaffoh et al., 2020; Chawanpaiboon et al., 2019; Desalew et al., 2020). In Cameroon, the high infant mortality rates (37% - 47%) pointed to the significance of investigating the health care services these preterm babies receive.

Preterm birth results in mothers giving birth to babies before 37 completed weeks of gestational age (Liu et al., 2016). Preterm babies face difficulties adapting to extrauterine life due to the immaturity of many organs (Mahwasane et al., 2020; Heringhaus et al., 2013). These difficulties often lead to complications such as learning disabilities; and visual and hearing problems that may persist through childhood among preterm birth survivors (Kelly & Li, 2019; Soleimani, Zaheri, & Abdi, 2014). In addition, preterm infants are at higher risk of readmission and medical complications, including increased morbidity and mortality compared with term-born infants (Karnati et al., 2020; Thygesen et al., 2016). Therefore, preterm babies require extra health care services, and this requirement contributes to a financial burden to the preterm baby's family and society.

Improved women's experience with health care services provided to their preterm babies seemed to lead to better health outcomes (Jones et al., 2012). Earlier studies revealed a positive effect on the outcome of neonatal health care because of positive parents' experiences with postnatal health care services (Jones et al., 2012). However, healthcare workers' negative behavior and attitude in sub-Saharan Africa were reported to cause poor health care experiences among women in sub-Saharan Africa (Jonas et al., 2017). To better advocate these women's health care experience and improved health outcomes of their babies, more conclusive and generalizable data were needed to define the extent of the problem (Jonas et al., 2017).

This phenomenological study of the experience of Aghem women with health care services provided for their preterm babies used data collected from semistructured interviews. The study's purpose was to understand Aghem women's experience with health care services provided for their preterm babies in the NIC. I aimed to understand how these women perceived that their experience with health care services provided for their preterm babies in the NICU influenced the health care outcome of the babies.

The study revealed women's experiences as they go through the caring and health service delivery processes while interacting with health care workers. The study also provided a baseline that will hopefully inform national policies and programs to reduce and eliminate poor healthcare experiences among women in Cameroon. I addressed the following two research questions were in this study:

RQ1: What are the experiences of Aghem women of Northwest Cameroon with health care services provided to their preterm babies in the NICU?

RQ2: How do Aghem women perceive that their experience with health care services provided to their preterm babies in the NICU influences the health care outcome for the babies?

The study was based on Swanson's (1991) caring theory. Swanson's caring theory stipulated health care workers' respect of the five categories of care to improve patient or family experience of a healthcare encounter (Cook & Peden, 2017; Welch & Fournier, 2018). The five categories of care include (a) maintaining belief: health care workers encourage women to respect and believe in health care worker's capacity to make the best decisions for preterm babies' welfare; (b) knowing: health care workers understand and consider women's experiences and their endless efforts to protect their preterm babies; (c) being with: health care workers spend time and engage with the women both physically and emotionally; (d) enabling: health care workers provide information including available possibilities to the women; and (e) doing for: health care workers help women navigate the system and create an environment for the women to make decisions (Kavanaugh et al., 2015).Swanson's theory provided further insights into the actors and factors that might lead to women's poor health care experience, resulting in poor health outcomes of the preterm babies.

#### **Summary of Findings**

The data analyzed in this study were derived from the interviews with 10 Aghem women who had experienced NICU health care services provided to their preterm babies in Cameroon. All the women in this study had their deliveries in a health care facility before transferring the preterm babies to the NICU. Ten percent of the women gave birth to preterm babies in a referral hospital, 50% in the district and regional hospitals, 20% in a health center, and 20% in a clinic. Generally, the women had a positive experience with health care services provided for their preterm babies in the NICU. However, 40% of women lost their preterm babies during their stay in the hospital. The women's experience of child's death, their confrontation with HCWs, and the lack of information on available health care services got the women frustrated, resulting in the women losing hope in their preterm babies' survival.

