

ANGLIA RUSKIN UNIVERSITY

**SUSPENDED LIMINALITY: BREASTFEEDING AND
BECOMING A MOTHER IN TWO NICUs IN JORDAN**

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A thesis in partial fulfilment of the requirements of Anglia Ruskin
University for the degree of Doctor of Philosophy

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In the name of Allah, the Compassionate, the Merciful

NOTE

This thesis includes English translations of some verses of the Qur'an, the purpose of which is to indicate the generally accepted social and ethical perspective of the study's participants. The source for these translations is Ali (1989). The translation is subject to human interpretation, it is therefore not to be regarded as the words of God (Allah) or as a holy scripture. There is only one original Arabic version of the Quran preserved by Allah and it has never been changed since it was revealed to the prophet Muhammad (PBUH) more than 1400 years ago. These verses are included in the thesis to provide a baseline to indicate societally accepted perspectives in Jordan (an Islamic country) on issues raised within the thesis. This may assist non-Jordanian readers.

The phrase (PBUH) is routinely used after writing the name of the prophet Muhammad and is often used by Muslims after saying or hearing the name of one of the prophets, peace be upon them all.

DEDICATION

With my love and appreciation, I dedicate my work to the mothers and staff members who participated in the study.

I also dedicate this work, with much love, to my caring family for their love, patience and support.

Finally, with much love, I dedicate this work to my husband Adnan for his patience and support and to my children: Doa'a, Rua'a, Hisham, Ammar and my sweetheart Rahmah for their understanding.

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ANGLIA RUSKIN UNIVERSITY

ABSTRACT

FACULTY OF HEALTH, SOCIAL CARE, AND EDUCATION

DOCTOR OF PHILOSOPHY

SUSPENDED LIMINALITY: BREASTFEEDING AND BECOMING A
MOTHER IN TWO NICUs IN JORDAN

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OBJECTIVES: To explore why so few mothers breastfeed when their babies are admitted to neonatal intensive care unit (NICU), and to gain an understanding of the impact of this for the mothers and staff involved.

DESIGN: This study adopted an ethnographic approach. The data collection involved 135 hours of participant observation over a 6-month period and 32 semi-structured interviews of 17 mothers, 10 nurses, and 5 physicians.

FINDINGS: Data from the participants' interviews and the participant observation were analysed focusing on the two different perspectives; one relating to the mothers and the other to the staff members and their working conditions. The mothers' experiences were revealed as a developing process as their feeling changed from fearful and terrifying toward becoming and feeling like a 'real' mother. Their experience of mothering and breastfeeding differed from their expectations in that breastfeeding became a complex process for some and impossible for others. Five distinct themes emerged; the first highlighted *the crisis*, which involved the mother's feelings of emotional instability, their strategies for coping such as not visiting the baby, and recognition of the NICU as a stressful environment. The second theme described issues relating to *control* and *power*. This involved the perception of having a lack of control and needing to seek permission, the use of language as a mechanism for control, and mothers being placed in a subordinate role. The third theme related to *the separation*, which included difficulties of acceptance, feeling like stranger and not being important, and the need for physical closeness. *Acceptance and adaptation* comprised the fourth theme in which gradual acceptance occurred and a spiritual aspect emerged. The final theme, *becoming a mother*, included issues such as the special moments, breastfeeding as a turning point, and practical and informational needs. Almost all the mothers in this study spoke about going through all these stages during their infants' stay in the NICU. Analysis of these findings suggests that mothers who deliver prematurely, may have their rite of passage into motherhood interrupted, resulting in them being placed in a position of suspended liminality.

The data also suggest that while staff members agree with the benefits of breastfeeding for preterm infants, the actual implementation of a breastfeeding policy within the neonatal units is more problematic. Three key themes emerged from the analysis relating to the staff perspectives. The first described the *contradiction* that exists between the staff beliefs and behaviours in relation to breastfeeding and supporting mothers. Elements that comprised this theme were “*breast milk is best*”, perceiving breastfeeding promotion as a nicety not a necessity; lacking support for mothers, and abdication of responsibility. The second theme related to their *working conditions*: this included a lack of institutional support for the health care team, and barriers to support breastfeeding. The final theme of *controlling relationships* captured the essence of the practitioner: mother association. Together, these elements revealed a situation whereby staff appeared more preoccupied in addressing the task aspect of care for the babies than supporting mothers in feeding and subsequently mothering their preterm child.

CONCLUSIONS: An understanding of the experiences of mothers of preterm infants who wish to breastfeed, and the connection that breastfeeding has to the process of becoming a mother, allows for the finding of more positive strategies to support mothers and breastfeeding within the NICU. This study reveals a new understanding of how breastfeeding is connected to the process of becoming a mother, within the context of two Jordanian NICUs. It also highlights the difficult working conditions for nurses within these units. It is anticipated that recognition of these findings may assist with service developments and lead to improvements in the NICU environment in Jordan, thus enhancing health care delivery in accordance with the individual needs of infants and their mothers.

KEYWORDS: Ethnography; breastfeeding; preterm infants; experiences; neonatal intensive care unit.

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CHAPTER 1: INTRODUCTION

“Breast is best” is a phrase well accepted by the health care professions. However, despite the well documented benefits of breastfeeding, preterm infants cared for in neonatal intensive care units in Jordan are routinely given artificial feeds and there are minimal strategies employed to promote or support breastfeeding, despite this being the normal mode of feeding for term infants. This PhD study sought to identify the reasoning behind the current situation of breastfeeding in two NICUs in Jordan and to explore the possible consequences as breastfeeding has been recognized as being intimately connected to the process of becoming a mother (Lupton and Fenwick, 2001).

The United Nations Children’s Fund (UNICEF) statistics data for the period of 2006 until 2010 showed that the percentage of early initiation of breastfeeding in Jordan was only 39%. This is compared to 56% in Egypt, 46% in Syria (UNICEF, 2012), and 81% in the UK (UNICEF UK, 2012). Twenty two percent were exclusively breastfed in the first 6 months of life in Jordan compared to 53% in Egypt, 43% in Syria (UNICEF, 2012), and only 1% in the UK (UNICEF UK, 2012). Sixty six percent were breastfed with complementary food for ages 6 – 9 months compared to 66% in Egypt, and 34% in the UK. Only 11% continued breastfeeding beyond age of 20 months in Jordan compared to 35% in Egypt and 25% in Syria (UNICEF, 2012).

There are no records for the incidence and duration of breastfeeding preterm infants born prior to 37 gestational weeks in Jordan. Yet, it has been known globally that the incidence and duration of breastfeeding preterm infants continues to be less than that of full-term infants (Callen and Pinelli, 2005). The lower incidence is probably related to breastfeeding difficulties that preterm infants and parents face.

Breastfeeding experiences within NICUs are an area of care not previously studied in depth in Jordan. As a result, there was no detailed information on how mothers and health care workers perceive breastfeeding experiences, and how breastfeeding is connected to the process of becoming a mother in an Arabic country. The aim of this ethnographic study, therefore, was to explore the experiences and perceptions of mothers and health care staff in relation to breastfeeding and mothering preterm infants in two hospitals within Northern

Jordan. The research settings were chosen because the units are located within two large referral hospitals in Northern Jordan. These hospitals provide health care services to a population of more than 1 million inhabitants (Ajlouni, 2011). The decision to choose two units was not for comparison purposes but to add depth to our understanding of the preterm breastfeeding experiences (Dykes, 2006).

In order to be able to contextualize this study, it is helpful to consider the health status of the population, and the position of nursing in Jordan before exploring the importance placed in the country on breastfeeding.

COUNTRY HEALTH PROFILE

Jordan is a small country with a population of 6,264,462 (Department of Statistics - Jordan, 2013). Its position in the middle of Palestine, Syria and Iraq; three of the most insecure countries in the region, with the pro-democracy revolutionary wave that has erupted on December 2010 across the Middle East and North Africa (known as the “Arab Spring”) signifies a major developmental challenge. Jordan is one of the most resource-poor countries in the Middle East. It has been classified by the World Bank as a lower-middle income country with restricted natural resources (Abdel-Gader and Abu-Ismaïl, 2009). Despite such challenges, Jordan has been able to establish an acceptable quality of life for most of its people.

Jordan has an advanced health care system when compared to the other Middle Eastern countries (Ajlouni, 2011). This consists of three main sectors: public, private and donors. The public sector is the main health services provider, which consists of two major health providers: the Ministry of Health (MOH) and the Royal Medical Services (RMS). Other smaller university-based programmes have their own finance and care delivery systems, including Jordan University Hospital (JUH) in Amman, and King Abdullah University Hospital (KAUH) in Irbid (Ajlouni, 2011).

The MOH provides primary, secondary and tertiary health care services via 31 hospitals, 86 comprehensive health centres, 371 primary health centres, 435 maternity and child health centres, 220 peripheral health centres, 12 chest disease centres and 377 dental clinics. The RMS operates 12 hospitals and is responsible for providing health services to military and security personnel and their families. The JUH and KAUH provide health services to their employees

and their families and to patients referred from the MOH, RMS and the private sector (Ajlouni, 2011).

The private sector has the largest number of hospitals as it runs 61 hospitals (World Health Organization, 2006; Directory of Information and Research, 2011). The donors' sectors include the United Nations Relief and Work Agency (UNRWA) and other non-government organizations. UNRWA runs 21 primary health care centres and 30 special care clinics for Palestinian refugees.

Approximately 75% of the Jordanian population is covered by health insurance. The RMS is the largest insurer and covers 28% of the population, followed by the MOH with 26.4%, UNRWA with 10%, private organizations have 9.2% and university hospitals cover 1.4% (Halasa, 2008).

In terms of health indicators, Jordan has an advanced health care system. It has achieved significant progress in reducing the major health risks to infants and children thus lowering the infant and child mortality rates (Ajlouni, 2011). Table 1 summarizes the country's demographic and health data for the period of 2007-2011. However, the Jordanian hospitals of the main public sector still face many constraints that hinder their ability to provide proper health care. These constraints include centralized management practices, lack of incentives for hospitals and their staff, inadequate information on costs and evidence-based medicine and nursing shortages (Al-Maaitah and Shokeh, 2009; Zahran, 2011).

Table 1: The country's demographic and health data profile

Country Demographic and Health Data	2007	2008	2009	2010	2011
Population	5723000	5850000	5980000	6113000	6249000
Adult Male Illiteracy Rate (%of 15+ Yrs of age)	4.3	4.1	3.7	3.7	3.6
Adult Female Illiteracy Rate (%of 15+Yrs of age)	11.6	11.4	10.8	10.8	9.9
Average	7.9	7.7	7.2	7.2	6.7
Crude Birth Rate (per 1000 pop.)	29.1	28	29.1	30.1	28.9
Population Growth Rate (%)	2.2	2.2	2.2	2.2	2.2
Average Person Per Family	5.4	5.4	5.4	5.4	5.4
Total Fertility Rate	3.6	3.6	3.8	3.8	3.8
Life Expectancy at Birth (Yrs) Male	71.6	71.6	71.6	71.6	71.6
Life Expectancy at Birth (Yrs) Female	74.4	74.4	74.4	74.4	74.4
Average	73.0	73.0	73.0	73.0	73.0
Crude Death Rate (per 1000 pop.)	7	7	7	7	7
Infant Mortality Rate (per 1000 live births)	19.0	19.0	23.0	23.0	23.0
Maternal Mortality Rate (per 100,000 live births)	41.0	19.1	19.1	19.1	19.1
Physician/ 10000 pop.	26.7	24.9	24.5	26.5	25.5
Dentist/ 10000 pop.	8.5	8.7	7.3	9.3	10.0
Nurse (Including Midwives)/ 10000 pop.	33.6	33.6	39.0	41.9	44.7
Pharmacist/ 10000 pop.	14.1	13.2	14.1	15	12.8

Source: (Directory of Information and Research, 2011) (Summary in English, page 2)

NURSING IN JORDAN

The first nursing school in Jordan was opened by the MOH in 1953 and was operated by American and British staff. By the mid-1960s, Jordan started to have Jordanian graduates who were trained in the USA and the American University in Lebanon. In 1962 the first military nursing school, Princess Muna College of Nursing, was established in Amman (Zahran, 2011). It is important to recognize that this Western approach to the medical profession has, and continues, to strongly influence the Jordanian nursing education system. Both British and American staff taught at the College.

Nursing education has been developing significantly from the 1970s with the return of postgraduate nurses from Western universities who assumed many

educational positions. In 1972 the first Faculty of Nursing was established at the University of Jordan, which offered a 4-year Bachelor of Science Nursing degree along with a bridging program for diploma and associate nurses to gain a baccalaureate level (Zahran, 2011). In 1983, at Jordan University of Science and Technology, the second Faculty of Nursing was established followed by an increasing number of nursing programmes in both public and private sectors. Jordan now has 15 Bachelor of Science nursing programmes offered by 15 public and private universities (Al-Maaitah and Shokeh, 2009). The University of Jordan was the first to offer a Master program in nursing in 1986, followed by Jordan University of Science and Technology in 1998 (Zahran, 2011). There is currently only one doctoral nursing program offered by the University of Jordan since 2005 (Maaitah and Shokeh, 2009). Nursing curricula, in various levels, are heavily influenced by the Western nursing education, where English textbooks are used and English is the language of education for all nursing programmes across the country (Shuriquie, While and Fitzpatrick, 2008).

The development of these educational programmes contributed to the development of nursing profession and enhanced nurses' competencies and abilities to be able to meet the health care needs of the country (Oweis, 2005). Other strategies were implemented to improve and develop the education of nurses in the country. One of these strategies was the establishment of Jordan Nurses and Midwives Council (JNMC) in 1972 and, recently, the Jordanian Nursing Council (JNC) in 2002, which aimed to develop nursing and midwifery services through regulating the nursing profession and enhancing its practice.

While the establishment of JNMC and JNC along with the other educational strategies contributed positively to the development and improvement of nursing education and nurses' status, there is still a recognized lack of development of nursing practice and a significant shortage of nurses in Jordan. Jordanian nurses lack governance authority and autonomy in many institutions (JNC, 2008). They still have unclear job descriptions, less support to resume their studies, unsupportive working environments and no incentives or clinical ladders that recognize their expertise (Al Ma'aitah et al., 1999). A high rate of turnover (44%) was, therefore, reported in some of these Jordanian hospitals (JNC, 2008). Nurses also have long working hours in many institutions, inadequate nurse to patient ratios and heavy workload (Al Ma'aitah et al., 1999) with a dominant task-oriented delivery of care method (Zahran, 2011).

Staff shortages in Jordan are considered one of the biggest obstacles in the country's ability to provide proper health care services. Among factors that contribute to this shortage are: increased population growth rate, an increasing number of hospital beds, negative workplace environment, and nurses immigration and movement from one hospital to another seeking better job opportunities (Al-Maaitah and Shokeh, 2009; Zahran, 2011).

BREASTFEEDING IN JORDAN

In 2007 UNICEF estimated 9.2 million under-five deaths around the world, 40% of these deaths occurred in the newborn period. In developing countries, 50% of all deaths in infancy occur in the first month of life (UNICEF, 2008). Jordan has an infant mortality rate of 18/1000 live birth and a neonatal mortality rate of 13/1000 lives for the year 2010 (UNICEF, 2012).

