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Esther Abena Adama
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Ghanaian Parents' Experiences of Caring for their Preterm Infants after Discharge from the Neonatal Unit-A Narrative Inquiry Study

This thesis is presented for the degree of

Doctor of Philosophy

ESTHER ABENA ADAMA

Edith Cowan University

School of Nursing and Midwifery

2018

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

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ABSTRACT

The care of preterm infants is associated with stress. In the busy neonatal unit where highly skilled healthcare workers are always present, parents have reported being stressed when caring for their preterm infants in the neonatal unit. In Ghana, preterm birth is the highest cause of neonatal mortality with 70% of these morbidities and mortalities occurring in the community. Yet to date, no study in Ghana has explored how parents experience their care giving role after discharge from the neonatal unit into the community.

This study explored the experiences of caring for preterm infants in the neonatal unit and after discharge from the perspective of parents. Narrative inquiry methodology was utilised as it explores lived experiences using stories as data. In all, 42 participant carers (mothers, fathers and significant others) of preterm infants discharged from one of four neonatal intensive care units in Ghana were interviewed at three different stages - one week, one month and four months after discharge. Data were collected from February to June, 2015 in the residences of parents. Interviews were conducted face-to-face and audio-recorded. As Ghanaians live communally, members of households were also engaged in informal conversation to explore their experiences of caring for preterm infants after discharge. In addition to this, participants were observed in their natural environment as they cared for the preterm infant in the community.

Results of the study suggest that in the neonatal units and after discharge, parents have concerns caring for their preterm infants. The findings suggest that after discharge, grandmothers of preterm infants who were not involved in pre-discharge education in the neonatal unit take charge of the care of preterm infants in the community. Grandmothers diagnose preterm infants' illnesses and decide whether to refer an infant to hospital or herbalist for treatment. Cultural practices mainly initiated by grandmothers resulted in adverse health problems for preterm infants and disruption in parents' mental health.

The current study also revealed that in the neonatal unit, fathers were excluded from caring for their preterm infants, making them less confident to assume the caring role after discharge. This study has deepened our understanding of some of the challenges parents of preterm infants face in the neonatal unit and after discharge as they assume full

responsibility of caring for their preterm infants in the Ghanaian community without any formal support from healthcare workers.

It is recommended that healthcare workers should identify the support persons of parents and involve them in the care of preterm infants while on admission in the neonatal unit and during pre-discharge education. In addition to this, the study recommends that healthcare workers place regular mobile phone calls to parents of discharged preterm infants to discuss areas of concerns about the care of the preterm infant in the community in order to provide evidence based support.

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I thank the Australian Government for financing my studies and living expenses during the course of my study. Without it, this work would not have been a success.

I am grateful to all my participants for welcoming me into their home and sharing their emotional stories of caring for their preterm infants in the neonatal unit and in the community. It is only strong people who can share these emotional but insightful stories with a researcher.

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DEDICATION

This thesis is dedicated to my husband, Mr I.B. Nabubie who has catapulted me to this academic level and to the sweet memories of my late mother, Mrs Mary Wodolf Adama, I feel your presence around me every day. I can see your proud face in heaven.

RESEARCH OUTPUT ARISING FROM THESIS

This thesis is presented in the thesis by publication format. All four journal articles arising from this thesis have been published in print or online in various nursing journals. Apart from Chapters One and Five, all the remaining chapters take the form of journal articles. They will be presented in the thesis as follows:

Chapter Two

1. Adama, E. A., Bayes, S., & Sundin, D. (2016). Parents' experiences of caring for preterm infants after discharge from Neonatal Intensive Care Unit: A meta-synthesis of the literature. *Journal of Neonatal Nursing*, 22(1), 27-51.
doi:10.1016/j.jnn.2015.07.006

Chapter Three

2. Adama, E. A., Sundin, D., & Bayes, S. (2016). Exploring the sociocultural aspect of narrative inquiry: A dynamic nursing research methodology. *Clinical Nursing Studies*, 4(4), p1. doi:10.5430/cns.v4n4p1

Chapter Four

3. Adama E.A, Bayes, S., & Sundin, D. (2017) Parents' experiences of caring for preterm infants after discharge with grandmothers as their main support. Published online in *Journal of Clinical Nursing*. doi:10.1111/jocn.13868
4. Adama, E.A, Sundin D., & Bayes, S. (2017) Fathers' experiences of caring for preterm infants after discharge: A journey of exclusion. Published online in *Journal of Neonatal Nursing*. doi: 10.1016/j.jnn.2017.05.003

STATEMENT OF CONTRIBUTION OF OTHERS

I, Esther Abena ADAMA, declare that I contributed more than 70% of the research publications that arose from this thesis. The rest were contributed by my supervisors, Dr Deborah Sundin and Associate Professor Sara Bayes.

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CHAPTER ONE: INTRODUCTION

Introduction

Preterm birth is the birthing of an infant before the 37th week of gestation and is classified according to the gestational age of the infant. Infants born less than 28 weeks are considered extremely preterm, those born between 28 and 32 weeks are classified as very preterm, and those born between 32 and 37 weeks of gestation are considered moderate or late preterm (Blencowe et al., 2012). Globally, preterm birth is the leading cause of mortality among neonates (Blencowe et al., 2012; Goldenberg, Culhane, Iams, & Romero, 2008). Although preterm birth is seen in both affluent and poor countries, its rate and impact is higher in the latter, probably due to their comparatively poor health systems. The most important effect of preterm birth in low income countries is neonatal mortality (Engmann et al., 2012; Welaga et al., 2013).

According to Blencowe et al. (2012), in 2010, an estimated 14.1 million preterm births were recorded globally, of which more than 60% occurred in South Asia and Sub-Saharan Africa (Ghana inclusive). In a related study to determine the ethnical difference in preterm birth, Goedhart et al. (2008), found a high incidence of preterm birth among Ghanaian women compared to other women from Morocco, Surinam, Netherlands and Turkey. In their study, out of the 8,266 women who participated, 5.5% of them had preterm births. Of this number, 11%, representing the majority of preterm birth was seen among Ghanaian women and the least (4.1%) was seen among Moroccan women. Although this study was conducted in Amsterdam, it shows that even with highly sophisticated medical services, Ghanaian women are at higher risk of preterm birth than their counterparts from Morocco, Surinam, Netherlands and Turkey. This suggests that genetics may have an influence in preterm birth.

Ghana's infant mortality rate stands at 36.3 deaths per 1,000 live births compared to 4.3 deaths per 1,000 live births in Australia and the United Kingdom (Central Intelligence Agency, 2017). Ghana's high infant mortality rate has been attributed to high neonatal mortality rate (Edmond et al., 2008). In 2012, the World Bank estimated that neonatal mortality rate in Ghana was 28.4 per 1,000 live births (World Bank Group, 2012). Preterm birth has been recorded as one of the leading causes of high neonatal mortality in Ghana and accounts for 26% of all early neonatal deaths in Northern Ghana (Engmann et al., 2012). In Ghana, preterm infants are six to 26 times more likely to die

during the first month from preterm birth complications and infections than infants born at term (Katz et al., 2013). Preterm birth complications contribute to one in three newborn deaths in Ghana (World Health Organization, 2013). Preterm infants who survive this critical period of their life are more likely to suffer from complications such as learning disabilities, behavioural problems, chronic lung diseases and long term cardiovascular diseases (Katz et al., 2013; Pearl & Donahue, 1995).