Key findings revealed 11 themes and one subtheme as determined by participants' responses and Swanson's caring theory. The women's ages ranged between 21 and 37 years; 70% were married while 30% were single. All the women had attained a secondary school level of education.

Women's positive experiences included the HCWs' practice of the five tenets of care following Swanson's caring theory. The HCWs knew the women and considered their opinions, spent time with them, taught them, helped them do what they could not do by themselves, and helped them be hopeful that their preterm babies were to get well during the interaction between the HCWs and the women,

However, not all the women perceived that their healthcare service experience influenced the health outcome of their preterm babies. Some women perceived that appropriate equipment was the only significant factor influencing their preterm babies' health outcomes. The women perceived more value on equipment than HCWs' poor behavior and disrespectful treatment of the women to positively affect their preterm babies' health. This study's findings showed that some women perceived available and affordable equipment as the only factor influencing their preterm babies' health outcomes. Meanwhile, other women perceived that their healthcare service experience influenced their preterm babies' health outcomes. The difference in women's perception of how their health care experience influences preterm babies' health outcomes might be due to the women's difference in age, educational level, marital status, income, previous experience the NICU.

# **Interpretation of the Findings**

As detailed below, the findings of this study were considered in light of existing research findings. Particular attention was paid to how the findings replicated or failed to replicate existing research. The women in this study knew other women who had experienced preterm birth. According to the women, preterm birth was increasing, and they were eager to know the reasons for the increasing number of preterm births. However, this study could not verify the reported increase in the number of preterm births. The report was based on the participants' experience prior to hospitalization. Nevertheless, the study focused on participants' experiences during hospitalization. The findings confirmed previous findings that preterm birth is a common public health problem in Cameroon (Ndombo et al., 2017). The women also experienced the loss of their babies during their experience with the health care services. This experience was consistent with other findings confirming preterm birth's complications, including the preterm baby's death (Hug et al., 2019; Liu et al., 216; Ndombo et al., 2017).

## **Financial Experiences of Health Care Service**

As detailed in Chapter 4, women experienced financial challenges, including a lack of money to pay for treatment, hospital referrals, and readmissions. As a result, there was a delay in the provision of health care services by the health workers, potentially resulting in increased complications of the baby's health and frustrations of the baby's mother. This study also verified that women had financial burdens due to extended hospital stays, missing medications, frequent prescriptions, and the cost of extra hospital room/space for the mother. The women selected what to buy from the prescription due to financial hardship. The women's inability to buy all the prescribed medications for their preterm babies contributed to their poor health care service experience. The health care service experience worsened with the medication missing from the preterm baby's bedside cupboard. The women repeatedly bought the same medication due to this loss of medication. The women were also frustrated because they could not trust the HCWs to keep their preterm baby's medications. These study's findings confirmed the findings of Karnati et al. (2020) and Zainal et al. (2019) that preterm birth was associated with higher health care costs than the cost of care for term-born babies. The findings also confirmed those of Lakshmanan et al. (2017) that preterm birth was associated with increased financial worries among parents of preterm babies. In addition, the women experiences related to findings that preterm babies had higher readmissions, morbidity, and mortality rates at 1 year compared with term-born babies (Karnati et al., 2020; Zainal et al., 2019). However, I did not compare the cost of care with that of term-born babies. Mothers of term-born babies might have also experienced financial hardship in the same hospital and time.

# **Social Experiences of Health Care Service**

As detailed in Chapter 4, women's social experiences included cordial interactions with HCWs and the presence of a support system including teaching, consoling, instilling hope in women by HCWs. The HCWs also bought food and diapers for the women and their preterm babies, respectively. The women's social experiences indicated an overall positive experience with the health care services provided for their preterm babies.