Each year more than 4 million deaths occur globally in the first 4 weeks of life, preterm birth (birth before 37 gestational weeks) is the cause of 28% of these neonatal deaths (Lawn, Cousens and Zupan, 2005; World Health Organization (WHO), 2005). Causes of infant mortality in the developing world tend to be similar to those in the developed countries. In the developing world, the three major causes of such deaths are serious infections (36%), prematurity (27%), and birth asphyxia (23%) (Lawn, Cousens and Zupan, 2005; UNICEF, 2008). In Jordan 70% of infant deaths are attributed to neonatal death (Bataineh, Shawagfeh and Twalbeh, 2008), where perinatal originating conditions, congenital malformation, respiratory system diseases and prematurity are the leading causes of infant death in the neonatal period (Khoury and Mas Ad, 2002). Prematurity alone was the cause of 54% of early neonatal deaths in Jordan (Abu-Heija, 1994). Recently, Bataineh, Shawagfeh and Twalbeh (2008) reported that prematurity is the leading cause of neonatal deaths in Irbid/Jordan with a percentage of 44.4%. Abu-Salah (2011) studied all live singletons over the period of 2009 – 2011 at Queen Alia Hospital in Amman, Jordan and found that preterm infants made up 10.7% of the cohort, with increased risks for respiratory distress, hypoglycemia, sepsis and feeding difficulties.

High rates of exclusive breastfeeding during the first 6 months of life prevent 13% of under-5 deaths each year (WHO, 2008). Therefore, interventions to improve feeding are likely to improve the wellbeing of infants and to have a

significant impact on neonatal and infant mortality rates (Edmond, et al., 2006). In order to increase the rates of exclusive breastfeeding UNICEF and WHO concentrated their efforts on the early initiation of breastfeeding in hospitals. They have developed the Baby Friendly Hospital Initiative (BFHI) in 1991, which is an accreditation process that requires the presence of certain guidelines in a hospital including the 10 steps for successful breastfeeding (Table 2). As a result of these efforts UNICEF reported a significant increase in the exclusive breastfeeding rates in the developing world, which is estimated to have reduced infant mortality rate by more than 1 million (UNICEF, 2012).

Table 2: The ten steps to successful breastfeeding

1. Have a written breastfeeding policy that is routinely communicated to all health care staff.
2. Train all health care staff in skills necessary to implement this policy.
3. Inform all pregnant women about the benefits and management of breastfeeding.
4. Help mothers initiate breastfeeding within one half-hour of birth.
5. Show mothers how to breastfeed and maintain lactation, even if they should be separated from their infants.
6. Give newborn infants no food or drink other than breast milk, unless medically indicated.
7. Practice rooming in - that is, allow mothers and infants to remain together 24 hours a day.
8. Encourage breastfeeding on demand.
9. Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.
10. Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.

Source: UNICEF website: Baby Friendly Hospital Initiative

Jordan is an Islamic country. Residents are linked by a common Arabic language and predominant Muslim identity (92% Muslims and about 6% Christians). Islam shapes the Muslims' lives. All Muslims believe that the Qur'an is the actual word of God (Allah) revealed to the prophet Mohammad (PBUH). Both the Qur'an and the Sunnah (the teaching and practices of the prophet) guide Muslims' lives. Muslims accept the words of Allah in the Qur'an as the truth and thus adhere to His teaching. The Qur'an gives awareness of the value of breastfeeding for children, which is why breastfeeding becomes the norm for most Muslim women.

It is mentioned six times in the Quran. Allah Almighty commanded mothers to breastfeed their children for two full years:

The Mothers shall give suck to their offspring for two whole years, if the father desires to complete the term. But he shall bear the cost of their food and clothing on equitable terms. No soul shall have a burden laid on it greater than it can bear. No mother shall be treated unfairly on account of her child. Nor father on account of his child, an heir shall be chargeable (Quran, Al-Bagharah, 2: 233).

Despite the strong adherence to religious norms and the Quranic's recommendations breastfeeding rates have rapidly declined. Only 11% of Jordanian mothers breastfeed their infants for the full two years (UNICEF, 2012). For decades, public breastfeeding was fairly common in Jordan. Women covering their bodies and wearing head cover (Hijab) were commonly seen breastfeeding their infants in public. However, this has changed, particularly in urban areas perhaps due to the influence of the secular Western life style. With the beginning of the 21st Century, Jordan was exposed to great changes as it experienced rapid industrialisation and westernisation that had an intensive impact on the traditional culture in general and on feeding practices in particular (Galal, 1995). The adoption of the older Western-style practices in hospitals, which included separating infants from their mothers after birth, reduced early colostrum intake and increased the possibility of supplemental liquid intake (Cai, Wardlaw and Brown, 2012). Modernisation has also been linked to the use of bottle-feeding which is considered more sophisticated and convenient especially for those living in urban areas and for working mothers (Trussell, et al., 1992). Data from a prospective study that aimed to describe the patterns of breastfeeding among rural Muslim women in Israel indicated that the western lifestyle of the surrounding Jewish population had an impact on lactating rural Muslim women. It showed that Muslim women were moving away from their traditional exclusive breastfeeding pattern to a supplementary Western style-feeding pattern (Azaiza, 1995).

The Ministry of Health and UNICEF in Jordan have worked together on raising the public awareness of the importance of breastfeeding. Training courses were also developed for health care professionals in order to gain skills that are required to support breastfeeding mothers. In addition, the Ministry of Health has implemented the BFHI in many hospitals across the country.

In spite of these efforts, the UNICEF statistics data in Jordan for the period of 2003 – 2008 showed delay in both initiating and maintaining exclusive breastfeeding. The percentage of early breastfeeding was only 39%. Twenty percent were exclusively breastfed for the first 6 months, 66% were breastfed with complementary food from 6 – 9 months and only 11% continued breastfeeding beyond the age of 20 months (UNICEF, 2008).

Contrary to these results were the findings of Oweis, Tayem and Froelicher (2009), they examined breastfeeding practices among Jordanian women in Irbid and reported a rate of exclusive breastfeeding of 77%. About half of the mothers in this study initiated breastfeeding immediately after birth with an additional 24.5% initiating breastfeeding within 2 hours, making the total percentage of those initiating breastfeeding within the first few hours 74%. An explanation for these contradictory results may be that the Oweis et al. study was limited to the Irbid region and the majority of their participants were multiparous women (65.5%) with previous breastfeeding experiences. Multiparous women tend to breastfeed more often than primiparous women (Chen, et al., 1998).

A previous study (Mubaideen and AL-Saraireh, 2006) examined the breastfeeding rates in three Jordanian governorates: Amman, Irbid and Al-Karak. Their findings showed that the rate of children who ever breastfed was high with a percentage of 92.3 with 63% of children breastfed exclusively. The mean duration of breastfeeding was 12.4 months. They also found a significant association between the mothers' employment and early weaning from the breast. Insufficient breast milk was the main reason that employed mothers gave for weaning their children from the breast. In a more recent study, Amayreh et al. (2007) suggested that breastfeeding seems to be on the decline in Jordan, as they found that the rate of exclusive breastfeeding at Aqaba, south of Jordan, is only 47.5% in the first 6 months of life and dropped to 41% in the next 6 months. According to their study insufficient milk was given as the main reason for switching from breast to formula feeding, while work and pregnancy are among the other reasons that mothers reported.

Studies in the adjacent countries to Jordan have shown similar results. In Saudi Arabia 92% of mothers initiated breastfeeding early, however, 76.1% of them introduced bottle-feeding within 3 months of the infants' life. 43.3% of them reported insufficient milk as the reason for starting early bottle-feeding. Other reasons included return to work or education and new pregnancy (Al-Jassir,

2006). Insufficient milk was also reported as a mothers' concern among Lebanese women (Osman, El Zein and Wick, 2009). Galal (1995) identified some of the infant feeding patterns in the Middle East that were responsible for the rate of exclusive breastfeeding below the recommended guidelines of the WHO and UNICEF. This included discarding colostrum and replacing it with various liquids, desire for another pregnancy, perceptions of insufficient breast milk, modernisation, urban residency and the wide use of supplementary liquids within the first 40 days of life.

Patterns of breastfeeding of preterm infants were studied at two NICUs in the Al-Qassim region of Saudi Arabia, one of Jordan's neighbouring countries. Results showed that only 13.2% of preterm infants (12 out of 91) were discharged on a mix of breast and formula feeding while the rest of them (86.8%, 79 out of 91) were on preterm formula (Khalil, et al., 2003).

Currently, bottle-feeding is the norm in many Jordanian NICUs with a delay in introducing breastfeeding for infants until after they tolerate a certain amount of formula feed with no complications. Public records in Jordan indicate that there are 30 NICUs and two university hospital based units. However, these do not cover those units attached to the private hospitals. The NICUs in Jordan often have a more child-centred care environment, where parents are treated as visitors. Many units are designed to accommodate new, high-tech environment, which necessitate more lighting and more activities around the infant's bedside (Browne, 2003). The increased levels of light and sounds, together with the added need for more medical and surgical interventions have negative impacts on the preterm infants' developmental outcomes (Blackburn, 1998; Hunt, 2011). In many developed countries, however, the NICUs are designed to accommodate the new family-centred care approach, which promotes more family participation in the infant's care plan (Browne, 2003) with the implication of the novel developmental care approach. These approaches are not routinely part of the NICUs in Jordanian hospitals.

There is very little research about breastfeeding preterm infants in Jordan and to date, no research has explored issues around the importance of breastfeeding and the mothers' experiences within the culture of Jordanian NICUs. It is this lack of knowledge that has guided me to carry out this qualitative study. The findings of this research contribute to the discipline of breastfeeding preterm infants by providing an awareness of the difficulties experienced by mothers

wishing to breastfeed in NICU, and offers a new understanding of how breastfeeding is connected to the process of becoming a mother. The study also highlighted issues related to the nature of nursing work undertaken within the two units and added to our understanding of the impact of the institutional model of care on the quality of care provided and the interaction between nurses and mothers. Although these findings were derived from specific Jordanian situations, they are likely to hold some relevance for mothers seeking to breastfeed their preterm babies in NIUCs elsewhere.

RESEARCH QUESTIONS AND AIMS

In this study, preterm infant is defined as an infant born prior to 37 weeks of gestation and the NICU is defined as level III care units that are designed to care for premature and seriously ill infants. The main research question for this study was:

How mothers are supported to breastfeed their preterm infants when admitted to NICU and what are the implications of this?

Secondary research questions are:

1. What are the patterns of breastfeeding preterm infants in the two units?
2. What are the mothers' experiences of breastfeeding their preterm infants in the NICU?
3. What are the mothers' experiences of having a preterm infant in a NICU?
4. How do mothers perceive the support given for breastfeeding in the NICU?
5. What are the health professionals' attitudes and practices to support breastfeeding in NICU?

The main aim of this study was to explore why few mothers breastfeed when their babies are admitted to NICU, and to gain an understanding of the impact of this for the mothers and staff involved.

Secondary aims were to:

1. Observe and describe the practices of breastfeeding preterm infants in NICU.

2. Identify factors that promote or interfere with early initiation of breastfeeding premature infants in NICU.
3. Identify variation in professional and mothers' perceptions of breastfeeding objectives.
4. Gain an understanding of the mothers' experiences of having a preterm infant in a NICU.

STRUCTURE OF THE THESIS

The first chapter introduces the reader to the process by which the research topic came to my attention and was chosen, and presents the research purpose and questions. The current health condition and breastfeeding practices in Jordan are discussed and a justification of the study provided. An overall view of the structure of the thesis is then detailed.

The second chapter provides the background for the breastfeeding of preterm infant topics including: benefits of breastfeeding/breast milk for preterm infants, challenges of breastfeeding preterm infants, the process of initiation and maintaining breastfeeding in the NICU, the mothers' experiences of having and breastfeeding preterm infants, and the support available to mothers within the neonatal intensive care units. In addition, it identifies gaps in the existing literature on preterm breastfeeding.

To familiarise the reader with the main theoretical assumptions underpinning the research process, Chapter 3 deals with the methodological issues including identifying the research, design and justification of the use of ethnography. Other topics covered are: epistemological and ontological perspectives, a historical look at ethnography and types of ethnographic research design.

To enable the reader to understand how I undertook this research and how I dealt with some methodological issues that arose during the research process the fourth chapter concentrates on describing the context in which the study took place. It details the data collection methods used including semi-structured interviews, observation and field notes. The analysis process, ethical considerations, the translation process and the study's trustworthiness were also discussed in detail. This is important to enable the reader to judge how transferable the study findings are to similar situations.

Chapter 5 begins with a description of the two hospitals studied and the participants. The study findings are presented in two separate sections; one giving the mothers perspective and another that of the health care team, in which themes are also identified. Later the research findings are discussed in relation to the available literature.

Chapter 6 and 7 address the major themes that emerge from the study and provide interpretations of the study findings from the perspective and experience of both the mothers and members of staff at each of the hospital sites.

The final chapter identifies the clinical and research implications of the study findings and suggests further studies for consideration as a continuation of this work. It also summarises the findings of the study and highlights its strengths and weaknesses.

CHAPTER 2: BACKGROUND LITERATURE

Whilst it is inappropriate to undertake an extensive literature review at the start of an ethnographic study, as this may inadvertently impose a specific frame on the investigation, nevertheless some consideration of the literature relating to breastfeeding is important. The importance of breast milk for preterm infants needs to be established as does the impact breastfeeding may have on the mothers' experiences of having a preterm infant in NICU. It has been suggested that breastfeeding is a deep human experience that embraces mothers' perceptions of themselves as women and mothers (Spencer, 2008), and therefore this activity holds the potential for affecting their long-term relationship with their infants and family.

This chapter critically reviews literature related to breastfeeding preterm infants. This includes benefits of breast milk for preterm infants, challenges of breastfeeding preterm infants, the process of initiation and maintaining of breastfeeding in the NICU. In addition, there is a description of the mothers' experiences of breastfeeding preterm infants, the impact of the experience on the development of mother-infant attachment process, breastfeeding in the neonatal intensive care units, the support of mothers of preterm infants, and becoming a mother. This review is crucial to understanding what work has been done in this field and to identify any gaps in our existing knowledge.

BENEFITS OF BREAST-MILK FOR PRETERM INFANTS

Breastfeeding is shown to have important short and long-term health benefits for both infants and their mothers (Labbok, 2001). With all the documented benefits of breast milk, it is considered the best food for both full term and preterm infants. Indeed, preterm infants can particularly benefit from breast milk as it enhances host defence mechanisms and influences their growth and development.

The breast milk of a mother of a preterm baby is different from the milk of a mother of a full term baby. Some studies claim that milk produced prematurely does not provide adequate nutrients to meet the demands of premature babies and should therefore be fortified with supplements including protein, carbohydrate, calcium, phosphorous, magnesium, and sodium (Kerr and Kirk,

2001; Schanler, 2001; Reali, et al., 2010). In their position statement number 3046, the National Association of Neonatal Nurses explained that the insufficiency of human milk is because of the infant's fluid-restricted status not because of the milk itself (NANN position statement 3046, 2009).

Conversely, Bauer and Gerss (2011) suggested that a mother produces milk specifically suited to her baby's nutritional needs at the time of birth. Gross, Geller and Tomarelli (1981) found that the mean concentrations of protein, sodium, chloride, potassium and energy in preterm mothers' milk were adequate to meet the estimated requirements for preterm infants. Bauer and Gerss (2011) reported higher protein production and gradual increase of carbohydrate concentration and fat content during the postpartum weeks in mother's milk of extremely preterm infants, indicating an adaptation to the higher protein needs of these infants. Rochow et al. (2010) measured the triglycerides and cholesterol level in breast milk for healthy preterm infants. Their results showed that breast milk feeding with its high fat intake of 7g/kg/d leads to serum triglyceride levels that are lower by 50% when compared to those reported under the standard recommended dose of parenteral fat administration of 3.0g/kg/d. These studies suggest that human milk, in its different stages of development, is particularly appropriate for preterm infants. King (2005) explained the variation in fat and protein levels in preterm expressed milk by the degree of breast emptying and the amount of fat-rich hind-milk (milk at the end of feeding) collected.