These figures of neonatal mortality arising from preterm birth may be underestimated as many preterm infants' deaths occurring in the community are not registered (Baiden et al., 2006; Edmond et al., 2008). Most Ghanaians do not report the death of a preterm infant as it is culturally unacceptable to mourn such deaths (Samarasekera, 2010). It is believed this may cause the subsequent birth of another preterm infant; a phenomenon that originated from the 'spirit child' belief. The spirit child is believed to have emanated from the bush and causes destructions and other misfortunes to their family (Denham, Adongo, Freyberg, & Hodgson, 2010). Thus, there is lack of accurate data on neonatal mortality resulting from preterm birth in Ghana. In addition, Baiden et al. (2006) reported that, only 13.2% of neonatal deaths in Ghana occur at the health facility. Thus in Ghana, officially registered preterm neonatal mortality is only likely to represent 13.2% of all neonatal mortality in the country and these are deaths that occur in healthcare settings. This confirms the findings of Engmann (2011) that, over 70% of neonatal mortality in Sub-Saharan Africa (Ghana inclusive) occurs at home or in the community. This raises concerns about the care-giving behaviour of parents after they have been discharged from the health facility.

The high rate of neonatal mortality and morbidity among preterm infants in Ghana poses a challenge to the attainment of the Millennium Development Goal four [MDG-4] (Bhutta et al., 2010; Lozano et al., 2011; World Health Organization, 2010). The Millennium Development Goals (MDGs) were a set of eight goals set by the United Nations heads of States in 1990 as a framework against which all developmental activities such as health, education and economic empowerment would be measured. The year 2015 was set aside as the deadline for the achievement of the eight goals (Hulme, 2009). The fourth was concerned with the reduction of infant mortality rate by two thirds by the year 2015. However, in 2008, when the United Nations Children's Fund (UNICEF) undertook a retrospect analysis of the outcomes of the MDG-4, Ghana was classified as a 'no progress' country as a result of the significantly high neonatal mortality in the country (UNICEF, 2009). The majority of this mortality was recorded in the community (Edmond

et al., 2008). By the year 2011, although significant progress in under-five mortality was documented worldwide, it was obvious that MDG-4 target in developing countries may require some years beyond 2015 to be attained (You et al., 2015). To attain this, intervention strategies at the community level were recommended (Memon, Khan, Soofi, Baig, & Bhutta, 2015). However, in Ghana, experts reported that implementation of these interventions were not neonatal-specific resulting in Ghana's inability to achieve the MDG-4 (Kayode et al., 2016). Therefore, there is the need for intervention strategies to improve neonatal health outcomes at the community level. [include sustainable goals??]

Not only does preterm birth reduce the chances of survival of the infant, it also poses a significant stress for the family (Griffin & Pickler, 2011): although the transition to parenting is associated with stress, the stress experienced by parents of preterm infants far outweighs that experienced by parents of term infants (Davis, Edwards, Mohay, & Wollin, 2003; Griffin & Pickler, 2005; Holditch-Davis, Bartlett, Blickman, & Miles, 2003). This high level of stress among parents of preterm infants has been shown to be related to the physical appearance of the child, the health condition of the infant, and the anxiety of caring for such fragile infants (Alkozei, McMahon, & Lahav, 2014; Ghorbani, Dolatian, Shams, & Alavi-Majd, 2014; Grosik, Snyder, Cleary, Breckenridge, & Tidwell, 2013; Raeside, 1996). Furthermore, the transition from the neonatal unit to home can be stressful and burdensome to mothers (Boykova & Kenner, 2012; Garfield, Lee, & Kim, 2014).

Most nursing research regarding parents of preterm infants' care giving experience to date has concentrated on the parental experiences of caring for a preterm infant in the neonatal unit where healthcare workers are generally available to provide support (Aagaard & Hall, 2008; Goutaudier, Lopez, Séjourné, Denis, & Chabrol, 2011; Obeidat, Bond, & Callister, 2009). Available evidence from previous research show that mothers experience a great deal of stress in the neonatal unit which often affect the mother-infant interaction, bonding and health of the preterm infant after discharge (Bakewell-Sachs & Gennaro, 2004; Feldman & Eidelman, 2007). Although studies have shown that breastfeeding a preterm infant after discharge increases the emotional bond between mothers and their preterm infant (Flacking, Ewald, Nyqvist, & Starrin, 2006; Flacking, Ewald, & Starrin, 2007), few studies have explored parents' experiences of how they breastfeed or bottle feed their preterm infants after discharge from the neonatal unit as part of caring for their infants (Kavanaugh, Mead, Meier, & Mangurten, 1995; Reyna, Pickler, & Thompson, 2006).

Despite the risk of parent-infant relationship problems after discharge, little has been done to explore how parents experience their role as primary caregivers when a preterm infant is discharged into the community where healthcare workers are not always available (Griffin & Pickler, 2011; Murdoch & Franck, 2012a; Obeidat et al., 2009). In particular, there is paucity of qualitative investigation into this topic in Ghana where discharged preterm infants are left to the ministrations of their parents without any community follow-up support. It is feasible that the lack of support such as home visiting after discharge might have contributed to the high (28.0 per 1000 live births) neonatal mortality rates and the death of over 70% of infants in the community (Engmann, 2011; World Bank Group, 2017).

In Ghana, there is no formal support for parents of preterm infants after discharge from the neonatal unit. At discharge, parents are encouraged to return to the hospital for postnatal review of their infants at a frequency determined by the gestational age and birth weight of the preterm infant. Failure to attend this follow-up appointment incurs no consequences resulting in more than half of parents refusing to do so. Factors such as ignorance and poverty have been blamed for this (Witter, Arhinful, Kusi, & Zakariah-Akoto, 2007).

In a study to explore mothers' experiences of caring for a preterm infant at home, Falleiros, Melani, Gracinda, and Lima (2002) recommended that the difficulties of caring for a preterm infant at home by families must be understood in countries where the incidence is high in order to ensure good child development and reduce mortality arising from preterm birth. After estimating the global rate of preterm birth and its consequences such as high neonatal mortality and lifelong disability among survivors of preterm birth, Blencowe et al. (2012) called for a rapid scale up of basic innovative low-cost community interventions in low and middle income countries in order to achieve the MDG-4 by the year 2015 and beyond. Understanding the current difficulties, local/cultural practices and parents' caring behaviours is essential to the development of interventions for improving neonatal care in the communities (Neonatal Mortality Formative Research Working Group, 2008). One way to determine these difficulties, factors and behaviours is to determine from the perspective of parents of preterm infants the experiences and challenges of caring for their preterm infants after discharge from the neonatal unit. There is the urgent need for research in Ghana to determine the most effective community intervention to improve the care of the preterm infants in the community.

Thus, this study is aimed at exploring the parents' experiences of caring for preterm infants after discharge from neonatal units. This will provide an in-depth understanding of the issues surrounding the care of preterm infants in the Ghanaian community and provide evidence that will underpin the development of policies and programs to further support parents and their infants after they have left the confines of the neonatal unit. Ultimately, it is hoped that implementation of findings from this research will contribute to improvement of the overall health of preterm infants after discharge and in effect contribute to the reduction of neonatal mortality rate in Ghana.

Rationale and significance of study (So What? and Who cares?)

The incidence of preterm birth is high among Ghanaian women (Goedhart, Van Eijdsden, Van Der Wal, & Bonsel, 2008), yet no research to date has investigated the emotional response of parents of preterm infants after discharge in this cultural context. Understanding the needs of parents of preterm infants after discharge by qualitatively exploring their experiences will enable healthcare workers and commissioners to put in place strategies to further support them. Herbert, Lee, Chandran, Rudan, and Baqui (2012) postulate that the effective strategies to improve neonatal survival in developing countries require a clear understanding of neonatal caregivers' perceptions and experiences. Similarly, Souza et al. (2010) posit that the difficulties of caring for preterm infants at home by families must be understood in countries and settings where preterm birth is high in order to ensure good child development and reduce mortality. Therefore, exploring the experiences of caregivers can influence the overall health outcome of neonates and is essential in reducing the neonatal mortality rate in these settings.