These experiences supported the findings of Linda et al. (2018) that women reported positive experiences with health care services for their preterm babies when HCWs treated them with respect and dignity. The women used the words competence, altruism, responsible, and empathy (CARE) to characterize the attitude of HCWs (Wei et al., 2018). The experiences also confirmed the findings of Kahabuka et al. (2012) that a welcoming environment alongside a supportive and empathic HCWs were crucial factors in ensuring a positive women's health care experience and better preterm babies' health outcomes. This study's findings also added information about women's social experiences of health care services provided for their preterm babies. The women felt more comfortable expressing themselves in front of the pediatrician than the nurses—the pediatrician dedicated time listening to the women and responding to their worries while heath care workers assisting with their preterm babies disrespected and argued with the women.

#### **Emotional Experiences of Health Care Services**

As detailed in Chapter 4, the women's emotional experiences of healthcare services included the feeling of surprise, becoming bitter, helpless, and frustrated. These findings were consistent with McLemore et al.'s (2018) findings that described women's overall experience with health care services during the birthing and postnatal periods as disrespectful and discriminating. Disrespect and discrimination were possible causes of the feeling of helplessness and frustration. The women felt that HCWs discriminately

cared for their preterm babies, putting in more time and attention to women who offered extra money for their preterm baby's care. In such circumstances, the women felt helpless and resorted to prayers for the preterm babies' welfare. Like McLemore et al.'s (2018) findings of overall disrespectful and discriminating women's health care services experience during the birthing and postnatal periods, this study's overall women's emotional experience with health services for preterm babies stemmed from the baby's unexpectedness, surprise, and early arrival. All the women experienced preterm birth for the first time. They were worried about the cause of preterm birth, preterm babies' health, and their selves' blame. These results also supported the findings of Lomotey et al. (2019) that mothers of preterm babies have emotional experiences when their preterm babies are in the NICU in part by their sense of guilt and fear of the baby's health outcome. Additionally, the findings of this study are consistent with earlier studies by Aagard et al. (2015) and Ionio et al. (2016), Linda et al. (2018), indicating that mothers are often surprised by the event of preterm birth, leaving them in stressful conditions.

#### **Other Findings**

Other findings that could not fit into the above clusters include the varying women's perceptions of how their experience with health care services influences the health outcome of their preterm babies. These findings were consistent with Linda et al.'s (2018) findings of varying mothers' perceptions of how the baby's health outcome was related to health care services provided to the mothers. Mothers' perceptions are often based on their expectations of the health care services. According to Amorim et al. (2019), women's perception of health care services provided for their preterm babies varies with different parental characteristics such as age, educational level, and previous preterm birth experience in the NICU. However, I did not investigate further the women's characteristics. The findings further support Fernandez-Perez et al. (2019), who highlighted the complexity and variety of factors of positive patient's experience with health care services, indicating the relevance of developing health care services from local evidence-based research findings (Adu-Bonsaffoh et al., 2020).

# Difference With and Confirmation of Existing Literature

In this study, women had positive experiences with the health care services provided for their preterm babies even with the lack of specialized equipment and resources such as incubators and oxygen apparatus. This study's finding is consistent with Wei et al.'s (2018) claim that the best health care service practices go beyond the availability of specialized equipment and include care for the heart and soul. Women's positive experiences were based on how well health care workers interacted with them by spending time with them, consoling, and sympathizing with them. The finding illustrated the importance of health care workers' positive interaction with the women in improving their experience with health care services provided for their preterm babies. Improving women's health care experience is helpful in sub-Saharan Africa, including Cameroon, where specialized equipment is limited or unavailable in certain areas.

Furthermore, women had negative experiences with health care services provided for their preterm babies even with the available specialized equipment. The women's negative experiences point to other factors than specialized equipment that influence women's health care experience. This finding added to the findings of Kadia et al. (2020)