Providing breast milk for preterm infants promotes their health and development. Studies have documented numerous short and long-term health benefits of breast milk for preterm infants of any gestation. These benefits include: improved oxygenation and temperature regulation during feeding, better oral development (Callen and Pinelli, 2005; Buckley and Charles, 2006; 2007), improved cognitive, behavioural and neurodevelopmental outcomes (Morley, 1988; Bier, et al., 2002; Edmond and Bahl, 2006; Vohr, et al., 2006; Richard, 2011), lower incidence of rehospitalisation (Vohr, et al., 2007; Richard, 2011) and the protection and development of the infant's brain (Hallowell and Spatz, 2012). A lower incidence of retinopathy has been observed (Callen and Pinelli, 2005), decreased rates of sudden infant death syndrome (SIDS) and post-neonatal infant mortality rates (Edmond and Bahl, 2006), and decreased incidence and/or severity of a wide range of infections including respiratory tract infection, otitis media, urinary tract infection, sepsis in preterm and necrotizing enterocolitis (American Academy of

Pediatrics, 2005; Buckley and Charles 2006; 2007; Vohr, et al., 2007; Schurr and Perkins, 2008).

Breast milk improves both short and long-term outcomes and decreases the incidence of chronic diseases (Arnold, 2010). These long-term outcomes including Type 1 diabetes (Gerstein, 1994), Type 2 diabetes (Buckley and Charles, 2006), obesity and overweight (Armstrong and Reilly, 2002; Arenz, et al., 2004) and Hodgkin's disease (Davis, 1998). Human milk also has long-term benefits for bone health (Fewtrell, 2011), long term sensory-neural development, lower risk of metabolic syndrome (Richard, 2011) and persistent effects on cognition for preterm population (Vohr, et al., 2007).

In addition to providing nutrients for preterm infants, breastfeeding also provides love and strengthens the bond between mothers and their children (Callen and Pinelli 2005), which contribute to successful breastfeeding. Some studies point to the soothing effect of the mother's own milk as results from these studies showed that pain responses of infants such as crying, grimacing, and motor activities were significantly decreased by odours from their own mother's milk (Rattaz, Goubet and Bullinger, 2005; Nishitani, et al., 2009).

Nurses are influential in increasing awareness of the benefits of breast milk for preterm infants. One of their roles is to educate mothers of preterm infants of the importance of early and regular pumping and hand expression which are critical in establishing a good milk supply (Schurr and Perkins, 2008). However, mothers of preterm infants are more likely to have difficulties in establishing a breastfeeding routine and are more likely to stop breastfeeding earlier without appropriate support (Ahmed, 2008).

CHALLENGES OF BREASTFEEDING PRETERM INFANTS

There are many challenges when breastfeeding in the NICUs. Preterm infants are more likely to face feeding difficulties such as drowsy or sleepy infant, easily fatigued infant, poor lip closure, weak sucking, poor intake and episodes of aspiration (Mathisen, et al., 2000; Ahmed, 2008). In turn, these difficulties are linked to many risk factors including respiratory distress, thermal instability, hypoglycaemia, hyperbilirubinemia and systems immaturity (Cleaveland, 2010). As a consequence, preterm infants start feeding by gavage tubes, cup or syringe

until becoming able to suck, when bottles with mothers' milk or formula are used. Yet, Collins et al., (2008) suggests that using a bottle may interfere with breastfeeding success as it delays the transition to at-breast.

Preterm infants can progress directly from gavage tubes to at-breast feeding (Jones and Spencer, 2005a). Failure to transition to direct breastfeeding is the main reason of early termination of breastfeeding among mothers of preterm infants (Leonard and Mayers, 2008). Buckley and Charles' (2006) study has highlighted the physiological and psychological benefits of feeding at the breast as opposed to bottle feeding of expressed breast milk for both mothers and their infants. Benefits to infants included improved oxygen saturation level, better temperature regulation, higher nutritional and immunological values, better coordination of sucking, swallowing and breathing reflexes and better oral development. Benefits to mothers included increased milk production, reduced level of stress, lowered risk for breast trauma and decreased incidence of maternal illnesses such as Type-2 diabetes and breast cancer.

The duration of human milk feedings are markedly shorter among infants who received only expressed milk feedings, compared to infants who transitioned directly to breast feeding (Smith, et al., 2003). However, direct breastfeeding may not be suitable for many preterm infants for weeks or even months after birth because of their inability to coordinate sucking, swallowing and breathing reflexes.

Researchers identified multiple contributing factors to the resistance or inability of mothers to transition their preterm infants to at-breast feeding. This included concern from the mothers about the adequacy of their breast milk supply and a maternal lack of confidence (Kavanaugh, et al., 1995; Wooldridge and Hall, 2003; Buckley and Charles, 2006). Other factors were an infant's immature feeding behaviours, a lack of commitment to breastfeed, the convenience of bottle feeding (Buckley and Charles, 2006), conflicting advice, a lack of information and emotional support, inadequate supplies (Kavanaugh, et al., 1995; Jaeger, Lawson and Filteau, 1997), hospital settings and infant health status (Smith, et al., 2003).

Mothers, whose preterm infants cannot breastfeed directly from the breast, are advised to start expressing their milk as early after delivery as possible in order to achieve adequate milk supply (Buckley and Charles, 2006). Breastfeeding and

expressing breast milk were an important and uniquely maternal practice, positive and rewarding experiences for some mothers (Lupton and Fenwick, 2001; Edmunds and Nevill, 2008,) while challenging and exhausting for others (Lee, Lee and Kuo, 2009).

With the absence of a mother's own milk, pasteurized donor breast milk is widely used in many neonatal intensive care units around the world (Bertino, et al., 2009). However, this is a complicated practice to implement in NICUs in Islamic countries. Wet nurses were very common among Islamic countries in situations where the biological mothers could not breastfeed the baby. According to Islam, children younger than two years old, who have been breastfed by a woman other than their biological mother become a blood relation to the nursing mother as well as a milk sibling to the biological children of their wet-nurse. This will forbid future marriages between them because it is thought that children inherit physical, mental and emotional traits from their wet nurses' milk (Ramli, Ibrahim and Hans, 2010). To overcome this conflict Ramli, Ibrahim and Hans (2010) have suggested some precautions which make the implementation of what they called a "*milk sharing initiative*" possible for Islamic countries (p. 166).

Examples of these precautions are:

1. The donor should be limited to a minimum number instead of having multiple donors for a child.
2. Mixing of donor's milk is not allowed
3. Adequately label all the milk samples
4. Both donor and recipient (family) should be identified to each other
5. The identifications of the donor should be attached to the child's birth certificate
6. Mothers should try to get their own milk production so the number of donors can be limited.

There has been a satisfactory introduction of human milk donation as an alternative to human milk banking in some Islamic cultures involving meetings between the donor and recipient families (AL-Naqeeb, et al., 2000; Hsu, et al., 2012). In order to satisfy religious requirements AL-Naqeeb et al. (2000) recommended keeping clear and detailed information about the amount of the donated milk received in the infant's record.

Other strategies to help mothers maintain their milk production until their infants can be full breastfed are essential to increase breastfeeding success rates (Jaeger, Lawson and Filteau, 1997). Consistent education and support can increase maternal confidence thus increase the rate of preterm infants who are discharged breastfeeding successfully and exclusively.

INITIATION AND MAINTAINING OF BREASTFEEDING FOR PRETERM INFANTS

The timing of initiation of breastfeeding is a very important indicator for neonatal mortality. The longer the delay in initiating breastfeeding the greater the risk of death (Edmond, et al., 2006, Table 3), for example delayed breastfeeding may increase the risk of gut villous atrophy (Embleton and Tinnion, 2011) thereby increasing the risk of neonatal mortality.

Table 3: Risk of neonatal mortality according to the timing of the initiation of breastfeeding

Initiation of Breastfeeding	No. (%) of Infants	No. of Deaths (% risk)
Within 1 hour	4763 (43)	34 (0.7)
From 1 hour to end of day 1	3105 (28)	36 (1.7)
Day 2	2138 (20)	48 (2.3)
Day 3	79 (7.3)	21 (2.6)
After day 3	144 (1.3)	6 (4.2)
Total	10947 (100)	145 (1.3)

Source: Edmond et al (2006, p. 383)

Studies showed that mothers of preterm infants were less likely to initiate breastfeeding compared to mothers of full-term infants (Ryan, Wenjun and Acosta, 2002; Radtke, 2011; Ayton, et al., 2012). Mothers of preterm infants had delayed initiation of breast stimulation after delivery with low pumping frequency (Hill, Brown and Harker, 1995). Factors that contribute to this delay included maternal-infant separation, stress, fatigue, inadequate frequency of pumping,

inadequate breast emptying and obstetric complications (Hartmann and Ramsay, 2005). It was also reported that the use of exclusive formula feeding before the onset of lactation was one of the main risk factors for the delayed onset of lactation (Chapman and Pérez-Escamilla, 1999).

The American Academy of Paediatrics (AAP) policy statement on *Breastfeeding and the Use of Breast Milk* has established principles to guide health care professionals in assisting women and children in the initiation and maintenance of breastfeeding (American Academy of Pediatrics, 2005). Table 4 is a summary for these recommendations.

Table 4: A summary of the recommendation from the American Academy of Paediatrics for initiation and maintaining of breastfeeding.

1. Health care professionals should recommend breast milk for all infants, unless contraindicated, and parents provided with current and comprehensive information on the benefits and techniques of breastfeeding to ensure that decisions about feeding are fully informed. In situations where direct breastfeeding is not possible expressed breast milk should be provided.
2. Peripartum policies and practices that optimize the initiation and maintenance of breastfeeding should be encouraged.
3. Direct skin-to-skin contact should be initiated between infants and their mothers immediately after delivery and maintained until the first feeding has been accomplished.
4. Supplements such as glucose water, formula and other fluids should not be given to breastfeeding infants unless medically indicated.
5. Pacifiers should be avoided during the initiation of breastfeeding possibly used only after breastfeeding is well established.
6. Mothers should be encouraged to feed 8 to 12 times at the breast every 24 hours when the infant shows early signs of hunger such as increased alertness, physical activity, mouthing and rooting.
7. Breastfeeding should be evaluated by a well-trained health care professional twice daily and fully documented in the patients records during each day in the hospital.
8. Breastfed infants should be seen and assessed by a paediatrician at 3 to 5 days of age and again at 2 to 3 weeks of age.
9. Parents should be aware of the importance of exclusive breastfeeding for the first 6 months of an infant's life. Breastfeeding should be continued for at least one year, with the introduction of complementary foods rich in iron around 6 months of life for full term infants and earlier than that for preterm infants.
10. All breastfed infants should receive 1.0 mg of vitamin K intramuscularly within 6 hours of life and 200 IU of oral vitamin D drops daily beginning during the first 2 months of life until the daily consumption of vitamin-D fortified formula or milk is 500 ml.
11. Supplementary fluoride should not be provided during the first 6 months of life.
12. Mothers and infants should sleep in close proximity of each other to facilitate breastfeeding.
13. If mothers or infants are hospitalised direct breastfeeding should be maintained if possible, otherwise, pumping and feeding expressed milk should be encouraged.
14. For high risk infants health care professionals should recommend human milk either by direct breastfeeding and/or using the mothers' own expressed milk. Maternal support and education should be provided early and skin-to-skin contact should be encouraged.

Source: The American Academy of Paediatrics (AAP) policy statement: 2005

Fairbank et al. (2001) have identified five categories of intervention to promote breastfeeding initiation (Table 5).

Table 5: Categories of intervention to promote the initiation of breastfeeding

Category of Intervention	Description
Health education interventions	Factual information about breastfeeding often delivered via leaflets or educational sessions usually grounded in professional expertise.
Health sector initiative	Interventions which aim to change the organizational nature of health services in favour of promoting breastfeeding, including health professional training, social support from health professionals, the Baby Friendly Hospital Initiative and the Women, Infant and Children Programme.
Peer support programmes	Interventions delivered by knowledgeable peers
Media campaigns	Interventions which use a public medium such as TV and the press.
Multifaceted interventions	Interventions which have more than one component.

Source: Fairbank et al., 2001, p. 123

The BFHI recommendations of the AAP, WHO and UNICEF are important steps for successful breastfeeding in hospital settings. Most of these recommendations are applicable only in the case of full-term infants, as they do not give attention to the difficulties that preterm infants have with breastfeeding. Based on these steps therefore, the UNICEF UK (2012) has established ten steps for maintaining breastfeeding in the neonatal intensive care units. Spatz (2004, p. 386) has also suggested ten steps to promote breastfeeding for preterm infants. Table 6 compares these two strategies with the original WHO/UNICEF BFHI strategy.

Table 6: Comparison of the ten steps to promote successful breastfeeding for preterm infants

WHO/UNICEF Ten Steps to successful breastfeeding	UNICEF UK Baby Friendly Initiative in NICU	Spatz (2004) ten steps to promote breastfeeding in NICU
Have a written breastfeeding policy that is routinely communicated to all health care staff.	Written breastfeeding policy that is routinely communicated to all staff.	Breast milk management (storage and handling) techniques.
Train all health care staff in skills necessary to implement this policy.	Educate all staff on the skills to implement the policy.	Methods of feeding breast milk.
Inform all pregnant women about the benefits and management of breastfeeding.	Inform all parents of the benefits of breast milk and breastfeeding.	Parents make an Informed decision using relevant information.
Help mothers initiate breastfeeding within one half-hour of birth.	Facilitate skin-to-skin contact (Kangaroo Care)	Skin-to-skin (Kangaroo Care) (SSC)
Show mothers how to breastfeed and maintain lactation, even if they should be separated from their infants.	Support mothers to initiate and maintain lactation through milk expression.	Establishment and maintenance of milk supply through frequent milk expression.
Give newborn infants no food or drink other than breast milk, unless medically indicated.	Encourage exclusive breast milk feeding.	
Practice rooming in - that is, allow mothers and infants to remain together 24 hours a day.	Support mothers to establish and maintain breastfeeding.	Transition to breast.
Encourage breastfeeding on demand.		Measuring milk transfer through test weighing procedures.
Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.	Avoid the use of teats or dummies.	Non-nutritive sucking at the breast.
		Preparation for discharge.
Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.	Promote breastfeeding support through local and national network.	Appropriate follow-up.

Adapted from Arnold (2010)

Many studies found that feeding intention was a strong predictor of breastfeeding initiation and duration (Donath, 2003). However, for mothers of preterm infants many factors play a role in predicting breastfeeding initiation and duration. Maternal experience of anxiety, vulnerability, depression or guilt that might be associated with the preterm delivery may change her initial reasons for breastfeeding (Buckley and Charles, 2006). Thus, intention alone is not helpful for predicting the initiation and duration of breastfeeding of preterm infants.

Jaeger, Lawson and Filteau (1997) studied the impact of prematurity and neonatal illness on the decision to breastfeed. Twenty three percent of the mothers changed their mind about their feeding method when the baby was born prematurely. The decision by some mothers to switch to feeding their babies formula rather than breast milk was significantly related to whether or not they perceived they expressed enough milk. Mothers also reported having difficulties with hand pumps at home. The reasons mothers gave for changing their minds from formula to breastfeeding was the baby's vulnerability and because they felt it was the only thing that they could do for their infants.