In addition, although, it is a documented fact that parents experience high level of stress in the neonatal unit (Holditch-Davis et al., 2003; Muller-Nix et al., 2004; Raines, 2013), no studies in Ghana have explored how the initial stress in the neonatal unit affects parenting after discharge. It is possible that the high re-admission rate after discharge may be a result of parenting or caring issues. It is thus important for a qualitative study to be conducted in Ghana to explore how parents of preterm infants experience their care giving role when the preterm infant is discharged into the community. The findings of this doctoral study will provide a basis for the formulation of interventions that will improve the care-giving experience of parents and subsequently improve the health of preterm infants. The potential is that this work will contribute to the development of strategies to

reduce the over 70% neonatal mortalities occurring in the Ghanaian communities (Engmann, 2011; Engmann et al., 2012).

Aim and objectives

The aim of the study was to explore Ghanaian parents' experiences of caring for preterm infants after discharge from a neonatal unit.

Objectives

To achieve the above aim and answer the research question, the following objectives were developed:

1. To describe how mothers of preterm infants experience their care giving role within the first 4 months after their preterm infants were discharged from neonatal unit.
2. To describe how fathers of preterm infants experience their support giving role or caring role after discharge of preterm infants.
3. To explore from the parent's perspective how discharge education in the neonatal intensive care unit influenced their ability to care for their preterm infants after discharge.
4. To compare the parents' perception of the health education given at the hospital and the health advice given by their social support system.
5. To explore the cultural and /or social factors that affects the care of the preterm infant at the community level.

Inquiry puzzle (Research Question)

To fulfil the above aim and objectives, the study attempted to inquire into the research puzzle:

“What are the experiences of Ghanaian parents in caring for preterm infants after discharge from neonatal unit?”

Study setting

Participants for this study were recruited from four neonatal units in Ashanti and Western regions of Ghana. Ghana is located in West Africa few degrees north of the Equator. There are ten administrative regions in Ghana. It has a total area of 238,538 sq km with a population of 28,308,301 (Ghana Statistical Service, 2016). Ghana is well known for its natural resources such as gold, diamond, bauxite and recently oil. Agriculture provides one-quarter of Ghana's Gross Domestic Product (GDP). Ghana's hospital bed density is 0.9 beds /1,000 population with an infant mortality rate of 38.0 deaths/1,000 live births (Central Intelligence Agency, 2017; Ghana Health Service, 2017).

Participants for this study were recruited from four government hospitals (one tertiary and three district hospitals) in two regions - Ashanti (Kumasi) and Western (Tarkwa). People in these regions belong to the larger Akan ethnic group and speaks mainly Twi and/or Fante (Central Intelligence Agency, 2017).

Ashanti region is the second largest region in Ghana with Kumasi as its capital. Kumasi is the most populated city in Ghana with a population of 1,730,249. It has five health districts and one teaching hospital that serves as a tertiary referral centre (Ghana Statistical Service, 2014a). In addition to this are traditional healers/herbalists who provide herbal remedies for residents. In Kumasi, participants for this study were recruited from two district hospitals and one tertiary teaching hospital.

Tarkwa is an urban area in the Tarkwa Nsuaem Municipality of Western region. It is the capital of the municipality with a total land area of 1,832 sq km. The municipality has a total population of 90,477 (Ghana Statistical Service, 2016). Mining is the main economic activity in the municipality. There are both private and public hospitals in Tarkwa. However, like most regions in Ghana, there are traditional/herbal and spiritual healers as well. Participants for this study were recruited from a district government hospital in Tarkwa in which neonatal services are provided.

There were between 15-40 cots in the neonatal units of district hospitals and 100 cots in the tertiary hospital. However, due to limited equipment and space, there is overcrowding resulting in two or more neonates sharing cots and incubators. The nurse to patient ratio is an average of one registered nurse to 3-7 neonates. Due to the busy and crowded nature of the facilities, early discharge of stable preterm infants is practised.

Neonatal units are manned by registered and unregistered health professionals, including doctors, nurses, nurse assistants and other paramedical staff. The majority of the neonatal unit in-patients are preterm infants followed by those born with congenital abnormalities and other illnesses.

Methodology and Methods

Research Design – Narrative Inquiry

The research design employed for this study was narrative inquiry. The term narrative inquiry was first coined by Connelly and Clandinin (1990), who took their inspiration from Dewey's (1938) assertion that life is education, or in other words, our life experiences and education are intricately linked. Educational researchers Clandinin and Connelly (2000) drew on this assertion to place emphasis on lived experiences as key to teaching and learning. Although Connelly and Clandinin (1990) were not the first to conceive the idea of 'narrative', they were the first to conceive narrative inquiry as a research methodology in their professional field. The definition of narrative inquiry has undergone several evolutions since its inception; Connelly and Clandinin (2006) have most recently defined narrative inquiry as follows:

'... the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study' (p. 479).

Narrative inquiry enables the researcher to journey into the life-world of the researched by using story telling as the entry point (Green, 2013). As nurses use narratives to gain insight into the health needs of their clients, the use of narrative inquiry methodology is a perfect tool in nursing research as it provides deeper understanding of issues and phenomena from the perspective of those living the phenomena (Connelly & Clandinin, 2006). Narrative inquirers understand and inquire into the experiences of participants by "collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus" (Clandinin & Connelly, 2000). Clandinin and Huber (2010) refer to these three areas of collaboration as the three 'commonplaces' of narrative inquiry. These are incorporated into the three-dimensional narrative inquiry space. A simultaneous exploration of all the three commonplaces of narrative inquiry must be undertaken in narrative inquiry methodology (Connelly &

Clandinin, 2006). This means the narrative inquirer cannot focus on one of the commonplaces at the expense of the others. This unique feature of narrative inquiry distinguishes it from other qualitative research methodologies (Clandinin, Pushor, & Orr, 2007). By focusing on all three commonplaces simultaneously, the narrative inquirer is able to study the complexities of the lived experiences both inside and outside an inquiry and also forecast future possibilities of the phenomenon (Connelly & Clandinin, 2006).

In narrative inquiry, the researcher thinks narratively by inquiring within the three commonplaces or three-dimensional narrative inquiry framework: temporality, sociality and place/location/ spatiality (Clandinin & Huber, 2010). In this PhD project, the three-dimensional narrative inquiry space described by Clandinin and Connelly (2000) was used to analyse field text/data. Using this framework, each participant's story was analysed narratively and simultaneously within temporarily (time), sociality (social-interactions) and spatiality (location).

Three-dimensional narrative framework

Temporality

Temporality refers to the passage of time as an experience unfolds. Connelly and Clandinin (2006) assert that experiences under study are in temporal transition; that is, experiences and people have a past, present and future. Therefore, it is recommended that, narrative inquirers understand people, places and events as being in constant temporal transition. It is also important for narrative inquirers to attend to the temporality of their own lives and that of their participants' (Clandinin et al., 2007).

Sociality

Narrative inquirers simultaneously take into consideration the personal and social conditions that affect a phenomenon under study (Clandinin & Huber, 2010). Connelly and Clandinin (2006, p. 480) refer to the personal conditions as "the feelings, hopes, desires, aesthetic reactions and moral dispositions" of the researcher and the researched. They refer to the social conditions as the environment (milieu), existential conditions, surrounding factors and forces, people and otherwise within which the experiences and events are unfolding. Social conditions also involve the cultural, social, institutional and linguistic narratives (Clandinin & Huber, 2010). In addition, as narrative inquirers cannot distant themselves entirely from the participants, Connelly and Clandinin (2006) also

referred to sociality as the inquiry relationship that exist between the researcher and the researched.

Spatiality/place/location

Spatiality in the three-dimensional narrative inquiry space refers to “the specific concrete, physical and topological boundaries of place or sequence of places where the inquiry and events take place (Connelly & Clandinin, 2006, p. 480). The spatiality commonplace recognises that experiences and events happen in a place and this place have influence on the phenomenon under study. The specificity of location is crucial...place may change as the inquiry delves into temporality (p. 480). By thinking narratively, the narrative inquirer analyses the impact of the place on the experience or phenomenon under study (Clandinin et al., 2007).