and Mahwasane et al. (2020) that insufficiencies in specialized equipment are significant challenges in improving health care service experience in sub-Saharan Africa. The different findings within this study indicated that health workers' behavior and specialized equipment play a significant role in providing health care services and improving women's experience with the health care services. Therefore, there is a need to improve the health care worker's behavior and the necessary equipment to assist in improving women's health care service experience and preterm baby's health outcomes. As detailed in this chapter, the women's social experiences with health care services confirm the five tenets of Swanson's caring theory. According to Nurse-Clarke et al. (2019), this theory can be used to better understand and improve mothers' experiences with health care services and enhance their relationship with health care workers. In the same light, Westmoreland and Wojnar (2019) showed that Swanson's theory might help build trusting women-clinician relationships and women's confidence in meeting their breastfeeding goals. This study's findings support the findings of Westmoreland and Wojnar (2019) that women's experiences of health care services are positive and negative. Swanson's five categories of care, knowing, being with, enabling, doing for, and maintaining belief, described the women's positive experiences in this study; meanwhile, the theme The Acts of Care described the women's positive experiences in Westmoreland and Wojnar's (2019) study. Also, in this study, women who had negative health care service experiences were subject to surprise, unhappiness, confrontation, bitterness, and frustration; meanwhile, the theme Lapses in Caring referenced negative health care experiences in Westmoreland and Wojnar's (2019) study. While this study

investigated women's experiences with health care services provided for their preterm babies, Westmoreland and Wojnar's (2019) study investigated women's experiences of care received from clinicians during breastfeeding initiation. Both studies illustrated the leverage of Swanson's caring theory to understand mothers' experiences with health care services.

Unlike the studies by Nurse-Clarke et al. (2019) and Westmoreland and Wojnar (2019), which were limited to analyzing secondary qualitative data, this study used primary data collected from women with preterm birth experience. The study likely brought more insights to Swanson's caring theory when compared with the study by Nurse-Clarke et al. (2019).

Unlike most previous studies on preterm birth in many developing countries that focused more on parents' perception to improve health care services (Gondwe et al., 2016), this study relied on women's experiences to reveal the factors and actors influencing health care services. Interestingly, this study's findings revealed financial, social, and emotional factors that potentially influence women's experiences with health care services provided for their preterm babies. The study's findings also noted health care workers and mothers of preterm babies as significant actors in the process of health care service delivery. In line with this study, Beattie et al. (2015), Liu et al. (2016), and Mohale et al. (2017) noted that one way to improve mother's experience with health care services provided to their services with the health care services provided to the preterm babies. There was little information on women's experience with health care services provided to their preterm babies, as noted by Gondwe et al. (2016) and evident

in chapter 2. Therefore, this study's findings added the needed information on women's experience with health care services provided to their preterm babies.

The information might provide a base for health care providers and policy-makers to better understand the problem and develop strategies to ameliorate women's experiences with health care services. Abeasi and Emelife (2020), Kalhor et al. (2016), and Yang et al. (2019) documented that as an effort to prevent long term hospitalization of preterm infants and to reduce associated consequences, it was necessary to consider mothers' experience with health care services provided to the newborn. Therefore, the findings of this study added to the body of scientific literature regarding women's experience of preterm birth in the developing world by examining the situation of health care services for preterm babies in Cameroon. Also, the findings added information related to the perception of women regarding the influence of their experience with health care services on preterm babies' health outcomes.

#### **Limitations of the Findings**

Using a convenience and small sample limited the ability of the findings of this study to be transferred to a larger population. This limitation is not uncommon in a phenomenological study. However, the limitation was addressed by interviewing women of diverse ages, place of residence within Cameroon, economic background, and care facility. Furthermore, the aim of this study was not to provide conclusive findings of the phenomenon but to understand Aghem women's experience with health care services provided for their preterm babies Another limitation was the nature of interview data collection. Respondents often tend to want to appear appropriate to researchers. This behavior might prevent the respondents from providing valuable details. To address this limitation, I used phone and face-to-face interview methods and provided respondents with a comprehensive introduction of the study, allowing them to open up freely to the interview.

Potential problems with translation to and from English made up another limitation. Subtext and even context can be lost in translation. I am a native speaker of Pidgin English and I have also been trained in health services management in the United States and Cameroon, and therefore had a solid understanding of the linguistic nuances. Furthermore, to confirm the reliability of the translation, I repeated the translation two days after the first translation while keeping away the previous translations and compared both translations to find that the results were similar.