Initially after the birth of her baby, a mother's decision to express milk is because of the health-related benefits of breast milk for the preterm infant. Mothers who had intended to use artificial formula will often change their decision if they receive guidance from health care professionals (Hilton, 2010). Mothers may change their initial feeding decision and choose to breastfeed if they receive information about the benefits of breast milk for the preterm infants (Miracle, Meier and Bennett, 2004). In Jaeger, Lawson and Filteau's study (1997) for example, eight mothers out of 44 changed their initial decision about feeding methods after having preterm infants; three of them changed from formula to breastfeeding.

Whether mothers planned to breastfeed before delivery or not they all decided to express breast milk for their preterm infants. This was their way of making up for the preterm birth that they felt responsible for (Lee, Lee and Kuo, 2009). Jones and Spencer (2005b) however identified some obstacles that mothers of preterm infant experience which inhibit lactation including immature mammary development, poor hormonal responses, infant-maternal separation, stress, anxiety, fatigue, and inappropriate milk expression equipment and techniques.

Kruse et al. (2006) found that the recurrence rates for feeding patterns were high. Sixty nine percent of mothers who exclusively breastfed their first infants also breastfed their second, while of those mothers who exclusively formula fed their first infants only 16% initiated exclusive breastfeeding for their second baby. This suggests that increasing breastfeeding awareness and initiation rates for the first birth is critical to promote future breastfeeding.

With appropriate support and guidance, it is possible to overcome many of these obstacles. Ahmed (2008) used an experimental design to implement and examine the effect of a five-session breastfeeding educational programme on breastfeeding knowledge and practices for Egyptian mothers of preterm infants. Sixty mothers and their preterm infants were randomly assigned to intervention and control groups and were followed during hospitalisation and up to 3 months after discharge. Phase 1 started with psychological and emotional support for the mothers by answering their questions and discussing problems related to prematurity. Phase 2 included teaching basic breastfeeding skills such as breast massage, milk expression and breastfeeding positions. Phase 3 was a testing phase in which mothers had to demonstrate and practice what they had learnt. Phase 4 was a follow up stage from which Phase 5 emerged to help mothers deal with any potential breastfeeding problems.

Results of Ahmed (2008) showed that mothers' knowledge was significantly increased for the intervention group when compared to the control group. Mothers in the intervention group demonstrated better improvements in the breastfeeding practices than the control group. Eighty percent of the intervention group was discharged on exclusive breastfeeding compared to only 40% in the control group. Nevertheless despite the small sample size (n=60), the study's findings gave an awareness that breastfeeding education, support and follow up for mothers of preterm infants resulted in earlier and more frequent milk expression, increased feeding rates, decreased breastfeeding problems and increased breastfeeding duration compared to mothers in the control group (Ahmed, 2008).

MOTHERS' EXPERIENCES OF HAVING AN INFANT IN NICU

The neonatal intensive care unit is a complex and highly sophisticated environment that provides continuous technical support to maintain the wellbeing

of sick and premature infants. Premature babies who are born as early as 24 weeks and up to 37 weeks gestation are the largest group of infants who require this high-tech environment. The NICU environment is described as being noisy, with bright light, too many visitors and staff and with infants being attached to a range of intrusive machines such as ventilators, monitors, oxygen hood, and infusion pumps (Lupton and Fenwick, 2001).

Having a baby in this critical unit is a very stressful situation and distressing experience for the family. For the parents, the NICU environment “*signalled life and death*” being described as “*entering a fiction world or making a time travel into the future*” (Flacking, et al., 2006, p. 73). Such environment creates many challenges to mothers as it generates feelings of extreme emotional vulnerability (Hurst, 2001a; Obeidat and Callister, 2011), powerlessness, alienation, frustration, resentment, despair and grief (Lupton and Fenwick, 2001; Flacking, et al., 2006). Mothers of preterm infants have a higher level of psychological distress; this is connected to the threat of their infants’ death (Flacking, et al., 2006) and the lack of confidence in their role as mother because of the difficulty of caring for a high-risk baby (Singer, et al., 1999; Eisengart, et al., 2003). This psychological distress creates feelings of fear, sadness, disappointment and worthlessness or failure as a mother (Flacking, et al., 2006; Obeidat, Bond and Callister, 2009).

Parents of preterm infants struggle with the uncertainty that they experience when entering the unfamiliar and potentially threatening environment of the NICU (Cleveland, 2008) and they are at risk of developing postpartum depression (Bergstrom, et al., 2012). The literature identified many parental needs during this period. This included accurate information regarding their infants health status, physical contact, a supportive environment, being able to participate in their child’s care and being part of the decision making process determining their infant’s care plan (Cleveland, 2008; Discenza, 2009; Axelin, et al., 2010; Hopwood, 2010; Reis, et al., 2010; Wigert, Berg and Hellström, 2010; Cricco-Lizza, 2011; Robert, 2011).

Hurst (2001a) used a critical ethnography approach to explore the strategies that 12 USA mothers used to meet the needs of their premature infants in the NICU. Mothers’ primary needs were informational in nature and interactional. Other needs included emotional support, learning caregiving, getting adequate rest and developing confidence in their ability to provide care after discharge. Mothers

employed their actions and addressed their needs in a way that did not divert resources from their babies and at the same time minimized potential conflict with health caregivers. In order to watch over their premature infants and to fulfil their needs, the mothers demonstrated a range of actions; 1) negotiating actions with health care providers to reach an agreement about their infants' care needs and their own needs; 2) the cautious use of challenging institutional authority about when and how to voice their wishes, needs and concerns; 3) the use of institutional knowledge to challenge the institutional authority, such as using the institutions' written guidelines for the use and storage of human milk to question the contradictory information; 4) using other sources of information such as other parents' or peers' experiences; 5) seeking higher organisational authority to raise their concerns; 6) building supportive relationships with other mothers in the NICU; and 7) obtaining support from family members and friends. The mothers in this study expressed a strong desire to have a collaborative relationship with the health care professionals in order to provide the best outcomes for their babies.

SUPPORTING MOTHERS OF PRETERM INFANTS

Counselling mothers of preterm infants to increase the incidence and duration of successful breastfeeding and to decrease mothers' stress and anxiety has been proven (Sisk, et al., 2006; Bergstrom, et al., 2012). When mothers receive assistance and support the rate of breastfeeding increases to more than that of mothers with full term infants. In Colaizy and Morriss's (2008) study, for example, a total of 138,359 surveys including 29,940 NICU-admitted infants were analysed to examine the positive effect of the NICU admission on breastfeeding of preterm infants in 27 US states. Results showed that mothers of preterm NICU-admitted infants were more likely to initiate breastfeeding and more likely to breastfeed for at least 4 weeks than were mothers of non-admitted preterm infants. These results suggested that NICU admission is a positive factor that influences breastfeeding continuation. The positive effect could be explained because of educational interventions and the presence of a lactation consultant in these units. In their study, Embelton and Tinnion (2011) indicated that a single experienced neonatal nurse, who provided hands-on support, increased rates of expressed breast milk in their unit from 75% to 95% over a period of a few months.

Junior and Martinez (2008) evaluated the effect of a very simple intervention consisting of offering support and any needed information by the researcher to the mothers of preterm infants from the delivery room to outpatient follow up. Eighty and a half percent of children in the intervention group were breastfeeding when discharged compared to only 38.9% of children in the control group. Nineteen and a half percent of the intervention group was exclusively breastfed at discharge compared to 8.4% of the control group. These significant results provide evidence of the importance of early support for mothers of preterm infants.

Parents who are supported and kept informed of the condition of their infants gain a feeling of control (Franck and Spencer, 2003). Obtaining answers to their questions and concerns is critical for a mother's ability to transform herself into the "*real*" mother for her premature infant (Hurst, 2001a). Whereas parents who were not supported or counselled during their infant's stay at the NICU had a 60% higher risk of developing postpartum depression (Bergstrom, et al., 2012). Mothers need empowering information that enables them to understand their infants' behaviours and situation this then guides parents in their interactions and negotiations in the NICUs (Hurst, 2001a; b).

Wigert et al. (2006) documented that feelings of exclusion dominate when mothers feel a lack of interaction and sense of not belonging to either the NICU or the maternity unit. On the other hand when mothers feel they are participating they report feeling positive. Obeidat, Bond and Callister (2009) reviewed 14 articles about parental experiences of having an infant in the NICUs. Their analysis revealed themes such as feelings of stress, strain, separation, depression, despair, disappointment, ambivalence and lack of control. These studies showed that there was a shift from a passive to an active role when mothers were involved in care giving.

Nurses' and midwives' attitudes and the amount of support given by them may have a positive or negative impact on the mothers' decision to breastfeed within NICUs (Miracle, Meier and Bennett, 2004; Nyqvist, 2008). Aagaard and Hall (2008) suggested that nurses and midwives have to continuously develop and strengthen the mothers' skills with the care of their children while in the NICUs using three strategies: a care delivery plan, a guided participation and discussion. A care delivery plan included coaching and facilitating the mother's involvement in the care of her child. In the guided participation the nurse

supervises the mother and develops her skills as a real mother, it is imperative that the mother feels that the baby is hers and that she is the most important person in her baby's life. Finally, nurses and midwives have to be trained to talk and communicate effectively with the mothers to maintain and enhance their confidence (Aagaard and Hall, 2008).

Nurses are in positions that enable them to support mothers of preterm infants in their emotional grief and concern to help them adapt to the crisis and attach to their infants (Orapiriyakul, Jirapaet and Rodcumdee, 2007). Hurst (2001a) described how touching and holding became important rituals for every visit until mothers could actually hold their babies outside the isolette. Mothers need to have opportunities to act as normal mothers (Bass, 1991) and to experience a sense of control concerning their babies (Griffin, Wishba and Kavanaugh, 1998). A positive relationship between mothers and the health care team tends to facilitate maternal competence and enable mothers to connect with their infants (Lupton and Fenwick, 2001).

BREASTFEEDING EXPERIENCES IN THE NICU

Breastfeeding is a strategy that can be used to facilitate the mother-infant relationship and attachment process (Flacking, et al., 2006). Kearvell and Grant (2010) reviewed the literature on how nurses can support the mother-infant attachment process in NICUs. They found that Kangaroo Care, breastfeeding and participating in daily routine care such as changing nappies, bathing, or changing positions were essential elements in promoting the mother-infant attachment, the mothers' feeling of closeness, the mothers' confidence, and the physiological and behavioural status of the infants. They also reported that providing mothers with psychological support and effective communication helped in facilitating mother-infant attachment, alleviating maternal anxiety and enhancing mothers' satisfaction and confidence.

The Kangaroo Care method that involves placing the infant skin-to-skin with the parent chest has been associated with improved mother-infant interaction, milk production, optimal infant growth, increased maternal confidence and increased duration of breastfeeding (Buckley and Charles, 2006; Franklin, 2006; Flynn and Leahy-Warren, 2010). Immediate physical skin-to-skin contact is required after

delivery to promote attachment and future breastfeeding success (Bialoskurski, Cox and Hayes, 1999).

Physical closeness with the infant by skin-to-skin contact or breastfeeding is described as a “*healing state*” that strengthened the bond between mothers and their children and promoted reciprocal interaction (Flacking, et al., 2006, p.75). However, there are barriers to the implementation of kangaroo care in NICUs. These barriers include infant safety, staff reluctance and uncertainty, fear of something going wrong with the infant such as accidental extubation, staff shortage and time constraints (Flynn and Leahy-Warren, 2010; Kearvell and Grant, 2010).

Many healthcare professionals’ practices were considered detrimental to breastfeeding success including giving conflicting advice, offering bottles, maternal-infant separation and timed feeds (McInnes and Chambers, 2008). McInnes and Chambers (2008) analysed 47 qualitative studies which explored mothers’ and healthcare professionals’ experiences and perceptions of breastfeeding support in developed countries between 1990 and 2007. Studies showed that mothers tended to rate social support as more important than health service support. Mothers identified the supportive or helpful healthcare professional as non-judgmental, encouraging, reassuring, sympathetic, patient and understanding

Lee, Lee and Kuo (2009) used a descriptive qualitative design to explore the experiences of mothers in breastfeeding their very low birth weight infants in Taiwan through in-depth interviews at 2 and 6 months after infant discharge from NICU. The mothers initially decided to express their breast milk because they felt responsible for the preterm birth and wanted to compensate for the harm they caused their infants. Yet mothers needed extra help and support from family and staff that was very important to enhance the mothers’ confidence.

With regards to the experience of breastfeeding preterm infants in Jordan, only one recent phenomenological study was identified which described the experience of Jordanian mothers having their infants admitted to the NICU (Obeidat and Callister, 2011). The researchers interviewed 20 Jordanian mothers of preterm infants. Their findings demonstrated that mothers are confronted with multiple physical, emotional and psychosocial stresses. Mothers described feelings of emotional instability, living with challenges in family

relations and feeling isolated, experiencing challenges in religious observances and finding strength through spiritual beliefs. Although the study raised awareness of the Jordanian mothers' experience of having their babies in NICU, it did not consider the impact that breastfeeding might have on that experience. The research also took place in Amman, the capital city of Jordan, which has a population with a wide range of backgrounds and the findings may not therefore be transferable to other Jordanian regions with more rural lifestyle.

Breastfeeding may give the mothers a level of satisfaction which contributes to their feeling of being a real mother. Mothers considered breastfeeding as an important part of being a good mother because it is a unique maternal act that no other person could provide (Lupton and Fenwick, 2001). Kavanaugh et al. (1997) indicated that providing milk was a rewarding experience for preterm infants' mothers as participating in caring for their infants helped them to cope with the emotional stress. However, many factors in the neonatal intensive care unit may affect breastfeeding including long-term maternal-infant separation, the infants' condition, delaying of milk expression and the strange environment (Hartmann and Ramsay, 2005).

Studies of women's experiences of breastfeeding in the neonatal units revealed that failure to breastfeed is associated with feelings of being a bad mother (Fenwick, Barclay and Schmied, 2001a), accompanied by feeling of grief, sorrow, guilt and dissatisfaction (Shakespeare, Blake and Garcia, 2004, McInnes and Chambers, 2008). A 'good mother' is described by both nurses and mothers, as being physically available for her child, interested in gaining knowledge about the baby's condition and keen to care for the baby when possible (Lupton and Fenwick, 2001, p. 1019).

BECOMING A MOTHER

The transformation of a woman into a mother is a complex experience that includes both physical and emotional involvements (Redwood, 2007). The ease of this transition depends not only on the quality of the birth experience, but also on the support provided for the mothers and the personal characteristics of the person involved (Redwood, 2007).

The challenge faced by the mothers of preterm infants in their transition may be different from those of full term infants, and may be affected by the context in which this transition occurs. It has been documented that mothers of preterm

infants experience more difficulties in their transition to motherhood than mothers of full term infants (Shin and White-Traut, 2007).

In a study by Flacking et al. (2006), the researchers interviewed 25 mothers from seven different neonatal units in Sweden to explore their experiences of becoming a mother and breastfeeding their preterm infants. The results highlighted the importance of the quality of the mothers' social bonds with their infants, the father, the nurse and other mothers. The quality of these bonds was affected by the interpersonal interplay between staff and parents, and the contextual setting of the NICU, this in turn had an effect on the mothers' emotions and thus breastfeeding and "*becoming a mother*". Three areas of the experience were described: loss of the infant and emotional chaos "*putting life on hold*", separation as a sign of being unimportant as a mother and critical aspects of becoming more than a physical mother (Flacking et al., 2006, p. 73). In another study, Flacking, Ewald and Starrin (2007) explored the process of becoming a mother and breastfeeding after the infant was discharged from the NICU. The results indicated that mothers who successfully breastfed their infants reported feelings of pride and security, while those who failed to achieve at-breast feeding reported feelings of disappointment, frustration, rejection, shame and inadequacy. Such feelings may have a negative effect on the mother-infant relationship.