In this thesis, using the three-dimensional narrative inquiry framework, temporality, sociality and spatiality/place were analysed simultaneously. The experiences of parents were analysed in chronological manner (temporality); that is, at the neonatal unit and after discharge (in the community). Sociality or social interactions were analysed based on the roles other people played in informing the participants’ experiences. In this study, the participants’ interaction with healthcare workers in the neonatal unit and family and friends and other people in the community were analysed to get a deeper understanding of the participants’ experiences. The spatial analysis was based on the location and the particular experience at the said location. Experiences in the neonatal unit were analysed differently from the experiences in the community.

Data Collection Methods

The selection criteria for participants included in this study included: being a parents or carer or significant other of a preterm infant; being over 18 years old; fluent in English language or local language-Twi; having a baby who has no other birth deformities other than being born preterm and being in a psychologically stable condition to share experiences. A total of 42 parents comprising of mothers, fathers and significant others were included in the study.

The studies employed in-depth semi-structured face-to-face interview approach to elicit responses from participants. Participants who agreed to be interviewed were contacted after discharge via telephone to book an appointment for the interview in their

home. A semi-structured interview guide was used for the interviews. The semi-structured interviews also enabled the researcher to ask further questions for clarification. All interviews were conducted by the researcher; interviews were digitally recorded and field notes taken as the interview was ongoing. Participants' facial expressions and other body languages were recorded in the filed notebook. A total of 172 interviews comprising both formal and informal interviews were conducted during the four months' data collection period

In addition, non-participant observation was employed at the end of the formal interviews to observe how the household or family and friends cared for the preterm infant. The role of other family and household members were observed and documented in the field notes. Where there was a practice that the researcher did not understand, the researcher later clarified from the participants or the household member through informal interview which were either recorded or written in the field notes.

Participants were visited and interviewed in their homes at least two times-one weeks, one month and four months after discharge. The same interview guide with minimal modification was used at visitation two or three. Participants were asked the same questions and further questions based on their responses to ascertain any changes in their experiences from the first week of discharge till the fourth month after discharge. This consistency also enabled the researcher to determine saturation of data. When no new information arose from the second interview, the researcher considered that to be at the point of data saturation.

The researcher's position

The researcher's position in qualitative research should be made known in all aspects of the study (Deppermann, 2013). In this section, I will discuss my position as a researcher and the methodological stance for this study.

Narrative inquiry enables the researcher to journey into the lives of the researched (Etherington, 2004; Kramp, 2004). Hence, it is considered doing research *with* the researched rather than doing research *on* the researched (Bleakley, 2005). Since the narrative inquirer is considered part of the research (Bleakley, 2005), there is the need to clarify the researcher's position in the research. The commonest way of doing this is through reflexivity.

Reflexivity is a conscious self-awareness activity by the researcher that allows the researcher to journey into their personal lives and become fully aware of their feelings, actions and perceptions they are bringing into the research (Darawsheh, 2014). It is an immediate continuous and dynamic subjective self-awareness activity (Finlay, 2002). Being reflexive is a way of increasing the trustworthiness and rigour of a qualitative study (Morrow, 2005; Shenton, 2004). It is recommended that researchers disclose their personal and professional identity prior to data collection and maintain a progressive reflective commentary before each data collection and analysis in order not to impose their ideas on the participants (Band-Winterstein, Doron, & Naim, 2014; Shenton, 2004).

Thus, in this PhD project, my professional identity as a registered/neonatal nurse who has worked with parents of preterm infants was disclosed at the beginning of the project, during data collection, data analysis and report writing. I engaged in a deeper self-examination to be aware of my own feelings and perceptions I was taking to the field. After interviewing participants, I revisited my reflective account to ensure that I was not imposing my views and feelings on them. For this reason, a disclosure on how I became interested in exploring the phenomenon of caring for preterm infants in the community was necessary.

It started some nine years ago when I had my first child and he was admitted to the neonatal unit of a prominent tertiary hospital in Ghana for three days for observations as his Apgar score was low at birth. Although I had previously worked in this unit as a registered nurse, I never had time to engage parents in lengthy conversation due to high workload. During the time I spent in the ward as a mother of an inpatient, I had the opportunity to be in the shoes of my patients and their families. I befriended a lot of the parents whose infants were on admission. I listened to their stories of pain, distress, loneliness, encouragement and victory. I mourned with parents who lost their infants and rejoiced with those who were discharged home with a live infant.

Later in my practice when I became a ward manager of a children and neonatal unit, I paid particular attention to the needs of parents of neonatal unit inpatients by providing psychological, physical and informational support. My neonatal unit inpatients were mostly preterm infants. As a ward manager, I noticed that preterm infants who were medically stable and discharged were readmitted to the unit in deplorable conditions. I began to nurture the idea of an empirical study to explore the care of preterm infants in the community. Therefore, it was a dream come true when I was offered admission to pursue a PhD. It created an opportunity for me to explore the issues in the community

that affect the care of discharged preterm infants from the perspective of parents and carers.

Choosing the research methodology (narrative inquiry)

As parents' experiences of caring for preterm infants is an area that has not been explored in Ghana, it was important to use a methodology that would provide a deeper understanding of the phenomenon. Among the two main research paradigms, qualitative methodology was deemed relevant as it aims to describe and understand a phenomenon or a situation and sometimes foster change but ultimately recommend interventions for improvement in service delivery (Smith, 2012). Thus, using a qualitative narrative inquiry methodology, I listened to parents of preterm infants as they shared their stories of the journey of caring for their preterm infants from the neonatal unit till discharge and some of the factors in the community that affect the care of their preterm infants.

Narrative inquiry also presented a unique opportunity for me to study both the essence and the cultural influence of caring for the preterm infant in the community. By engaging with participants for a period of four months, we built a researcher-researched relationship respecting each other's unique characteristics we brought to the study. By welcoming me into their home, lives and stories, I observed the shared responsibility of caring for preterm infants by the members of participants' household and listened to the stories that influenced the care of the preterm infant.

Not only did this project increase my understanding of the gap that exists in patient education in the neonatal unit, it also showed me as a registered nurse my previous disregard for the power of culture in the Ghanaian community that most importantly affects the health outcome of my patients (preterm infants) after discharge.

The use of a reflective account and description of my position in this study made me aware of my own potential perceptions and feelings I brought into the study. This personal awareness made it impossible to influence research data or its interpretation hence increasing the trustworthiness of the study.

Ethical considerations

As with all other research methodologies, narrative inquirers are expected to follow the rules governing research ethics. Narrative inquirers begin their study by subjecting their proposed project to the ethics committees of a reputable institution for clearance

before going into the field for data collection (Clandinin & Huber, 2010). In the field, narrative inquirers form an initial trusting relationship by seeking the consent of their respondents after explaining the research to them (Clandinin & Huber, 2010).

In this study, approval was sought from the Edith Cowan University Human Research Ethics Committee, Australia (Project Number: 11568) and Kwame Nkrumah University of Science and Technology, Committee on Human Research, Publication and Ethics, Ghana (Ref: CHRPE/RC /008/15). In addition, approval was sought from heads of participating hospitals for recruitment of participants. In the neonatal units, permission was sought from heads of units. Participants who met the inclusion criteria were approached by the researcher and the research explained to them. An information letter (See Appendix 1) was given out for eligible participants to read and for those who could not read, the ward managers or the researcher explained the study to them in the local language (Twi). When participants agreed to participate in the study, the study was again explained to them and their contact details collected. They were told that the researcher (the candidate) would contact them after discharge from the neonatal unit.

Upon discharge, parents were contacted via mobile phone to confirm whether they still agreed to participate and a date and time for meeting was scheduled. The first set of visitations to participants' homes were familiarisation visits which enabled the researcher to further explain the study to participants and to get them to sign the consent form (See Appendix 2). The initial familiarisation visits also allowed the researcher to create a rapport with the participants and assured them of confidentiality of their responses as many participants thought that the researcher was an undercover journalist. This visit was very essential in setting the ground for face-to-face interviews. During this time, the researcher maintained a non-judgemental attitude towards the participants, their family and friends and their responses. However, where the activities of parents and households posed risk to the preterm infants, the researcher who is also a registered nurse intervened after the face-to-face interview by providing informational support or referring the parents to the hospital. For example, in two instances, the researcher had to teach mothers how to position the preterm infant on the breast for successful breastfeeding. In addition, the researcher provided informational support to parents to care for their preterm infants.