The analysis of the qualitative interview data required interpretations, possibly using value judgment on the researcher's part. Strategies to mitigate this limitation included reflectivity and bracketing and the implementation of feedback from the research committee at every study stage.

I could not collect additional data by observing the interviewee's body language using the phone interview. This data collection method might have non-verbal information. I asked follow-up questions to ensure the interviewee exhausted responses as much as possible to address this limitation.

#### Recommendations

The literature review included several topics on preterm birth, but few had addressed customers' experiences with health care services from both the consumer and health care workers. Though beyond this study's scope, investigating mothers' experience with health care services provided for their preterm babies from the perspective of both the mothers and healthcare workers may provide a more comprehensive picture of the phenomenon. This finding opens doors for further research. The recommendation would be to investigate mothers' experience with their preterm babies' health care services from the perspective of mothers and health care workers.

Factors that led to poor women's experience with health care services included contentious and attacking interactions between the women and health care workers. These types of interactions often resulted in women being discouraged, helpless, and hopeless. The women tended to have less confidence in HCW and less hope for the welfare of their babies. The grim that characterized the interactions between women and health care workers points to a great need for professional development. The recommendation would be to educate health care workers on health care service planning, health care worker-patient communication, and health care worker-patient interaction.

Awareness of the emotional state of the women suggests a need for additional support for these women, including emotional support. Increasing access to emotional support services is crucial in preventing the consequences of the women's emotional state. Emotional support services also led to an improved women's experience with health care services. The recommendation would be to increase women's access to emotional support services, such as offering encouragement, reassurance, and compassion through verbal expressions or physical gestures of affection to mothers of preterm babies.

# Implications

Understanding women's experiences with health care services are known to inform better strategies to improve health care experiences (WHO, 2017). Poor women's experience of health care services in sub-Saharan Africa reflected a lack of understanding of this phenomenon or a failure to implement strategies to improve women's experiences.

This study was one of the few studies to investigate the experience of mothers of preterm babies with health care services in the NICU in North West, Cameroon, and Africa. The study added substantially to the pool of knowledge on this issue which had very little available information and awareness. The study shed light on crucial factors and actors that affect women's experiences with health care services. Hopefully, the findings provided a much-needed understanding of women's experiences and informed strategies to improve these experiences and preterm babies' health outcomes.

# Conclusion

The behavior of health care workers in sub-Saharan Africa increasingly challenges efforts to improve women's experiences with health care services (Haile-Mariam, 2012). There is no reason for this challenge to increase. This study's purpose was to understand Aghem women's experiences with health care services provided for their preterm babies and how they perceived that their experience with health care services provided to their preterm babies in the NICU influenced their preterm babies' health outcomes. The study's findings showed that health care workers demonstrated the five tenets of Swanson's caring process. However, several aspects of care challenged women's experiences, including lack of preparation of care, contentious and attacking interactions between health care workers and mothers of preterm babies. The study's findings point to the importance of adequate information about women's experiences with health care services for a practical understanding of the challenges. The findings might provide the information needed to develop interventions to improve women's experiences with health care services, such as providing continuous professional development for health care workers and improving access to additional emotional support to the women. Hopefully, recognizing the challenges mothers of preterm babies face as they experience health care services provided for their preterm babies will spur policy-makers and other stakeholders to dedicate efforts to improving women's experiences and preterm babies' health outcomes.

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1. Pseudonym:.... 2. Age:.... 3. Native of Aghem Yes 🗌 No 🔲 4. Place of birth:.... 5. Marital status: Married , Single, Divorced , Widow Other 6. Level of school education: None  $\Box$ , Primary  $\Box$ , Secondary  $\Box$ , University  $\Box$ 7. Hospital of child's birth..... 8. Age of pregnancy at delivery(in weeks):  $< 28 \square$ ,  $= > 28 < 32 \square$ ,  $= < 32 < 34 \square$ , =< 34<37 🗖 9. Number of preterm births:.... 10. Date or Year of last experience of preterm birth: 11. Religious denomination: Christian  $\Box$ , Muslim  $\Box$ , others  $\Box$ 12. Family income:.... 13. Employment: 14. Place of residence: Thank you for your participation. Let me know if you will be available for any follow-up

questions to clarify certain points that might come up. Please feel free to contact me if you have any questions or concerns about the way your answers will be used, or any other problems related to the study. The information will be used solely for the purpose of understanding women experience with health care services provided for their preterm babies. Appendix B:Interview Questions Guide for Participants – English Version Interview questions and probes relating to experiences with health care services will include the following:

- Please tell me about your experience when you interacted with health care workers (e.g. nurses and physicians) who provided health services for your preterm infant in the NICU.
- 2. Do you think the health workers knew you? If yes, what did the health workers do to show that they knew you? If no, what did the health workers do to show that they didn't know you?
- Describe the time you spent with the health workers? Was it satisfactory? Not satisfactory? Please explain.
- 4. Describe how health workers helped you to do what you could not do during hospitalization?
- 5. Did the health workers teach you how to take care of a preterm baby? How? Was there something you felt you still needed to know after you were discharged?
- 6. What did the health workers do to give you hope that your child will be well?
- 7. Is there anything that made you happy about your interaction with the health care workers? If yes, please tell me more about it.
- 8. Is there anything that made you unhappy about your interaction with the health care workers? If yes, please tell me more about it.

9. Is there any other thing about your experience you would like to tell me that has not been mentioned?

Interview questions and probes relating to mothers' perceptions of the influence of their health care experience on health outcome of their preterm babies will include the following:

10. Do you think the health services you experienced will help improve your baby's health? If yes, can you think of something special that a health worker did? If not, what more do you think a health worker could have done?

Thank you for your participation. Let me know if you will be available for any follow-up questions to clarify certain points that might come up. Please feel free to contact me if you have any questions or concerns about the way your answers will be used, or any other problems related to the study.

The information will be used solely for the purpose of understanding women's experience with health care services provided for their preterm babies.

Appendix C:Interview Questions Guide for Participants - Pidgin English Version Interview questions and probes relating to experiences with health care services will include the following:

- 1 A beg tory me about your esperiense wen you be di mit wit docta or nurses weh dem be di tek care for your premature pikin for hospito..
- 2 You tink say docta and nurse dem be kno you? If yes, wetti dem be do for show say dem be kno you? If no, wetti dem be do for show say dem no be kno you?
- 3 Tory me about de time weh you spenam wit de docta or nurse dem? You fit talk say you be dey satisfayd? Not satisfayd? I beg me why.
- 4 Tory me how dis docta and nurse dem be helep you for do ting weh you no for fit doam time weh your pikin be dey hospito?
- 5 De docta and nurse dem be tich you how for tek care for your premature pikin? Wetti dem be tich you? You tink say som ting be dey weh you be wan for still lenam befo wuna be comot hospito?
- 6 Wetti de docta and nurse dem do weh e give you hope say your pikin go well?
- 7 Som ting dey weh e mek you happy wen you be di mit wit de docta and nurse? If yes, A beg tory me more.
- 8 Som ting dey weh e mek you worry wen you be di mit wit de docta and nurse? If yes, A beg tory me more
- 9 Eni oda ting dey about your esperiense weh wan tory me?

Interview questions and probes relating to mothers' perceptions of the influence of their health care experience on health outcome of their preterm babies will include the following:

11. You tink say de way docta or nurse dem treet you fit mek pikin yi helth be bettert? If yes, tory me eni special ting weh de docta or nurse dem be do.If not, wetti you tink say dem for fit do for mek pikn yi helth better?

Tank you for your time you fit tell if go fit get time again in case I get som oda qyestion after about your tory? Feel free for kall me if you get eni question for me about the way I go use your tory or if you get eni worry about the risach.