Hutchinson, Spillet and Cronin (2012) interviewed 12 preterm infants' parents from diverse racial backgrounds with the majority being Caucasian. They developed a model of parental progression during their infants' transition from the NICU to home, in which parents proceed through four phases from not being a parent to being a parent. Additionally, the transition has been described for Swedish parents as a time-dependent process with four syntheses of the experience, where alienation and feeling of responsibility gradually changed into confidence and familiarity (Jackson, Ternstedt and Schollin, 2003), and for Korean mothers as three critical attributes 1) time-dependent process: where mothers navigate from unfamiliarity to acceptance; 2) psycho-emotional swirling: in which mothers begin the transition in confusion and mixed feelings instead of the joy as in the case of full-term infant's mothers; 3) hovering around the edge of mothering where factors such as maternal diminished roles and fears that their infants will die may lead mothers not to actively engage as a mother (Shin and White-Traut, 2007).

Lindberg and Öhrling (2008) interviewed six mothers whose infants were cared for on an NICU. Despite the very small sample size, their results showed that mothers were not prepared for having a preterm infant and that initially they did not feel like a mother. Physical closeness to the infant was important to mothers, while separation was very stressful for them. Mothers felt that they would have coped better with the crisis if they received support from the hospital staff and if they were equipped with the appropriate knowledge and training related to the care of a preterm infant (Lindberg and Öhrling, 2008).

For mothers of preterm infants' the transition includes devastating feelings of fear, disappointment and anxiety because of uncertainties regarding their baby's survival (Bialoskurski, Cox and Wiggins, 2002). Barclay et al. (1997) detected not only a biological but also an emotional and personal sense of becoming a mother. These mothers were unready to become a mother and they undergo reconstruction of self. Becoming a mother for these mothers made them feel isolated and depleted instead of feeling nurtured and supported.

Becoming a mother is a transformation process in which women move from one state to another. The transformation involves being "betwixt and between", in which a person often feels isolated or disconnected from the before and after states (Turner, 1987). During this process, a phase of ambiguity and uncertainty occurs, which was described as being in liminal state (Van Gennep, 1960).

The use of liminality as a framework to understand breastfeeding experience was first introduced by Davis-Floyd and Sargent (1997) and further elaborated by others (Schmied and Lupton, 2001; Mahon-Daly and Andrews, 2002; Sachs, 2005). However, there is only one study detected that identified liminal properties with parenting transitions in parents of very preterm infants (Watson, 2011).

In seeking to explore mothers' experiences of breastfeeding in Jordanian NICUs, this study revealed a number of aspects relating to women's experiences of breastfeeding and becoming a mother during their infant stay in the NICUs that hold relevance to both Jordan and a more universal perspective. The concept of suspended liminality that will be introduced in Chapter 6 will build on the small volume of literature around the concept of liminality and becoming a mother for mothers of preterm infants.

CONCLUSION

Modernisation has had a profoundly negative impact on the breastfeeding rates in Jordan. Increased industrialisation and adoption of western attitudes have impacted on many traditional and religious feeding beliefs and practices. Breastfeeding rates have declined rapidly and the use of supplementary formula feed become commonplace. Maintaining a breastfeeding regime in Jordanian hospitals that adopt the institutional practice patterns developed in western hospitals is likely to lead to further decline in breastfeeding rates. Nevertheless, the literature indicates the importance of supportive practices within NICUs that promote early initiation of breastfeeding and so meet the needs of infants, mothers and the whole family. With the appropriate support and guidance, it is possible to overcome many of breastfeeding obstacles within NICUs.

There is a body of knowledge on breastfeeding experiences of mothers of preterm infants, however, most of these studies took place in Western countries and such research is not always transferable to Arabic and Islamic cultures. Little is known about patterns of breastfeeding and mothers' experiences of breastfeeding their preterm infant within NICUs in other cultures, including Jordan. What is needed therefore are culturally appropriate studies of mothers' experiences during their infant's admission to NICUs. This study designed to add to the existing literature of the breastfeeding experiences and becoming a mother in NICUs in Northern Jordan.

CHAPTER 3: METHODOLOGY

In this chapter, I describe the research design adopted. My decision to conduct an ethnographic study was because I wanted to capture the mothers' and practitioners' breastfeeding experiences and attitudes in their natural setting within the context of NICU. Following is a discussion of the rationale for choosing this research design in order to address the previous research questions in page 11.

RESEARCH DESIGN

Literature has over-emphasized the differences between qualitative and quantitative approaches especially with regard to the role of the researcher and epistemological issues. Quantitative research considers that human behaviour is objective, observable and measureable. Within quantitative research, the researchers attempt to confirm predetermined theories through their work with subjects. They construct structured investigation in order to produce hard data while maintaining a distant relationship with research subjects. Quantitative research has added greatly to the knowledge about the positive health outcomes associated with breastfeeding and the links between variables related to breastfeeding. However, criticism of quantitative research has been that it only measures what can be easily measured (Freshwater and Rolfe, 2001).

Although the positivistic quantitative approach is very important to study the link between variables related to breastfeeding premature babies, it was not considered appropriate for this study because it fails to explain why such a link exists in the first place. It will not allow for an exploration of the culture of the NICU or obtain the true meaning of the breastfeeding experiences. In contrast to the positivistic approach, the naturalistic, qualitative paradigm takes the position that there are multiple interpretations of realities. Individuals subjectively construct these interpretations (Spencer, 2007). Naturalism recommends "*natural*" not "*artificial*" settings for collecting data in which the social world is studied in its "*natural*" state (Hammersley and Atkinson, 1995, p. 6).

The qualitative approach has a long history in human studies. The importance of using this approach in the study of human life was established by the Chicago school between the 1920s and 1930s (Denzin and Lincoln, 1994). Qualitative research is all about seeking a deeper truth by exploring issues, understanding phenomena and answering questions. It aims to discover the meaning and gain an insight into people's attitudes, behaviours, concerns, lifestyles and culture.

Given the need to seek to understand the breastfeeding patterns and the mothers' experiences in the NICU context, I considered that a qualitative approach would be more appropriate. Such a research perspective would help build a picture of the complexities of breastfeeding experiences and give an understanding of the meanings that guide the breastfeeding behaviours. Qualitative approaches are considered appropriate if little is known about a phenomenon or if what is known seems inconsistent (Fain, 2009). It is exactly the case with breastfeeding preterm infants within NICU in Jordan. While nobody can argue against the importance of breastfeeding and breast-milk for premature babies, there is little known about the patterns of breastfeeding or the support that mothers receive to breastfeed their babies within these units. The qualitative paradigm includes a holistic way for understanding the social situation of breastfeeding preterm infants and a strong emphasis on comprehensive description and interpretation of this phenomenon.

The four main qualitative approaches are ethnography, phenomenology, case study and grounded theory. Ethnographic fieldwork/participant observation, qualitative interviews, focus groups, discourse analysis, and textual analysis are among the many formal methods used in qualitative approaches (Bryman, 2008). These methods are adaptable to deal with multiple realities and give the qualitative approach its holistic feature. By using these methods, qualitative researchers attempt to interpret and make sense of phenomena, they aim to study things in their natural setting and they use a holistic perspective which sustains the complexities of human behaviour. The results may provide a theoretical framework and identify variables or a theory that may be tested in subsequent research (Morse, 1991a).

For this study, a flexible and a field oriented approach was necessary to understand and interpret what is happening within the neonatal intensive care units. Although the experience of breastfeeding mothers within the NICU is crucial to the success of the breastfeeding process, there are also the competing

interests of nurses, doctors and other individuals involved with the management of the unit and the care of the infants within it. It was therefore necessary to understand the staff views and their perceptions of breastfeeding in addition to exploring those of the mother. The choice of adopting an ethnographic research methodology appeared appropriate for the study's aims. Aamodt (1982) recommended ethnography as the only appropriate way to study human responses such as nurse-patient interactions. While Leininger (1987) considered other approaches rather than ethnography, to be ineffective in influencing professional care decisions. Ethnography offered me a way of observing in detail social processes that take place within NICUs including breastfeeding activities, nursing interventions, parent participations and medical procedures. Our understanding of these issues will lead to designing accessible, comprehensive and effective breastfeeding strategies in Jordan's NICUs.

Ethnography has been used in nursing to study a variety of important topics such as: emergency nursing practices (Walsh, 2009), computer-based patient record (Bickford, 2000), speaking about death (Winton, 1998), experiences of children and young people with long-term renal illness (Waters, 2008), gerontological nursing (Brandriet, 1994) and breastfeeding (Dykes, 2005; 2006; Sachs, Dykes and Carter, 2006; Cricco-Lizza, 2009).

HISTORY OF ETHNOGRAPHY

Ethnographic research developed from the discipline of anthropology. It has its origin in the image of the American anthropologist Franz Boas who studied an Eskimo village and established the fieldwork paradigm (Sanday, 1979). The ancient Greek Herodotus (484 – 425 BCE) was an ethnographer who recorded variations in the cultures to which he was exposed. In the United Kingdom, British anthropologist Malinowski established ethnographic fieldwork in the 1920s. Malinowski (1884 – 1942) was one of the most important “*manifestos*” for the British social anthropology intellectual movement (Atkinson, 2007, p. 60).

In Fact, Ahmed (2000) argued that anthropology was rooted in Islam more than 1400 years ago. “*The Qur'an teaches us to look at societies, peoples, and groups around us and to wonder at and understand them, and through them reflect upon the greatness of God who created everyone and everything*” (Ahmed, 2000, p. 105). Ahmed (2000) considered Al-Biruni, (973-1048 C.E) as

the first anthropologist. According to Ahmed (2000), Indian scholars often refer to Al-Biruni as a reference to ancient India. Al-Biruni studied Indian culture, religion and language. He spent a long time in India (from 1017 to 1031) as an objective observer and wrote his masterpiece “Kitab al-Hind” centuries before European experts studied Indian villages in the 20th Century. In his writings, he used concepts such as cross cultural comparison, inter-cultural dialogue and phenomenological observation.

Before the work of Al-Biruni there was the work of Al-Masu'di (896 – 957 C.E.) who was considered as the Herodotus of the Arabs. In his book Muruj-al-Thahab, Al-Masu'di described his experience of various countries and their people. He also wrote a huge book called Muruj al-Zaman in thirty volumes in which a comprehensive description was given about the geography and history of the countries that he had visited. He introduced the elements of analysis, reflection and criticism in his writing, which was later improved by Ibn-Khaldun (Palestine Academy for Science and Technology Newsletter, 2005).

Ibn-Khaldun was born in Tunisia in 1332 C.E. He is a well-known Muslim scholar recognized for his contribution to the philosophy of history and sociology. His work was originally begun as a history of Berbers but widened later to represent a universal history of humankind. His work is divided into seven books: the first part the Muqaddimah or “Prolegomena” is his masterpiece and has become a reference in literature on the philosophy of history and sociology (Islamic Academy of Science newsletter, 2000). According to Stanfield (cited in Denzin and Lincoln, 1994, p. 183), *“the most striking classical African intellectual who created an indigenous qualitative research paradigm to study his world and that of Europeans was the fourteenth-century Arab scholar Ibn-Khaldun”*.

TYPES OF ETHNOGRAPHY

Morse and Field (1996) classified ethnography into two types, classical ethnography and focused ethnography. In classical ethnography, which is also called full, macro- or maxi- ethnography, the researcher becomes a participant-observer over long periods of time and examines the culture in a broader context. While, focused ethnography, also called micro or mini-ethnography, has a narrower intention and it is often used in health contexts. Leininger (1985)

identified the mini-ethnography as the method of choice for nursing students who want to experience the richness of studying the real world of people but have less time for long term field work.

Nurses became interested in ethnography as a research method that gives better understanding for patients from diverse cultures in the mid-1950s (Fain, 2009). In the mid-1960s, Leininger went beyond the borrowing of ethnographic methods to develop the “*ethnonursing*” method. Ethnonursing was derived from general ethnography. Leininger defined ethnonursing as “*the study and analysis of the local or indigenous people’s viewpoints, beliefs, and practices about nursing care phenomena and processes of designated cultures*” (Leininger, 1985, p. 38). According to Leininger (1985), ethnography and ethnonursing are used when there is limited knowledge about a phenomenon and when the researcher attempts to discover what is happening, how and why.

In recent years, there has been a growing interest in the use of critical ethnography approach in the health care system. This approach is useful to examine the relationship between the human experience and power and truth (Harrowing, et al., 2010). It offers a way to uncover the sociocultural knowledge about the culture as well as patterns of exclusion and social injustice (Averill, 2008). While the study aims to examine the pattern of breastfeeding in NICUs, there are no expectations as to what kind of sociocultural knowledge and relationships the research might find. Thus, a wider ethnographic approach was needed.

In this study, the two NICUs were conceptualized as two social units with their own organization, culture and practices (Hurst, 2001). The study focused on breastfeeding meanings and activities and studied a narrowly defined group within the NICU. This complies with a micro or focused ethnography rather than full or classical ethnography as it dealt with a relatively narrow experience (preterm as opposed to full-term breastfeeding) within a narrow local world (NICU as opposed to the whole hospital). Focused ethnography can facilitate improvement in the practice (Muecke, 1994), which is one of the study purposes. Dykes (2009), suggests that critical ethnography is useful to extend the micro focused ethnography and to probe further into the lived experiences of individuals of the studies group or culture. This is therefore an opening study that could be followed with more in depth studies.

THE PHILOSOPHICAL ASSUMPTIONS OF ETHNOGRAPHY

The work of any researcher is guided by basic belief systems called paradigms or interpretive frameworks (Denzin and Lincoln, 2005a). These beliefs are based on answering three fundamental questions. The ontological question, what is the nature of reality and, therefore, what is there that can be known about it? How things really are and how things really work? The epistemological question, what is the nature of the relationship between the knower and what can be known? Finally, the methodological question, how can the inquirer go about finding out whatever he or she believes can be known? (Guba and Lincoln, 1994). These beliefs influence the way the researcher understands the world and behaves in it (Denzin and Lincoln, 2005b). Denzin and Lincoln (2005b) have identified four paradigms that are; guiding qualitative inquiry, positivist and post positivism, constructivist-interpretive, critical (Marxist, emancipator), and feminist-post structural.

Naturalism is applied to the natural sciences, it proposes that the social world should be studied in its natural setting, not disturbed by the researcher and conducted in a way that is sensitive to the nature of that setting and to the phenomena of study (Hammersley and Atkinson, 2007). According to this model the researcher should describe what is happening, how people see and talk about their actions and others' actions and the setting in which these actions take place (Hammersley and Atkinson, 2007). Some requirements of social research, according to naturalism, are respect and appreciation of the social world and fidelity that is directed toward the phenomena of study not toward any methodological approach (Hammersley and Atkinson, 2007). Ethnographers propose that people are constructing the social world "*through their interpretations of it and through actions based on those interpretations*" (Hammersley and Atkinson, 2007, p. 11). Those interpretations reflect differences in people's cultures and backgrounds.