In order to maintain research participant's privacy, all the names of participants in this study and in all related publications were pseudonyms and do not bear any relation to the study participants.

Structure/map of thesis

This thesis does not follow a traditional format. Instead, this work is presented in the format of thesis by publication. The following chapters and evolving thesis are underpinned by papers peer reviewed for publication in high impact journals. To date, four publications have resulted from this study. These papers have been interwoven with introduction, discussion and conclusion chapters. The thesis has been divided into five chapters. A brief overview of the thesis follows:

Chapter One: Presented above, introduced the thesis, background, rationale for, significance of the study and methodology used to explore the experiences of caring for preterm infants after discharge followed by a map of the thesis.

Chapter Two: Presents a review of the existing literature and demonstrates the need for the current study. As this review has been published in the Journal of Neonatal Nursing, a copy of the published article (Paper One) will be presented here.

Chapter Three: This chapter will discuss the research methodology for the thesis - Narrative Inquiry. This information was published in Clinical Nursing Studies. In the article, a demonstration of the narrative inquiry methodology in exploring parents' experiences of caring for preterm infants after discharge from neonatal unit was presented using data from the PhD project. This article (Paper Two) is presented in full in Chapter Three.

Chapter Four: This chapter is the findings/results chapter of the thesis. The chapter features two published journal articles (Papers Three and Four) to demonstrate and discuss the findings arising from this study.

Chapter Five: This chapter discusses the main findings of this study, recommendations arising from these findings, and the strengths and limitations of the study. This chapter also includes a reflective account of the learning that has taken place in the researcher's PhD journey.

Summary of chapter one

This chapter has introduced the reader to the research study reported herein. The background to the study has been demonstrated, and it has been situated within its social and political context. The rationale for the study, its significance, and the researcher's

position in the research have been outlined. Finally, the structure/ map of the thesis has been outlined and a brief summary of following chapters provided for the reader.

The next chapter will detail a review of the existing literature on the parents' experiences of caring for preterm infants after discharge in order to show the gap in literature and thus the need for the current study. All useful research is embedded in and contributes to current evidence base.

CHAPTER TWO: LITERATURE REVIEW

Published as: Adama, E. A., Bayes, S., & Sundin, D. (2016). Parents' experiences of caring for preterm infants after discharge from Neonatal Intensive Care Unit: A meta-synthesis of the literature. *Journal of Neonatal Nursing*, 22(1), 27-51. doi:10.1016/j.jnn.2015.07.006

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CHAPTER THREE: METHODOLOGY

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CHAPTER FOUR: RESULTS

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CHAPTER FIVE: DISCUSSION AND CONCLUSION

Foreword to chapter five

This study explored the experiences of parents caring for preterm infants after discharge. Narrative inquiry was employed to work with parents and significant other to understand those experiences within their social contexts. This concluding chapter will revisit key aspects of the study beginning with a summary and discussion of the key findings of the study. Then the study's strength and limitations will be discussed as well as general recommendations and proposed areas for future research. A reflection on the researcher's PhD journey will also be presented followed by a summary of the chapter.

The aim of this research was to explore the parents' experiences of caring for preterm infants after discharge from neonatal unit. Narrative inquiry methodology was used to collect and analyse data from 42 parents and significant others of preterm infants. Participant observation was used after face-to-face in-depth interviews to augment the insights arising from this project. Participants were interviewed at one week, one month and four months after discharge. Four publications demonstrated the development and evolving results of this study. Paper one is a synthesis of the literature on parents' experiences of caring for preterm infants after discharge. Paper two is a discussion and demonstration of the narrative inquiry methodology in relation to the current study. Paper three explored the experiences of grandmothers caring for preterm infants in the community as the sole support providers, while paper four looked at the experiences of fathers of preterm infants in the neonatal unit and in the community.

Following the Joanna Briggs Institute approach to systematic reviews (Joanna Briggs Institute, 2011), the systematic review revealed that no study has been conducted in Sub-Saharan African or more specifically, in Ghana, to explore the experiences of caring for preterm infants; this is despite the high rate of preterm birth among Ghanaian women (Goedhart et al., 2008) and the high rate of neonatal mortality in the community. Three themes arose from the synthesis of data from the 12 qualitative studies reviewed, namely: (1) support improves confidence in care; (2) dealing with challenges of caring for preterm infant; (3) overprotective parenting.

The findings of the systematic review revealed that for parents to be confident in caring for their preterm infants after discharge, they need to be supported by the healthcare workers during their admission in the neonatal unit. This way, parents are empowered to care for their preterm infants independently. This finding is in accordance with the work of Blomqvist, Rubertsson, Kylberg, Jöreskog, and Nyqvist (2012), in which fathers of preterm infants who were trained in facilitating Kangaroo Mother Care reported feeling confident in their paternal role after discharge. In addition, the work of Cano Giménez and Sánchez-Luna (2015) also confirms that support for parents of preterm infants in the neonatal unit reduces anxiety and stress after discharge. Supporting parents in the neonatal unit is thus clearly important for building their confidence in care and in providing optimum care for the preterm infant.

Parents of preterm infants are also faced with many challenges after neonatal unit discharge. Having been cared for by specialist healthcare workers in the neonatal unit, parents of preterm infants find it challenging to assume the responsibility of caring for their preterm infants after discharge. The abrupt interruption of pregnancy, prolonged hospitalisation and limited parental roles in the neonatal unit resulted in delayed parenting. Parents who experienced delayed parenting have issues of bonding with their preterm infants after discharge. Bonding problems may negatively affect parents' confidence of caring for the preterm infant post-discharge and may lead to feeding problems (Buckley & Charles, 2006).

With a gap in literature and the significance of answering the question:

“What are the experiences of Ghanaian parents in caring for preterm infants after discharge from neonatal unit?” identified, a search for a relevant qualitative research methodology was commenced. The five most common qualitative research methods: phenomenology, ethnography, grounded theory, case study and narrative inquiry (Creswell, 2012) were considered and the last was chosen for this study. Narrative inquiry was deemed most relevant because it enabled the researcher to explore the lived experiences of caring for preterm infants and at the same time explore the sociocultural issues affecting the phenomenon through storytelling (Clandinin, 2006).

Narrative inquiry as a research methodology was explored in detail in the second peer reviewed published paper included in this thesis (Paper two in Chapter Three). In this paper, the application of narrative inquiry to the current study was also demonstrated. Using the three-dimensional narrative space analysis, the researcher thought narratively

throughout the process. By thinking narratively, data were analysed simultaneously within temporality, sociality and spatiality (Clandinin & Huber, 2010). In this paper, it was argued that narrative inquiry can do more than studying lived experiences through storytelling. It also included the study of sociocultural factors affecting the phenomenon under study. In other words, narrative inquiry includes characteristics of phenomenology and ethnography. Thus for a study that involved the exploration of the experiences and sociocultural context of parent and significant others caring for discharged neonates in Ghana, narrative inquiry ideally suited this and its purpose.

Through narrative inquiry, the influence of cultural practices on the care of the preterm infant was also identified. The use of various concoctions and traditional medications were also explored. It was obvious from the participants' responses that family-centred care approach was not practised in the neonatal units resulting in fathers not feeling like fathers until after discharge.