De information A go gada go be use only for understan Aghem woman dem tory about the time dem be spenam for hospito wen dem be born premature pikin. Appendix D: Flyer – English Version

# **STUDY ADVERTISEMENT**



# WOMEN WITH PRETERM BIRTH EXPERIENCE NEEDED!!!

I am looking for women who have experienced preterm birth to participate in a taped interview concerning their experiences of interacting with health care workers during their baby's stay in the hospital.

I am a PhD student in Health Services at Walden University in Minneapolis, Minnesota, USA conducting a graduate research on women's experiences with health care services provided for their preterm babies in the NICU.

# Let's hear your story!The confidentiality of participants is ensured

Who can participate?

Aghem women with preterm birth experience in the NICU within the last 1 year who are not currently having their preterm baby in the hospital, and who are willing to participate in an audio taped private interview.

Every participant will receive a token of five thousands francs for their transport, time, and participation.

For more information, or to participate, please call the researcher.

Deadline to enroll is July 28, 2021.

#### Make your voice heard!

Research is conducted through Walden University-Minneapolis Walden University IRB

Approval # 06-28-21-0744724 and it expires on June 27, 2022

Appendix E: Flyer – Pidgin English Version

#### Advertisement



#### We nid woman dem weh dey don born premature pikin!!

A di find woman dem weh dem don get premature pikin for participet for tape interview about dia esperinse for hospito, time weh dia pikin be dey for hospito.

A be na studen for Health Servis for Walden University for Minneapolis, Minnesota, USA. A di condukt graduate risach for understan woman e esperinse for hospito after yi born premature pikin.

## A wan hear your story! A go kip olting sikrit!

Wou fit tek pat for dis interview?

Aghem woman weh yi born premature pikin for hospito dis las 1year, weh e no still dey hospito, and e likam for tek pat for tape interview. Eni woman weh e go tek pat go get 5.000frs for pay taxi.

If you wan mo information, or you wan tek pat, please koll risecha for dis numba

Last day for tek pat na July 28, 2021.

#### Mek we hear your voice!

Na Walden University weh e dey for Minneapolis di do the risach and dem don check oting.

### Appendix F: University of Buea Ethics Committee Approval

UNIVERSITY OF BUEA (20 BCR 40) Mark CAMIRCON Mark CAMIRCON MAR	REFUELC OF CAMEROON
FACULTY OF HEALTH SCIENCES- INS	ITTUTIONAL REVIEW BOARD
IREDNOORS   7-US Office for Hamma Research   screatery : Professor, Haffe-Eleans Edia Gragery	Freinriken (CHERF)SCHRCONTAIN
our Ref	
Der Ref: 2021/ 1468-05/UB/SG/IRB/FHS	0 4 MAI 2021
Notice of Ethical	Approval
Application number: 1468-05	
Principal Investigator: DEUDONNE KUM AMUAM	
Study Title: NEO-NATAL INTENSIVE CARE UNIT SERVI AGHEM WOMEN OF NORTH WEST, CAMEROON	CES FOR PRETERM BABIES: EXPERIENCES OF
Application Type: Initial	
Sporsor: Student Review Type: Normal	
Date of Approval: 4" May 2021	
Expiration Date: 4" May 2021	
Principal Investigator's responsibilities:	
I. The study must be conducted in strict accordance a	with the protocol approved by the Board
2. Changes to the protocol or its related consent	
implementation 3. Adverse events or unanticipated problems must be	second second by the Brand
4. Participants must receive a copy of the coreoni do	
5. The Principal Investigator is responsible for the	con-going conduct of the study. The shady must i
humans. He must collaborate with the IRB's mon	
<ol><li>Any future correspondence must include the appli-</li></ol>	cation number, and the PI's name in the subject line.
<ol> <li>A renewal application or project closure report surgination data indicated shows. These must be de-</li> </ol>	means he submatted at least one month prior to a
	reference the application mander indicated above. Th
form is evailable at http://www.heukhreneuchmet	
standingrality 800	-
	- 161
Prof. Halle Ekane Edie Gregory Secretary; Institutional Roview Board	
Faculty of Health Sciences University of Baca	