Hilton (1987, p. 14) summarized the assumptions that underlie the ethnographic approach which formed a set of orientations that guided my research strategies and design and indicated which research methods were appropriate for collecting data. These assumptions are:

- A person's behaviour in a situation is inextricably linked with the meaning that the situation has for her.
- A person's understanding of a situation changes as she interacts with others. As her understanding changes, so does her behaviour.
- Within any situation there will normally be different perspectives reflecting different experiences and understandings. The ethnographer is not seeking a "correct" perspective; rather, she wants to understand the different perspectives.
- A person's behaviour and beliefs have to be understood not only in the light of her immediate interactions, but also in the light of the broader organization or culture.
- In order to understand the culture of a group it is necessary for the researcher to "enter the world" and to study it as it is, rather than in an artificial or experimental situation.

This study adopted a constructivist-interpretive approach which assumes a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent cocreate understanding) and a naturalistic (in the natural world) set of methodological procedures (Denzin and Lincoln, 2005b).

CHAPTER 4: METHODS

The purpose of this chapter is to describe the research methods I employed in this study and the context in which they took place. I detail the principal data collection methods that have been used including semi-structured interviews, observation and field notes. I also provide an overview of the ethical considerations, the data analysis techniques, the translation process, and issues relating to trustworthiness and reflexivity.

THE RESEARCH SETTING

Two NICUs in Northern Jordan were selected for multiple reasons. Firstly, there is little qualitative research that has been undertaken in the Northern Jordan. The second reason was that the two units are located within two large hospitals in Irbid governorate, which has the second largest population and the highest population density in the kingdom. Finally, they are among the main level III referral units in Jordan.

The two research hospital settings provide health care services to more than 1 million inhabitants of Irbid, Ajloun, Jarash and Mafraq governorates in particular and to all of Jordan in general. Both units are described in detail at the beginning of the Finding Chapter on page 69.

Patients admitted to these units include:

- Full term infants weighing less than 2.5Kg at birth.
- Neonates transferred from the hospital newborn nursery and found to need special medical care.
- Premature infants less than 35 weeks sent from the delivery room or normal nursery.
- Any patient delivered at the hospital's obstetric room and found to need special medical care.
- Any neonate referred from another NICU.

- Any outpatient newborn less than or equal to 7 days old who needs hospitalization and monitoring.

THE PARTICIPANTS

As the goal of this qualitative study was to enrich our understanding of how breastfeeding preterm infant affects the mothers' experience of becoming a mother within NICUs, it was important to include information-rich cases from which I could learn. Ethnography is not about selection criteria; it is about observing everything and meeting anyone the researcher comes across.

I intended to include participants who have different experiences of being in the NICU. During the early observation periods, my initial interactions with the mothers and staff helped to verify the most appropriate people to target for this study. I also reviewed the admissions register with the assistance of the NICU staff members to identify other potential target mothers. I invited mothers who were currently having a preterm infant, less than 37 weeks gestational age, admitted to the NICU with no congenital malformations. All staff members who worked in the NICU were also invited to participate, as they were part of the NICU culture. I selected participants based on their knowledge and experience of having been either a mother for a child in the NICU, or a health care professional working at the NICU; as participants who are directly involved with the NICU they would provide a closer view of the everyday experience (Sweet, 2004).

My observations involved everyone who attended the NICUs. For my interviews however, 17 mothers of various ages, parity, levels of education and previous breastfeeding experiences; and 15 members of the medical staff of various ages, educational levels, work experience and gender were invited and consented to be interviewed. Individuals who participated in the study are described in detail in the Finding Chapter on page 71. Data collection continued until a saturation level was achieved, that was when a redundancy of emergent issues occurred and no new information was gained (Morse, 1991b).

ETHICAL CONSIDERATIONS

Researching the private lives of others raises ethical issues for the researcher. These issues concern the “*morality of human conduct*” (Edwards and Mauthner, 2002, p. 14). It is about being sensitive to the rights of others and involves a respect for human dignity. Miller and Bell (2002) suggested that gaining ethical approval at the beginning of the research does not mean that ethical issues can be forgotten; instead, these issues should be an on-going part of the research. When designing a study, researchers have to consider many ethical principles such as informed consent, privacy, confidentiality and avoidance of harm to the participants. Particular consideration needs to be paid to the mothers as they are in a vulnerable position.

My fieldwork began with gaining ethical approval from the Faculty of Health, Social Care and Education Research Ethics Panel (FREP) at Anglia Ruskin University (see Appendix A). Once gained, ethical approval was then sought from the Jordanian Ministry of Health (MOH) for the research setting 2 (Appendices B and C) and research setting 1 hospital’s institutional review board (IRB) (Appendix D). Both granted their specific ethical approval.

At the beginning of my fieldwork I approached the ward managers for each hospital and informed them about my study’s aims and obtained their consent to participate. They then introduced me to the neonatal units’ personnel to whom I gave a general idea about my research.

When I started my fieldwork at each unit, the target health care team and mothers of preterm infants were approached individually. Each was invited to participate after being given a clear idea about the research aims and objectives. None of the people approached refused to be observed, however some nurses and mothers did not want to be interviewed because of their busy schedules. Those who showed interest in participating were then given copies of the participant information sheet (Appendices E & F) and consent forms (Appendices G & H) to sign.

Oliver (2010) highlighted the importance of informed consent, which indicates that potential participants should be free to choose to take part in the study after they have been introduced to a full description of the study including potential risks. Therefore, I discussed the information sheet with each participant and made sure they clearly understood what was being said. Two copies of the

consent form were then signed by the participant, one of which was for them to keep.

In qualitative research, it is difficult to obtain informed consent since it is not clear from the beginning what the participant is consenting to and where participation begins and ends (Miller and Bell, 2002). "*The precise nature of 'consent' for the participants might only become clear eventually, at the end of a study, when the researchers' impact on shaping the study is visible*" (Miller and Bell, 2002, p. 54). This suggests a different approach would be more appropriate. This demands a different approach to be used. Miller and Bell (2002) recommended that consent should be ongoing and should be renegotiated throughout the research process. Speziale and Carpenter (2007, p. 64) recommended that "*consensual decision making*" or so called "*process informed consent*" is more appropriate for qualitative research. Here the researcher re-evaluates the participants' willingness to continue to be involved at different points in the research study. According to Speziale and Carpenter (2007), a "*process consent offers the opportunity to change the original consent as the study emerges and change becomes necessary*" (p. 64). This study therefore adopted the process informed consent approach by reassessing the participants' willingness to continue as the study progressed.

An important ethical principle is that social research may have consequences and may cause harm to research subjects and to researchers. Researchers have to take responsibility for the effect of their actions on the research subjects. In this study it was made clear to participants that participation was entirely voluntary, and that, at any point of the research, if participation caused any stress or discomfort for them, they had the right to withdraw from the study. Counselling support was arranged for the participants in case any kind of distress occurred during the interviews. Even though five of the mothers cried during the interviews, none of them chose to stop the interview or to withdraw from the study. In fact, they stated that being able to express their feelings actually helped them feel much better.

Another ethical principle is safeguarding the confidentiality of data. Participants were assured that the data that was collected from them or about them was only needed for the study purposes. Participants were also assured that all information provided in the interviews and during the observation would be treated confidentially. Confidentiality of the subjects was maintained by not

identifying them by name and by concealing any identifying characteristics. Each participant was assigned a code number known only to me. All of my digital recordings and transcripts were stored in a secure place accessible only by myself. The fact that the data collection was carried out in Jordan while the data management was completed in the United Kingdom meant that the ethical requirements regarding confidentiality and anonymity for this study were maintained (Gelling, 1999).

DATA COLLECTION METHODS

Methods are the tools and processes used to gather data. In ethnography, the researcher is the research instrument; therefore her senses and interpersonal skills are extremely important for gathering data (Fetterman, 1998). The ethnographic research approach is valuable because it provides a flexible set of methods. The use of multiple methods, including semi-structured interviews, observation and field notes, which is also called triangulation, reveals a way of ensuring an in-depth understanding of the phenomenon in question (Denzin and Lincoln, 2005b). This study was based on fieldwork adopting the observer participant role as the primary data collection method, supported by formal and informal interviews. I also kept a research diary of personal reflections where I recorded emerging themes and my own observations and attitudes, which all form part of the data. The use of these methods provided a total picture of the phenomena of study and validated each other (Roper and Shapira, 2000).

Fieldwork is the core of ethnography, as all ethnographic research occurs in the field. Data collection and data analysis form an iterative process; ideas build up throughout the study with the choice for further collection and cross checking of the data (Speziale and Carpenter, 2007). Rather than being sequential steps, Wolcott (1995), described fieldwork and interpretation as being concurrent with each other. Researchers have to enter the field with an open mind as a learner with no presuppositions as to what she will find. This does not mean to enter the field with no experience at all, but rather to enter the field with no theory to test or a clear idea of what to find (Hilton, 1987). For this study, I initially took time to identify my own assumptions, beliefs and understanding of the situation so these could be set aside. When I approached the data for analysis, one of stages of

this analysis was to review the data in the light of my own assumptions to see if I was influencing it.

Participant Observations

A unique feature of the qualitative approach is the nature of the researcher's participation in the data collection and analysis (Morse, 1991a). In fact, participant observation is often used as a synonym for ethnography (Seale, 2004). It involves participating in a situation, while, at the same time, observing the behaviour in the context in which it occurs and recording what is being observed. Savage (2000) referred to participative observation as a methodology rather than a method. This is because it incorporates a range of data collection approaches in which "*physical involvement in the field cannot be divorced from the researcher's theoretical or epistemological suppositions*" (pp. 324-325), as these suppositions will guide the researcher's way of thinking and acting during the research process. However, as ethnography is seeking the participants' view not the researcher's, this potential influence has to be acknowledged and guarded against. This issue discussed further in page 64.

Various levels of participation exist and are well documented. The degree of participation depends on certain situations and activities in the field and on the personal characteristics of the researcher. Gold's (1958) offered the most widely cited classic description of researcher involvement in the field. He described four categories:

- Complete participant: in which the researcher is a fully functioning member working in a completely covert fashion. This type of observation may restrict the character of data collected because the researcher becomes hedged in by the expectations of the adopted role. It also carries the risk of going native, where the researcher abandons the position of analyst and instead identifies with those being studied (Seale, 2004). It is also deemed unethical in most situations as consent cannot be obtained from participants.
- Participant-as-observer: this role is the same as the complete participant role but the researcher role is known to all members of the group being observed. Here the balance is in favour of participation and social interaction over observation. However, it still holds some risk of going native (Seale, 2004).

- Observer-as-participant: in this role, the researcher is an interviewer with more formal observation and very little participation. The balance here is in favour of observation over participation. This type prevents the risk of going native but restricts understanding because of the limited participation (Seale, 2004).
- Complete observer: in this type the researcher observes people but does not interact with them. There is no risk of going native, but there is a potential risk of ethnocentrism instead, in which the observer may judge people studied from his/her own cultural point of view because he/she is not interacting with them (Seale, 2004). Jorgensen (1989) believed that non-participation has the greatest capacity to miss the meaning of what we observe.

Spradley (1980) proposed five different levels of participation: complete, active, moderate, passive and non-participation. Whereas Schatzman and Strauss (1973) outlined six roles that might be adopted by the investigator: participant with hidden identity, observer as participant, watching from the outside, active control, limited interaction and passive presence. The important issue here however, is not which role to adopt, but to maintain an awareness of that role and a consciousness of the social position it holds but still allows for an understanding of what is going on (Hilton, 1987). These roles are not fixed, but may change over the course of the study (Seale, 2004). For example, Pope (2005) started her study as a non-medic outsider and a complete observer. As her relationship with the participants developed over time she moved closer to the participant role. In the hospital context, Wind (2008, p. 79) argued that it is impossible to ever truly participate, suggesting the term “negotiated interactive observation” as a more appropriate way to refer to ethnographic fieldwork at hospitals.

For the purpose of this study, I chose to adopt the observer-as-participant role (Gold, 1958). This helped to give me more time to interact with mothers and other health care professionals. In addition, as I was a former clinical instructor nurse in the two units, I could freely move around both units without being intrusive, which allowed for spontaneous observation and access to opportunistic informal interviewing with mothers.

I visited the wards intermittently and at different times during the day which made it possible for me to obtain a broader range of data. Each period of observation

lasted for four to six hours and was conducted at different times and on varying days of the week over the study period. I did not undertake fieldwork during night shifts, because visitors, including mothers, were not allowed to visit at this time, and because staff members work shifts, which gave me the chance to meet them all during normal fieldwork hours. Each time I introduced myself to staff and mothers as a nurse researcher and told them that I wish to learn about their experiences and perspectives about breastfeeding within the NICU. My observations focused on mothers' interactions with their infants, nurses' interactions with mothers and families, any breastfeeding or breast pumping activities, and other daily nursing activities. I achieved 65 hours of observation in site 1 and 70 hours in site 2 over a period of 6 months. My fieldwork commenced in February 2011 for a total of three months at each hospital. I undertook two consecutive months at each location, starting with site 1, then returned to follow up my research for a further month at each unit.

Contemporaneous written notes were taken as far as possible. In cases where this was not possible, brief notes were made as an 'aide memoire', and then detailed notes written up as soon as possible afterwards. I described what I had observed during the day such as what individuals were doing, the nurses' reaction to the presence of mothers, any breastfeeding activities and the mothers' interactions with their children. I also wrote down my feelings and any additional notes related to my interviews.

Observation is insufficient on its own to explore either an individual's intentions or motives or the meanings and values attached to an activity. Therefore, undertaking interviews was considered important to be able to capture this element of understanding.

Interviewing

In addition to my fieldwork observations it was very important to know how the mothers and the health care team viewed breastfeeding preterm infants within the context of the neonatal intensive care wards. Qualitative interviewing was thus selected as part of the data collection methods. Interviewing is appropriate to the exploration of the participants' perceptions and opinion regarding complex issues and, at the same time, allows for clarification of answers (Barriball and While, 1994).

Interviewing is the most widely used research method in general and one of the main methods in collecting data in ethnography. It is a professional way that changes the spontaneous everyday conversation to a purposeful, semi-structured questioning and listening approach in order to gain systematic knowledge about what people have to tell of their lived experiences (Kvale, 2007). Anthropologists and sociologists have used informal interviews for a long time to obtain knowledge from their participants or to encourage them to talk about a certain topic (Seale, 2004). In social sciences, interviews have become a common research method for the last few decades as it is “*useful as a research method for accessing individuals’ attitudes and values – things that cannot necessarily be observed or accommodated in a formal questionnaire*” (Seale, 2004, p. 182). Interviewing generally takes many forms (Gilbert, 2008):

1. Structured or standardized interviews. In which questions are asked in the same wording and same order for each interview.
2. Semi-structured or semi-standardized interviews. In which the researcher asks major questions the same way each time, but is free to change their order and can ask for further information or clarification.
3. Unstructured, non-standardized or focused interviews. In this type the interviewer has a list of topics that they want the participants to talk about. They are free to phrase the question in any way and are able to participate in the discussion with the participants. This type of interview is valuable as a strategy for discovery where little is known about the topic, while structured interviews are more suitable when something is known about the participant’s experience.

My interviews were semi-structured. My position reflected Morse and Field’s (1996) suggestion that semi-structured interviews are appropriate when the researcher has an idea about the research questions but not the answers. I used any empty room within the NICU units at a convenient time for the participant. Two of my interviews were conducted at the bedside (incubator’s side). One with a mother who preferred not to leave her infant and one with a nurse who had to cancel many previously arranged dates for the interview because of her busy schedule; she finally chose to do it at the bedside while working.