Chapter Four presented papers three and four: the results of the current empirical study. In paper three, the influence of the grandmother in child health care in the community was reported. Using the narrative inquiry methodology discussed in Chapter Three (paper two), 30 parents of preterm infants were each engaged in an in-depth interview on their experiences of caring for preterm infants after discharge. Participant observation was also used to supplement interview data. This study found that parents of preterm infants do not have absolute control over the care of their infants in the community. Rather, their degree of control is determined by elderly women in the community, usually the grandmother of the preterm infant. This finding is similar to the findings of Aubel (2012) whose review revealed the grandmother's traditional role of advisors of young parents on child care. Importantly, in contrast to previous studies that reported that fathers or heads of households determine maternal and child healthcare practices in Ghana (Adongo et al., 1997; Shaikh & Hatcher, 2005), this study revealed that elderly women or grandmothers were the most influential decision makers about care and treatment options when a preterm infant is in the community. In this study, grandmothers were seen as proxy doctors and nurses, diagnosing childhood illness and determining whether an illness should be referred to hospital or not. This finding has been reported in earlier studies in which grandmothers' power as a child healthcare advisor was explored (Bowers & Myers, 1999; Douglass & McGadney-Douglass, 2008; Gupta et al., 2015).

A common traditional illness known as ‘asram’ was noted in the current study to require out-of-hospital care. After being diagnosed with ‘asram’ by grandmothers, herbal or traditional medicines were used for its treatment to the detriment of the child. The effect of the grandmothers’ actions was that some preterm infants required re-admission to hospital for cord sepsis and haemo-transfusion. As a result of these findings, a recommendation to identify and include parent’s support systems – particularly grandmothers - in health education during the initial hospital admission of a preterm infant was made.

In paper four, the journey of fathers of preterm infants from the neonatal unit to the community was explored. Nine fathers of preterm infants were engaged in an in-depth interview using narrative inquiry methodology over four months. Like mothers of preterm infants, fathers also experience a great deal of stress when the preterm infant is admitted to the neonatal unit (Hugill, Letherby, Reid, & Lavender, 2013). However, unlike mothers, fathers were not involved in the daily care of the preterm infant. Fathers reported feeling excluded from the care of their preterm infants. For fathers, the “caring space” was dominated by mothers leaving them with only a “financial space” to occupy. Ghanaian fathers, unlike their counterparts in other countries (Lundqvist & Jakobsson, 2003), were excluded from the daily care of the preterm infant and pre-discharge education. The consequence of this action was the lack of caring confidence reported by fathers post-discharge. Fathers reported that due to this lack of confidence, they could not support mothers to care for their infants after discharge leading to unnecessary presentation to the hospital. This finding may be as a result of the cultural expectation of men in the Ghanaian society in which fathers are expected to be heads of households and breadwinners. Fathers are barely expected to be actively involved in day-to-day child care activities (Ampofo & Boateng, 2007; Miescher, 2005). It was recommended that healthcare workers should make fathers active participants in the care of their preterm infants while on admission. This way, fathers can provide relevant support to mothers to care for preterm infants after discharge.

Summary of study findings

In this study, parents' experiences of caring for preterm infants after discharge from the neonatal unit have been explored in depth. Four major findings were reported and discussed in the published papers that are included in this thesis. An overview of the major findings is now provided.

1. In the systematic review conducted to determine the state of the knowledge on this topic, a gap for the study of parents' experiences of caring for preterm infants after discharge was identified. In this review it was revealed that, for parents to care for their preterm infants effectively at home, they should be supported in the neonatal unit; this support increases parents' confidence in care.

The major findings of the empirical study were that:

2. When a preterm infant is discharged, their grandmothers become the sole support providers providing informational support to parents. They are responsible for diagnosing and treating diseases especially traditional childhood illness. Grandmothers decide whether a particular childhood illness requires a hospital or out-of-hospital treatment. For some traditional illnesses, especially 'asram', the study revealed that grandmothers take the role of diagnostician and determine treatment, which is by using traditional herbs or the herbalists.
3. For fathers of preterm infants, the admission of the preterm infant in the neonatal unit can be stressful for them but is made more stressful by healthcare workers, especially nurses, who did not involve them in the care of their preterm infants in the neonatal unit. Fathers were excluded from the care of their preterm infants.
4. As fathers were not involved in the care of their preterm infants while on admission, they were not very confident to care for their infants independently after discharge. This finding is similar to the earlier systematic review of 12 studies from across the world in which it was revealed that support increases the confidence of parents of preterm infants after discharge (Adama, Bayes, & Sundin, 2016).

In conclusion, this study provides a new perspective on the challenges facing parents of preterm infants, and highlights previously unknown gaps existing in these infants and their families' care. The importance of the grandmother in the Ghanaian community when an infant is discharged home cannot be overemphasised. However, this study has revealed that the support rendered by grandmothers can be detrimental to the health of a preterm infant in the community. In addition, the study has also revealed that, not only were Ghanaian fathers excluded from caring for their preterm infant in the neonatal units, they also lack confidence in caring for their preterm infant after discharge as they were not involved in pre-discharge education. Education and support for these parents and their significant others during neonatal unit admission that reflects cultural norms in Ghana in relation this phenomenon is essential in developing the confidence of parents and carers of preterm infants. This support should be tailored towards the needs of parents and their social support providers. In resource limited settings such as Ghana, adequate support in the neonatal unit by teaching and involving parents and their support providers in the care of the preterm infant will empower them to provide the right care after discharge.

Implications for clinical nursing

In a setting where support for carers of vulnerable preterm infants in the community is not readily available, healthcare workers should endeavour to empower carers of preterm infants while on admission in the neonatal unit so that they can care for the preterm infant after discharge. The study has also shown that grandparents who are not usually considered in discharge education are the main carers of preterm infants in the community. In the clinical setting, healthcare workers should identify and support the main support providers of parents of preterm infants while on admission and include them in health education.

Recommendations and further studies

The results of the study call for some recommendations in the care of preterm infants in the neonatal unit and the community. Therefore, the recommendations in the neonatal unit and the community will be addressed within these contexts.

In the neonatal unit

While previous results have reported the emotional distress of parents of preterm infants in the neonatal unit, there has not been any empirical study in the Ghanaian context to explore this phenomenon making it hard for measures to be instituted. The family centred care model in neonatal units is yet to be fully understood by neonatal nurses in Ghana. In this study, parents reported how they were not included in the care of their preterm infants while they were admitted. It is recommended that nurses in the neonatal unit involve the extended family in caring for the preterm infants as they will be supporting mothers to care for their preterm infants after discharge. The support persons of parents should be identified during admission in order to include them in health education. By so doing, they will be empowered to provide the right support for the care of the preterm infant after neonatal unit discharge.

In the neonatal unit, fathers in the current study reported that the rigid routines of the neonatal unit affected the frequency of their visit. Thus, it is recommended that feeding times should not be too rigid. Parents should be allowed unlimited access to their preterm infants. Fathers should be seen as partners in care and not merely as financial support providers. In the current study, the small 'financial space' occupied by fathers while on admission affected their ability to support mothers and care for their preterm infants after discharge.

In the community

In the community, this study has shown that the care of the preterm infant is not solely that of the parents. It includes the households and the entire community. Parents especially mothers who have been empowered to care for their preterm infants are displaced by the grandmother or elderly women. They (grandmothers) use their previous experience in child care to dictate how the preterm infant should be cared for. From these findings, it is strongly recommended that grandmothers who provide support for parents after neonatal unit discharge be included in the pre-discharge education. They should be educated on evidence-based care of preterm infants before discharge.

Also, in the community, some childhood illnesses have been labelled as not-for-hospital. For instance, 'asram', one of the traditional childhood illnesses, is commonly associated with low birth weight and preterm birth. Therefore, discharged preterm infants are usually taken to herbal centres for treatment. As the potency of these herbal medicines

have not been studied, infants are at higher risk of developing complications such as lead poisoning (Karri, Saper, & Kales, 2008). Therefore, it is recommended that, parents and grandmothers be educated on the potential effect of subjecting preterm infants to herbal medicines whose efficacy has not been studied.

In Ghana, it is not a usual practice for parents to be visited by nurses or health visitors after discharge of preterm infants. Given the mortality rate of these babies and their vulnerability to grandmothers' interventions, it is recommended that after discharge, parents should be visited by community health nurses at least within the first two weeks of discharge to iterate education on the care of the preterm infants. In areas where this is impossible because of staffing constraints, it is recommended that parents be contacted by healthcare workers via mobile phones to discuss issues identified after discharge.

Further research

In the future, further studies on the support needs of parents of preterm infants in the neonatal unit should be empirically studied in order to render evidence-based support.

In addition, a study on the effectiveness of including fathers and grandmothers or significant others in pre-discharge education of preterm infants should be undertaken.

A nursing tool for the assessment of parents' and carer's competency of caring for preterm infants post-discharge should be developed empirically to assess parents in the neonatal unit before discharge.

It is important to also explore the benefits of involving fathers in the care of their preterm infants in the neonatal unit and after discharge.

Family centred care approach in the neonatal unit should be explored and if knowledge gap exists among staff, appropriate training should be instituted. In addition, a study on the implementation of family centred care approach in resource limited regions such as Ghana should be investigated.

Traditional or herbal medicines are very popular among Ghanaians and they are also used in treating 'asram' in preterm infants, hence, it is important to study the efficacy of these herbal medicines before using them on preterm infants.

Strengths and limitations of study

This study to the best of my knowledge is the first to explore the experiences of caring for preterm infants in the Ghanaian community. It has thus added to existing knowledge on neonatal care after discharge especially in the Sub-Saharan African region.

The results of the current study have deepened our understanding of parents' experiences of caring for the preterm infants in the Ghanaian community. The journey of parents from neonatal unit to the community also provided rich data on the overall experience in the neonatal unit. Although the study set out to study parents' experience post-discharge, narrative inquiry provided the platform to also include their journey from the neonatal unit to the community. The neglect of fathers in the neonatal unit and the power of the grandmother in deciding treatment options for the sick preterm infants in the community shows, for the first time, the need to identify and include support persons in the care of preterm infants prior to discharge into the community.

In this study, the use of narrative inquiry for the exploration of both experiences and cultural aspects of caring for preterm infants in the Ghanaian community has shown that narrative inquiry is not limited to only the study of experiences. The total number of the participants, although relatively small, has provided rich and in-depth data that has deepened our understanding about the phenomenon of caring for preterm infants in the community.

In this study, the opportunity for participants to recall their experiences in the neonatal unit served a therapeutic purpose as parents re-lived and reflected upon the aspects of their experiences that were very important to them. Although there was a psychologist available to attend to any parent who may be distressed by telling their stories, this service was not utilised – the experience was helpful rather than distressing to participants. This conclusion was drawn with consultation with the parents. Participating in these conversations was seen by those who took part as an avenue to speak out and get healed.

Despite the strengths of the study, some limitations were identified. The study relied on the recollection of past events. As some parents stayed in the neonatal unit for nine weeks, their experiences may be different from those who stayed for only a week. In this case, the stories will be different and different meanings will be ascribed to their experiences.

Also, as participants have to recollect their experiences in the neonatal unit, the possibility of recollection bias existed. However, as the aim of narrative inquiry is to understand the value the participants' place on their experiences rather than seeking the truth (Kim, 2015), the current study achieved its aim of exploring the phenomenon of caring among parents of preterm infants after discharge in the Ghanaian community.

In addition, the relatively small number of study participants makes it an issue to consider when transferring the results of the current study. However, as the study used narrative inquiry, this number is relatively large for the study. Although data for this study was collected until saturation was reached and the participants were contacted to validate their stories and their interpretations, the interpretation of the results are not entirely free from the researchers' interpretation as the researcher was considered part of the researched (Bleakley, 2005).

In the systematic review of studies that explored the experiences of caring for preterm infants, the available evidence was included in the systematic review using a well-defined search strategy. However, as qualitative studies are poorly indexed, there is the possibility of not including some quality studies (Atkins et al., 2008).

Reflecting on my PhD journey

I started this PhD journey in a very enthusiastic manner. However, in the middle of my journey, my energy was wearing off. I became discouraged in pursuing my once passionate project. However, every meeting with my supervisors was a bliss, it instilled a dose of strength in me. I was full of energy anytime I go for a supervisory meeting. I spent days and nights accomplishing what came up during the supervisory meeting. In this relationship, I learnt to be a motivator, to encourage others when they are down and to keep my mentees focussed and motivated. I have come to understand and have a very strong love for people I mentor just as my supervisors did for me. Their words of motivation and understanding kept me going. In this supervisor-student relationship, I learnt how to support others to keep moving.

Undertaking a study using an unfamiliar methodology (narrative inquiry) was intimidating at the beginning. I felt stuck with my PhD project when I had to choose a relevant qualitative method for the research. I spent nights in the PhD suite reading every article on qualitative methodologies. Reading and understanding a qualitative research methodology can be daunting for most postgraduate students including me. However,

after days and nights of reading many qualitative research methodologies and with my supervisors' guidance, I settled on narrative inquiry because of its ability to explore both experiences and sociocultural factors affecting the experience. As a story lover, narrative inquiry came in handy but not as easy as I thought it will be. I found myself being drowned by my data during the transcription and data analysis. Nonetheless, by successfully using narrative inquiry for my PhD project and publishing a paper on my once dreadful research methodology, now I can confidently say, "I am a narrative inquirer!"

Throughout my PhD journey, I have learnt to be critical and very constructive in providing feedback. Every time I spent with my PhD supervisors created an opportunity for me to reflect on my practice as a nurse educator in Ghana and to learn essential skills for providing student-centred teaching.

I have also learnt to become resilient. If there is anything I learnt outside my supervisory meeting, then it is resilience. When I applied for my ethical clearance in Australia and Ghana, I learnt to wait patiently even when there is no need to wait. I learnt to bounce back where I should be quitting. I learnt to become a stronger person than I can ever imagine. When I was collecting data, the disappointment of getting lost all day because of inaccurate residential address (GPS does not work in Ghana) were enormous. After spending a whole day searching and not locating my participant's home, I went home so disappointed but only to wake up early the next day to start the same search again. The numerous places I went without a mobile network service changed my perception about life and taught me not to easily give up. When I finally located my participants, not only did I feel relieved but they became extremely happy to see me amidst the challenges of the previous day. Most of them will say "Madam, I didn't think you'll come after getting lost all day; thank you for coming" This act of appreciating my presence in their homes taught me never to give up on people. One of my participants who relocated to a different region in order to be supported by her mother was amazed to see me when I went for the third round of data collection. I travelled 253 kilometres to interview her. In all these experiences, I have learnt to become very resilient and never to give up easily.

Having decided to go the "tough way" by choosing to do PhD by publication, I have also learnt a lot from reviewers and editors who have read and commented on my articles. They gave me a deeper understanding and appreciation of the peer review process. Their comments and suggestions taught me how different people see things differently. By responding to the comments, I reflected and learnt a lot which will inevitably help me in

the academic and research world. The various research workshops organised by Edith Cowan University Graduate School and other universities in Western Australia helped me to manage my emotions when heartbreaking comments from reviewers were received. Again, my supervisors comforted me when one of my papers was rejected by an academic peer review journal. This rejection taught me to be ready for everything in life-good or bad.

Another important thing I learnt from my PhD journey is the need to discuss ideas with other PhD students. I discussed everything from methodology to findings even when the person in question does not understand anything in nursing. This way, I learnt to listen to myself and draw on new ideas. For instance, when I was deciding on an appropriate research methodology for my PhD, these discussions with colleague PhD candidates helped me to understand some qualitative methods.

In conclusion, my PhD journey has been one full of ups and downs but enjoyable and exciting with a lot of knowledge and skills to take home as a nurse practitioner, educator and researcher.

Summary of chapter five

Chapter Five above has presented the discussion and conclusion of the major findings of the current study. It has also discussed the strengths and limitations of the study, the general recommendations, areas for future research and finally, the reflection of the researcher's PhD journey.