After collecting the participant’s demographic data, a general open-ended question was asked at the beginning of each interview about the participant’s perception of breastfeeding preterm infants. Demographic details that were

collected from the mothers included age, delivery type, parity, level of education, work, class level and infant's gestational age and birth weight. Those that were collected from the staff included age, gender, job, level of education, marital status, personal breastfeeding experience, and work experience. The class level of the participants was based on the Jordanian Economic and Social Council policy paper classification (Economic and Social Council, 2008). This identified individuals as middle class whose annual per capita income is at least two and no more than four times above the poverty line (poverty line at 680 JOD).

The interview consisted of a two way conversation in which I followed the conversational threads opened up by the interviewee (Polkinghorne, 2005, p. 142). After doing some interviews I found that starting with a warming up question like "tell me about your pregnancy" for mothers, and the question of "tell me about the situation of breastfeeding in your unit" for the health care team, was a good way to start the interviews. A guideline was used to direct the interviews (Appendix I), which was informed by the initial analysis of the previous interviews. This enabled for exploration of issues previously identified. Additional questions were then asked depending on the flow of the interview, which were followed by additional probing. Probes were used where more clarification was needed. Any non-verbal reactions e.g. facial expressions and body language were then written as part of my field notes.

I conducted single interviews which lasted between 30 to 40 minutes. Although researchers such as Seidman (1998) recommend a sequence of three interviews in order to gain data with sufficient depth, it was not possible for this study because of the time constraint. However, in addition to my individual interviews, I also had many informal talks with the participants before and after the formal interview. The talks before the interview gave me time to get acquainted with the interviewee and gave them more time to think about their experiences. Talking after the interview gave me additional time to ask follow-up questions. Consent was obtained to utilize data obtained in this manner, and the information gained was then taken into account during my analysis.

With consent I used a digital voice recorder to record interviews. The recording was checked instantly afterwards to ensure data capture and field notes were immediately completed reflecting on the interview event. The recorded interviews were then downloaded onto my personal computer on the same day of the

interview for later transcription; this also ensured a copy of the recording was available in case the original was lost.

At the beginning of each interview a complete explanation of all aspects of my study were discussed with the participants. Participants were informed that they had the option of stopping the interview at any time if they felt uncomfortable. All of my participants agreed to their interview being recorded except one; in this instance, contemporaneous notes were made throughout the interview and these notes were expanded on immediately after the interview.

When I listened to the recording of my initial two interviews I identified myself, forgetting my role as a researcher, and reverting back to my roles as a nurse and teacher. In both interviews I talked most of the time as I started teaching the mothers about breastfeeding issues. I learned from these two cases not to dominate the interview as the aim was to gain information from the participants, not the other way around. A conscious effort to achieve an active listening stance and to be aware of my researcher role was then maintained. I also identified that there were short responses from my interviewees and a lack of probing. As I gained more confidence in conducting interviews and promoting probing questions, the resultant interviews provided richer and more detailed data. The use of a pilot is less common in ethnography, but acknowledging that the researcher is the tool for data collection, I analyzed these two interviews as if they were a pilot. While these interviews were not included in my analysis, nevertheless perspectives raised did give an insight into some issues that needed to be explored. I interviewed 32 participants, 17 mothers and 15 staff. All interviews with mothers were conducted in Arabic; however, those with the medical staff were a mixture of Arabic and English, with Arabic predominating.

DATA ANALYSIS

There is no recognised formula or recipe for analysing ethnographic data and the analysis is not a distinct stage of the research; rather it starts from the pre-fieldwork phase and continues through to the process of writing an ethnography (Hammersley and Atkinson, 2007). This means that data collection and analysis forms an iterative process in ethnography. My analysis started from the moment of entering the fieldwork and continued whilst writing up my thesis. Preliminary analysis of the data during the data collection stage was important as it allowed

me to identify gaps that required further exploration before leaving the research context.

Given the bulk and complexity of ethnographic data, it is essential that there is a proper analysis, interpretation and presentation of the data (Brewer, 2000). Analysis of ethnographic data involves bringing order and structure to the information to be able to discover recurrent patterns, categories and relationships. These patterns and categories and the relationships between them then need to be explained and interpreted in order to add meaning to the research data (Brewer, 2000).

Brewer (2000, p.109) recommended to begin focusing the analysis on the original research questions and on the insights about analysis that occurred during data collection. This was followed by a series of steps including:

- Data management (organizing the data into manageable units);
- Coding (indexing the data into categories and themes);
- Content analysis;
- Qualitative description (identifying the key events, people behaviour, providing vignettes and appropriate forms of counting);
- Establishing patterns in the data (looking for recurring themes, relationships between the data);
- Developing a classification system of 'open codes' (looking for typologies, taxonomies and classification schemata which order and explain the data);
- Examining negative cases (explaining the exceptions and the things that do not fit the analysis).

Following Brewer's recommendations, I approached my data initially by addressing my research questions. I started with organizing the data for each research question from each hospital separately. Yet this way proved unhelpful and rather confusing for this study. Another approach where I organized the data by groups rather than research questions proved more useful, here similarities and differences between the different participant groups and the two hospitals could be identified.

My data consisted of 32 interviews with 17 mothers and 15 staff and a total of 135 hours of participant observation field notes. All interviews and observational data were transcribed to form the material for analysis. Although transcribed,

voice recordings stayed as part of my data to be analysed because repeated listening to tapes is often a “*neglected area of analysis and yet one of the most essential*” (Skeggs, 1994, p. 84). Data analysis began with listening to the voice recordings and repeatedly reading the field notes and transcripts in order to identify categories and patterns. Richness of understanding is achieved through an analysis of not only the words but also the tone in which they were spoken.

Following this, I started the process of coding. Coding is not only labelling but linking. It is a transitional process between the data collection and data analyses processes (Saldaña, 2009). Coding is a process where I manually highlighted words or statements and provided a short descriptive name on what that text implied. I commenced the first cycle coding process where I coded anything and everything that was collected (Saldaña, 2009). Each transcript was coded individually and observational data was coded by giving a label to each paragraph based on its meaning (Fetterman, 1998). Below is an example of my first cycle coding process:

This surgery was very tiring for me¹. I had to stay in bed for two days without moving². This is my fourth Caesarean section yet never been tired and exhausted as this time, I was so tired I could not leave the bed for two days³. When I got out of bed I immediately came to visit him⁴, but she [the nurse] refused to let me in because there was a medical round⁵. So I returned back to my room and waited until they were done. When I came back he looks tired and he was connected to many tubes⁶. When I asked the doctors about his condition they reassured me. However, it stills very difficult for any mother to have a sick child in this unit⁷. This is heartbreaking⁸. I wish if I can hold him between my arms and return with him to my house now⁹. I want to breastfeed him as long as possible¹⁰.

¹ BIRTH EXPERIENCE

² BIRTH EXPERIENCE

³ EXHAUSTION

⁴ THE FIRST VISIT

⁵ PERMISSION TO VISIT/ NURSES AS GATEKEEPERS

⁶ FIRST SIGHT

⁷ NICU ENVIRONMENT

⁸ EMOTIONAL BURDEN

⁹ NEED FOR PHYSICAL CLOSENESS

¹⁰ NEED TO BREASTFEED

The second cycle recoding process involved further managing, sorting, arranging and linking data, to generate patterns and categories. Visual representation of the codes and their relationships helped me during this stage by displaying codes in tables for further analytical thought. These display tables were organized according to mothers’ perspectives, staff viewpoints, and those that I derived from my observations. Table 7 and Table 8 are examples of the final

presentation of the mothers' and staff accounts, respectively, which show the connections between the coding elements of both the participants' narratives and field notes, and how the final themes have been developed.

Once the coding was complete categories were determined by organizing the research materials into manageable pieces with the aim of looking for patterns, sequences or wholes (Jorgensen, 1989). A category was identified when codes seemed to cluster and interrelate (Saldaña, 2009). A final theme was then given to each set of categories in order to reconstruct the data in a meaningful manner (Jorgensen, 1989). Emergent themes were examined within individual participants as well as among other participants, and within each research setting. Segments from each transcript and observational data with similar themes, within the two research settings, were then grouped together.

Initially, themes were identified in the interview transcripts and the observational data separately. These were then integrated with each other, enabling the overall picture to be viewed from alternative perspectives. Emergent themes were based on the participants' voices, and my interpretation confirmed after discussions with my supervisors and research mentors. Throughout the process of analysis, member check was maintained. Member check, also called "respondent validation", is a process that involves returning data analysis and interpretation back to the participants for approval which "*may materially alter the plausibility of different possible interpretation of the data*" (Hammersley and Atkinson, 2007, p. 182). While it was inappropriate to ask all busy staff and distressed mothers to check their transcripts, I did randomly provide four of them with their accounts to review and minimal modifications were needed. During the analysis process, particular issues about the need for translation arose. These are discussed in depth in page 60.

A final step of the data analysis is the interpretation process, which included interpretation and explanation of the patterns and relationships of the emergent themes in order to make sense of them and to make general discoveries about the breastfeeding phenomena (Seidel, 1998). Following this, I started a process of relating back to the literature to make more sense of my identified themes.

Table 7 : Coding, categories and themes generated from the mothers' accounts

Codes	Categories	Themes
<ul style="list-style-type: none"> • Sudden change • Terrified, fear, anxious • Guilt feelings 	<ul style="list-style-type: none"> • Emotional instability 	The Crisis
<ul style="list-style-type: none"> • Not visiting to lessen the loss • Infants shocking appearance 	<ul style="list-style-type: none"> • Strategy of not visiting 	
<ul style="list-style-type: none"> • Scary environment 	<ul style="list-style-type: none"> • NICU as a stressful environment 	
<ul style="list-style-type: none"> • Nurses as gatekeepers • Anger and oppression 	<ul style="list-style-type: none"> • Lacking control 	The control power
<ul style="list-style-type: none"> • Permission to visit • Permission to touch 	<ul style="list-style-type: none"> • Seeking permission 	
<ul style="list-style-type: none"> • English and medical language 	<ul style="list-style-type: none"> • Language as control 	
<ul style="list-style-type: none"> • Not participating in care • Constant supervision by the nurses 	<ul style="list-style-type: none"> • Giving mothers subordinate roles 	
<ul style="list-style-type: none"> • Leaving without the baby 	<ul style="list-style-type: none"> • Difficult to accept 	The separation
<ul style="list-style-type: none"> • Physical closeness/ being there 	<ul style="list-style-type: none"> • Feeling like stranger 	
<ul style="list-style-type: none"> • First reaction toward baby • Feeling unwelcomed/ unimportant 	<ul style="list-style-type: none"> • Physical distance 	
<ul style="list-style-type: none"> • Feeling important • Physical closeness • Gradual acceptance 	<ul style="list-style-type: none"> • Gradual acceptance 	Acceptance and adaptation
<ul style="list-style-type: none"> • Relying on God • Submission to God's will • Reading Quran 	<ul style="list-style-type: none"> • Spiritual aspects 	
<ul style="list-style-type: none"> • First visit • First sight • First breastfeed 	<ul style="list-style-type: none"> • The special moments 	Becoming a mother
<ul style="list-style-type: none"> • Feeling like a mother • Breast milk as a reason of improved infant's condition • Breast milk as a connection • Positive feelings 	<ul style="list-style-type: none"> • Breastfeeding as a turning point 	
<ul style="list-style-type: none"> • Need to breastfeed • Practical / informational needs • Participating in infant care 	<ul style="list-style-type: none"> • Maternal needs 	

Table 8 : Coding, categories and themes generated from the staff's accounts

Codes	Categories	Themes
<ul style="list-style-type: none"> • Beliefs of superiority of breast milk • Beliefs of the importance of implementing a breastfeeding strategy • Beliefs of the importance of supporting mothers 	•Breast milk is best	The contradiction
<ul style="list-style-type: none"> • Relying on technology • Not communicating the presence of expressed breast milk • Medical priority • Mothers' support as a social interaction • Incidental teaching 	•Breastfeeding promotion as a nicety not a necessity	
<ul style="list-style-type: none"> • Inadequate support • Lack of facilities to support mothers • The negative influence of nurses on mothers 	•Lack of mothers' support	
<ul style="list-style-type: none"> • Responsibility of other wards/ family members • Lack of nurses' knowledge • Lack of nurses' confidence • Relying of personal experiences 	•Abdication of responsibility	
<ul style="list-style-type: none"> • Heavy workload/ time constraints • Limited resources • Lack of continuing educational courses 	•Lack of institutional support	Working conditions
<ul style="list-style-type: none"> • Staff shortage • Restricted resources • Unit design • Unavailability of mothers • Distance to hospital • Infant compromised physical condition 	•Barriers to breastfeeding	
<ul style="list-style-type: none"> • Protectors of the baby • Ownership of the place 	•Control relations	The control relationships

TRUSTWORTHINESS OF THE RESEARCH METHODS

Rigor of the Study

To ensure the research is rigorous, great consideration is devoted to reliability and validity in quantitative research methods. Many qualitative researchers, however, reject the criteria of reliability and validity that is accepted in quantitative research and suggest adopting new criteria to ensure reliability and validity in qualitative studies (Leininger, 1985, Lincoln and Guba, 1985). Lincoln and Guba (1985, p. 300) preferred to use the concept “*trustworthiness*” to substitute reliability and validity. Trustworthiness of the study is an important consideration that enables the reader to evaluate the worth of any research. Lincoln and Guba (1985) believed that in qualitative paradigms the term “*confirmability*” corresponds to objectivity, “*dependability*” corresponds to reliability, “*credibility*” corresponds to the internal validity, and “*transferability*” corresponds to external validity. These terms are to be the essential criteria for qualitatively rather than the traditional quantitatively oriented criteria. To ensure trustworthiness of the study, four major criteria were addressed: confirmability, dependability, credibility and transferability/applicability.

Confirmability refers to the degree to which the results could be confirmed or corroborated by others. To enhance confirmability an audit trail has been suggested (Lavender, Edwards and Alfirevic, 2004), in which a detailed description of the research steps undertaken was maintained from the start for checking and reanalysis by others if needed. I was also aware that being the research instrument I may influence the course of the research by my own personal assumptions and biases. Awareness of this concern enabled me to focus my attention on it and, through a process of critical reflexivity, to note and question these assumptions. This allowed the participant’s stories to be revealed and is discussed in more detail on page 64.

Dependability is concerned with the consistency and stability of the study over time and the possibility for another researcher to replicate the study. However, as the researcher herself constitutes the tool, to completely replicate the study would be impossible. Dependability is limited if the process of data analysis is unclear. It is important therefore to make this process as transparent as possible so all versions of the coding lists were maintained throughout the study. Decisions that I made during data collection and analysis were assessed and

discussed with colleagues, mentors and supervisors to ensure accuracy and consistency throughout the study.

Credibility involves establishing that the results of qualitative research are believable. One way to establish credibility was through the process of participants' validation, or "member checking", which involved asking some interviewees to review my analysis of their views to see whether they recognize the findings to be true to their own experiences (Speziale and Carpenter, 2007).