Conclusion

The current study aimed at exploring the experiences of caring for preterm infants in the Ghanaian community from the perspective of parents. In this study, a total of 42 parents and households of preterm infants were interviewed using narrative inquiry approach. Existing evidence on this phenomenon suggest that parents are overwhelmed with the care of their preterm infants after discharge and require support in order to be confident in caring for their preterm infants. This study which resulted in the publication of four research articles has provided a deeper understanding of the phenomenon in the Ghanaian context. Furthermore, it has resulted in recommendations that will provide support for parents and their immediate support providers in the neonatal unit and community which in turn can aid in reducing neonatal morbidity and mortality in the Ghanaian community.

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APPENDIX 1: Ethics Approval



KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES

SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL
COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS



Our Ref: [REDACTED]

6th February, 2015.

Ms. Esther Abena Adama
Edith Cowan University
School of Nursing and Midwifery
WESTERN AUSTRALIA.

Dear Madam,

LETTER OF APPROVAL

Protocol Title "Parents' Experiences of Caring for Preterm Infants after Discharge"

Proposed Site: Komfo Anokye Teaching Hospital- Child Health Directorate. Mother and Baby Unit Kumasi.

Sponsor: Australian Government's PhD Scholarship. The International Postgraduate Research Scholarship.

Your submission to the Committee on Human Research, Publications and Ethics on the above named protocol refers.

The Committee reviewed the following documents:

- A notification letter of 17th December, 2014 from Komfo Anokye Teaching Hospital (study site) indicating approval for the conduct of the study in the Hospital.
- A Completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Proposal.
- Interview Guide.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, renewable annually thereafter. The Committee may however, suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Thank you Madam, for your application.

[REDACTED]

Rev. Prof. John Appiah-Poku
Honorary Secretary
FOR: CHAIRMAN

Room 7 Block J, School of Medical Sciences, KNUST, University Post Office, Kumasi, Ghana
Phone: [REDACTED] Mobile: [REDACTED] Email: [REDACTED] / chrpe@knust.edu.gh

Dear Esther

Project Number: [REDACTED]

Project Name: Parents' experiences of caring for the preterm infant after discharge from the neonatal intensive care unit

Student Number: [REDACTED]

The ECU Human Research Ethics Committee (HREC) has reviewed your application and has granted ethics approval for your research project. In granting approval, the HREC has determined that the research project meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

The approval period is from 28 October 2014 to 1 December 2017.

The Research Assessments Team has been informed and they will issue formal notification of approval. Please note that the submission and approval of your research proposal is a separate process to obtaining ethics approval and that no recruitment of participants and/or data collection can commence until formal notification of both ethics approval and approval of your research proposal has been received.

All research projects are approved subject to general conditions of approval. Please see the attached document for details of these conditions, which include monitoring requirements, changes to the project and extension of ethics approval.

Please feel free to contact me if you require any further information.

Regards

Kim

Kim Gifkins, Research Ethics Officer, Office of Research & Innovation, Edith Cowan University, 270 Joondalup Drive, Joondalup, WA 6027

Email: research.ethics@ecu.edu.au Tel: +61 08 6304 2170 | Fax: +61 08 6304 5044 | CRICOS IPC 00279B

This e-mail is confidential. If you are not the intended recipient you must not disclose or use the information contained within. If you have received it in error please return it to the sender via reply e-mail and delete any record of it from your system. The information contained within is not the opinion of Edith Cowan University in general and the University accepts no liability for the accuracy of the information provided.

CRICOS IPC 00279B

APPENDIX 2: Information Letter



CARING FOR YOUR PRETERM BABY AFTER DISCHARGE FROM THE NICU

INVITATION TO PARTICIPATE IN STUDY

My name is Esther Abena Adama, a PhD student from the school of Nursing and Midwifery, Edith Cowan University in Australia. I am interested in your experiences as the parents of a baby who was born too soon, especially when you took your baby home from the hospital. I would like to interview you about caring for your baby and the help you had. With your permission, I would like to do this after you have been discharged from the Neonatal Intensive Care Unit (NICU). With this information, I hope to understand your concerns in order to start or improve services that will meet the needs of parents in a similar situation to you. Please be aware that in our conversation, when I use the words hospital or NICU I mean the neonatal intensive care unit (the special ward where your baby was cared for after they were born).

The interview will be tape recorded with your permission and should not last more than an hour. In all, three interviews will be conducted at one week, one month and four months after NICU discharge. During the interview I will be asking extra questions because I want to completely understand your words. As we are being audio taped, I will need your voice to be clear and audible (easy to hear) when responding to my questions. Also, you may be given a diary to record your experiences as you care for your baby after hospital discharge. Should your baby be readmitted after been chosen for this study, you will still remain a participant but will only be interviewed after your baby leaves the NICU. During the research project, if I find that your baby is "at risk", I will inform you and make a referral to the social welfare department according to hospital policy.

By telling your story about how you care for your baby at home, you may be at risk of emotional distress, therefore, the services of a clinical psychologist (Prof Rev. Fr. Appiah-Poku) has been employed and he will attend to you should you require his service.

All your responses will be kept confidential; however, this information will be shared with the research team during the project. When the project is complete, a summary of the findings will be shared with management of the NICU where you were admitted; they will also

be published without mentioning your name. This is so that parents like yourself can share in the improvements I am hoping will come from this project and your contribution. To protect your privacy, you and your baby's name will be changed in the stories shared with anyone other than the research team. Your responses will be transcribed (written down) and a copy sent to you for confirmation (agreement that I have written your words down correctly). Please note that it is not compulsory for you to respond to all the questions and you can decide to end the interview at any time if you want to without any consequences for yourself or your baby.

Should you have any concerns or questions concerning this study, please contact me or any of the research team below:

1. Esther Abena Adama,
PhD student,
Edith Cowan University
Mobile: [REDACTED]
Email: eadama@our.ecu.edu.au
2. Dr Deborah Sundin
Senior Lecturer,
School of Nursing and Midwifery,
Edith Cowan University, WA
Tel: +61 8 63043 488
Email: d.sundin@ecu.edu.au
3. Dr Sara Bayes
Associate Head of School,
School of Nursing and Midwifery
Edith Cowan University
Tel: +61 (0)8 63043508
Mob: [REDACTED]
Email: s.bayes@ecu.edu.au

If you have any concerns or complaints about the study and wish to speak to an independent person, you can contact;

1. Hannah Frimpong
Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra.
Tel: [REDACTED]
Mob: [REDACTED]
Email: Hannah.Frimpong@ghsmai.org

2. Kim Gifkins,
Research Ethics Officer,
Office of Research and Innovation,
Edith Cowan University,
270 Joondalup Drive,
Tel: 63042170
Mobile: [REDACTED]
[Email: research.ethics@ecu.edu.au](mailto:research.ethics@ecu.edu.au)

Please provide your signature and contact details if you want to be contacted for the interview and return the signed copy to the nurse manager of your NICU.

Name:.....

Signature:.....

Date:.....

Mobile:.....

Residential Address:.....

APPENDIX 3: Informed Consent



INFORMED CONSENT FORM

CARING FOR YOUR PRETERM BABY AFTER DISCHARGE FROM THE NICU

By signing this consent form, I declare that the researcher has explained the study to me; I have read the information sheet and voluntarily decided to be interviewed. I understand that I will be telling my story about how I care for my baby who was born too soon at home. I understand that all my responses will be tape recorded and I might have to provide extra information about my experiences in a diary that will be provided by the researcher. I am aware that three separate interviews lasting not more than one hour will be conducted one week, one month and four months after NICU discharge. I understand that all my responses will be kept confidential and only shared among the research team. I also understand that under no circumstance will my name or that of my baby be mentioned in the final results of the research or in any publication arising from the research.

I have been made aware that should I suffer from any emotional distress as a result of telling my story, the services of a clinical psychologist is readily available for me. I have the contact details of the research team and independent persons. I understand that I am welcome to contact them anytime regarding this study should I have any questions or concerns. I am aware that this study is not compulsory and I can end the interview anytime I wish without any penalty.

Name:.....

Signature:.....

Date:.....

Mobile:.....

Residential address:.....