Triangulation is also a method used to cross check the study findings, where one source of information is tested against another to eliminate alternative explanations and understand the whole picture (Fetterman, 1998). Denzin and Lincoln (2005b) outline four types of triangulation: a) data triangulation including time, space and person, b) investigator triangulation, c) theory triangulation, and d) methodological triangulation. Data triangulation involves using several data sources by including more than one participant at different times and in different sittings. Investigator triangulation is where more than one researcher in the field collects the data. Theoretical triangulation refers to the use of more than one theoretical position while collecting and interpreting the data. Methodological triangulation is the most common type of triangulation, this refers to the use of more than one method for collecting research data. Using multiple methods will ultimately lead to more trustworthy findings. Mathison (1988) indicates this by noting:

Triangulation has arisen as an important methodological issue in the evaluation literature as well. In particular, naturalistic and qualitative approaches to evaluation have demanded attention to controlling bias and establishing valid propositions because traditional scientific techniques are incompatible with these alternate epistemologies....the use of any single method, is just like the view of any single individual, will necessarily be subjective and therefore biased. (pp.13-14)

The idea behind the use of multiple methods is that the greater the agreement of different data sources on a particular issue, the more trustworthy the interpretation of the data and the more confident the researcher can be in reporting the results. Triangulation often allows access to different levels of reality. According to Hammersley and Atkinson (1995), trustworthiness is also improved if different kinds of data lead to the same conclusion. This proved to be an important mechanism in this study where I combined observations and fieldnotes with interviews.

Transferability or applicability refers to the degree to which the results of qualitative research can be transferred to another setting or context. Ethnographers are not concerned with the empirical generalization of the results but with making theoretical assumptions based on valid data for the specific situations being studied, in this case the two hospital wards. My responsibility is to accurately and transparently describe the culture of the study, thus the reader can judge how transferable the interpretations are to other situations and other cultural contexts.

As this study was based in Jordan, away from direct university supervision, an alternative guidance was seen necessary. Peer review was a strategy used to ensure the data was trustworthy. Guidance involved having formal, regular supervisory meetings with a knowledgeable and experienced researcher and less formal tutoring meetings with nurse researcher friends.

Another issue that has direct impact on the trustworthiness of qualitative research is translating into another language the data that is to be presented, as this process involves taking decisions related to the translation process.

The Translation Process

It becomes increasingly common among researchers to conduct a study in one language and present the findings in another, commonly English. Therefore, there has been an increasing awareness toward addressing the challenge and impact of translation on the study findings. Preparing cross-language data for analysis is a cultural issue because translation involves converting ideas expressed in one language from one culture into another language for another culture (Torop, 2010). Therefore, the translation process needs to be discussed in more detail and should be part of any research methodology.

This study was conducted in my home country so all of my interviews and field notes were written in Arabic and translated into English. For the production of trustworthy results and maintaining the overall rigor of the study, it is important to understand how the notes were translated whilst remaining culturally sensitive to the research population (Squires, 2009).

In the process of translation Birbili (2000) suggested that in order for researchers to appreciate the full connotations that a term carries for the people under study, they must have a proficient understanding of the participants' language and an

intimate knowledge of their culture. Maintaining the same meaning and relevance in the culture in both languages is fundamental in qualitative analysis. Birbili (2000) identified factors that affect the quality of translation: the linguistic competence of the translator; the translator's knowledge of the culture they are studying; the autobiography of those involved in the translation process; and the circumstances in which the translation takes place.

These factors were further developed by Squires (2009) who reviewed 40 qualitative studies addressing cross-language research. He identified four methodological issues for addressing language barriers between researchers and their study participants. These involved: maintaining conceptual equivalence, translator credentials, the translator or interpreter's role and specific recommendations for different types of qualitative approach. These four areas offer a plan for addressing translation issues in qualitative research (Squires, 2009).

To maintain conceptual equivalence, the translator needs to accurately translate, technically and conceptually, any concept spoken by the research participants (Squires, 2009). Larkin and Schotsmans (2007) argued that the cross-language research approach is appropriate with most qualitative research methods except with phenomenological studies, where an exact understanding of language used is required to understand the lived experience of the phenomenon. Squires (2008) however, argued that a researcher wanting to publish a phenomenological study must complete the analysis entirely in the language of the participant and then publish in another language. Although this suggestion was in relation to phenomenological studies, it proved to be appropriate for this ethnographic study, where I dealt with the data in its original Arabic form, and then translated it into English after categories and themes had been generated.

The credentials of the translators and their role also form an important component of the research process (Squires, 2009). The language competency of the translators will affect their ability to describe concepts and words when an equivalent word to the actual word or phrase does not exist. The role of translators is also important because their background and experiences may shape the translation process, and thus the analysis process (Temple and Young, 2004). Squires (2008), recommends that researchers need to have a high-level socio-cultural competence and significant background knowledge about the country of study.

The previous discussion highlights one of the strengths of this study, in that no translators were used because I was able to do the translation myself. I had the advantage of belonging to the same culture as my research participants and therefore did not have any problems associated with cultural equivalence. Participants were using colloquial rather than classical Arabic and as a native speaker, I was not only proficient in Arabic but also had an intimate knowledge of their culture and was therefore able to understand the cultural aspects of their language and the true meaning of what was being said during the interviews. (Birbili, 2000). However, the process of translation is still challenging because, in order not to distort meaning, one has to make some choices of how best to translate certain Arabic words that have no equivalent in English. Squires (2008), recommends an independent review to validate the conceptual accuracy of the translation; this I maintained through my peer review. The following example (Table 9) of one participating mother's account illustrates these meanings:

Table 9: Illustration of some translation issues

Original text/ NS2-M6	<p>بطلت اكل بالمره على الخيار والبنندوره واتعشى خس وافطر تفاحه. يحرم علي بناتي يقاتلن علي وزوجي يقاتل علي، بقول لي يا بنت الحلال ليش بتردي علي الدكاتره في كل اشي؟ كنت اقله يا ابن الحلال انت بذك تموتني يقول خلص اللي بذك اياه.</p>
Literal translation	<p>I stopped eating; I was only on cucumbers and tomatoes and have lettuce for dinner and apple for breakfast. Forbidden myself. My daughters were fighting me and my husband was fighting me. He told me: Oh "bent-el-Halal" why you respond to the Drs in everything? I used to reply: Oh "ibn-el-halal" you want to kill me? He then replied: enough do whatever you want to do.</p>
conceptual equivalence	<p>I was living on cucumbers and tomatoes, having lettuce for dinner and an apple for breakfast. My daughters and my husband begged me to eat some food. My husband used to say: "Oh dear, why do you need to follow all the physician's instructions?" I would answer: "Oh darling, do you want me to die by not following her instructions?" So he replied: "Well, do whatever you'd like to do".</p>

As seen in the previous example, "fighting" was the literal translation for the word (يقاتل) but in this context the word was used to indicate begging to do something. Another example are the phrases "*bent-el-Halal*" and "*ibn-el-halal*". "Halal" is something that is permissible in all matters of daily life in Islam. The opposite is Haram which means sinful or prohibited. So, the literal meaning of "bent-el-halal" and "ibn-el-halal" are: a female (bent) or a male (ibn) who was born to a legally

married couple. However, metaphorically they mean: a good woman and a good man. Jordanian people often use these phrases in their conversation, instead of using the person's name, when trying to convince him or her of their viewpoints. They are best translated into darling or dear. These are two examples of the need for cultural knowledge for the translation to be successful.

The omission of a word or a phrase while translating text could have a significant influence on the data interpretation, meaning, and the final representation of the cultural reality (Wong and Poon, 2010, p. 156). Therefore, I deferred any translation of the data until after I had generated categories and themes from the original Arabic. After transcribing the interviews verbatim in their original language I started using an English code for the Arabic transcripts. However, it proved difficult to find appropriate English words or terms for the identified codes at the beginning and for the generated categories and themes later. My intention was to achieve equivalence in meaning, rather than in literal form. Therefore, the translation from Arabic to English was based on the whole meaning not word by word. For coding, I used terms that could be translated exactly without losing their meanings. However, when a term or a phrase could not be translated exactly, as in the previously mentioned example, I tried to obtain a term that meets the definition of the concept, rather than to have grammatical equivalence (Birbili, 2000). In presenting my findings, I use verbatim quotes in Arabic with their English translations to represent the meaning of each theme so that a reader of both languages could judge for themselves the trustworthiness of my translation and interpretation of the research findings. I have also included examples of part of an interview transcript in both Arabic and English; Appendix J is a transcript in Arabic and Appendix K is the translation into English for the same section of the interview.

Some scholars suggest the process of back translating the translated data as a way to validate the translation process (Larkin and Schotsmans, 2007). However, given the volume of qualitative studies data, back translation is a time consuming process, and Squires (2008), argued that back translation does not enhance the trustworthiness of the study results to any greater extent than a critical review by a qualified bilingual person. Jagosh and Boudreau (2009) even criticise the process of back translation by pointing to its focus on linguistic equivalency while dismissing relevancies of cultural context.

The process of validation by a qualified bilingual person who, as Squires (2009) suggested, is not directly involved with data collection or initial translation was therefore maintained by peer review. It involved presenting the most complex portions of the translated findings and quotes to knowledgeable, bilingual, nurses with experience in research to ensure the appropriateness of my translation.

Reflexivity: Studying One's Own Culture, Insider or Outsider

Being a researcher in a familiar environment is challenging. In qualitative studies, it is common for researchers to study their own cultures, to be an insider. Therefore, they need to reflect on the process of their research and be aware how their own views and experiences could influence the research findings. Researchers have suggested positive and negative aspects associated with studying a familiar setting.

Some researchers are against the idea of undertaking research in a familiar setting because of the problem of trustworthiness (Hanson, 1994). Taylor and Bogdan (1984) recommend researchers stay away from familiar settings in which they have direct personal or professional considerations. They argue that, in such situations, the researcher will see things from only one point of view instead of the many possible ways of viewing the world. By studying an unfamiliar culture, ethnographers will be more sensitive to things that become so commonplace to informants that they ignore them (Spradley, 1979).

Spradley (1979) has identified many problems that come from studying a familiar culture. The first is the language differences that seem to be slight and are easily ignored. This means that the language of the informants may not catch the researcher's attention. For me, that was not such a problem, since I am not a neonatal nurse and I had no working experience in neonatal intensive care units. However, nurses within the unit were aware of my nursing background and did make assumptions about my knowledge. When they were talking to me they used a language that was understandable to medical personnel. For example, they commonly used medical abbreviations such as "NGT" referring to naso-gastro tube, "OGT" referring to oro-gastro tube, "IV" referring to intravenous, CPAP referring to continuous positive airway pressure and so on. They were also using the statement "*as you know*" repeatedly while explaining something to me. Following Goodwin's et al. (2003) suggestion, I repeatedly reminded

practitioners not to respond to me as a nurse or assume existing medical knowledge.

The second problem is that the analysis of field data becomes more difficult (Spradley, 1979) as researchers may fail to see things in the data because they are part of their own cultural knowledge and so familiar they may be taken for granted. Also, researchers may make assumptions about what they are observing without seeking the rational for certain actions. This is indicated by the famous Arab proverb "شدة القرب حجاب", which is best translated as "too much proximity is a veil". I experienced this problem myself when I failed to recognize that in the mothers' presence, the staff members were using English and medical language during their medical round. This action was so familiar to me that initially I did not identify it as an important issue until one of the participating mothers brought it up during her interview. Once identified, I had to be self-conscious and reflexive on my own perceptions and ideas during the rest of my research process. This is important in order to be able to describe phenomena as they are, rather than as I perceive them (Hammersley and Atkinson, 2007). It is important for the researcher to be reflexive and critical in examining her assumption throughout the data collection and analysis phase (Bonner and Tohurst, 2002). However, *there is no way in which we can escape the social world in order to study it.....rather than engaging in futile attempts to eliminate the effects of the researcher completely, we should set about understanding them* (Hammersley and Atkinson, 2007, p. 16).

The problem of familiarity can be eliminated by the researchers acknowledging their subjectivity; they can then strive to maintain an "open-minded" approach through continuous self-evaluation (Hanson, 1994, p. 941). It is recommended that researchers should keep a research diary on their reflexivity from the start, as this will give a clearer picture of how knowledge is produced (Skeggs, 1994). For this reason, I kept a research diary of my personal reflections on methodological issues such as sampling, interviews, translation and analysis.

The third problem that Spradley (1979) identified is the challenge participants from a familiar cultural scene present for interviewing. This means that if the research participants believe that I know the correct answer to my questions, they might feel that I am just asking such questions to test them in some way. For example: in one of my interviews with a nurse I asked "*what is your strategy in storing breast milk?*" after answering my question hesitantly, she asked me "*do*

you think this is the correct way of doing it?" I had to make it clear to her that I was not testing her knowledge in any way, and that I was seeking to understand rather than to criticise.

Bonner and Tolhurst (2002) have suggested some strategies to minimize the effects of being an insider and to avoid becoming a non-observing participant and going completely "native". These strategies are (Bonner and Tolhurst, 2002, p. 11):

- *Collecting data during off-duty hours where possible.* While participating in social events such as coffee breaks I had collected a good deal of data.
- *Not wearing a health professional's uniform while collecting data.* This worked very well for me. The policy in the two hospitals did not allow for wearing a uniform for non-staff members as part of their infection control strategies. So I had to wear a disposable gown in site 2 and regular clothes in site 1. However to be clearly distinguished, I always wore a name tag stating that I was a researcher.
- Avoid participating in clinical discussions or decision making during data collection periods.
- Avoid performing hands on nursing care.

The last two suggestions refer to adopting only one role in the research setting. Morse and Field (1996) were concerned about adopting the two roles of clinician and researcher at the same time. Goodwin et al. (2003) suggested that conducting participant observation in medical settings lead to role confusion or ambiguities and ethical dilemmas. They argued that the clinical role may take priority over the researcher role and thus neglect the collection of data. Whilst this did not prove a problem during participant observation, I did experience such a problem during my interviews when I found myself spending a great amount of time counseling mothers on breastfeeding issues rather than interviewing them. Yet ethically, this is not something you can avoid. Goodwin et al. (2003) suggested that *"the role of patient advocate is one deeply embedded in nursing culture, it was part of my legacy and, therefore, not a role I could easily relinquish whatever identity I was now assuming"* (p. 573). Skeggs, (1994) suggests that

researchers should give any information or knowledge that may be useful to the interviewees if they asked for advice and interpretations.

Reed and Proctor (1995), on the other hand, support the practitioner researcher from the inside arguing that this provides an enhanced understanding of the phenomena under investigation. Particularly in nursing practice, Greenwood (1984) argued that research must be carried out by insiders who fully understand the nurses' framework in order to avoid misinterpretation of the participants' behaviours. Hammersley suggested "*findings of non-practitioner ethnography are likely to be invalid because it is impossible for an outsider to a situation to understand it*" (1992, p. 143). Prior knowledge adds strength to the research, while a degree of familiarity with and an interest in the culture has the potential to make a positive contribution to nursing practice (Hanson, 1994). In addition, Borbasi, Jackson and Wilkes (2005), argued that nurses as researchers in their own environment have substantial benefits over other social researchers because many of the skills needed for data collection in qualitative approaches such as interviewing, careful listening and observations, are essential elements of effective nursing practice.

Bonner and Tolhurst (2002) identified three benefits of studying one's own culture (being an insider): the researcher has a greater understanding of the culture, the researcher does not alter the flow of social interaction and the researcher has an already established relationship with the participants that can promote truthfulness. As the aim of qualitative naturalistic studies is to explore the phenomenon in its natural occurrence with minimal external influences, my former position as a clinical instructor for nursing students made my presence in the two NICUs familiar and natural which allowed me to merge myself into the environment and the background without disturbing the situation. This also made it easy for me to locate sources of data and thus organize fieldwork accordingly. In addition, my familiarity with the research setting eased the first obstacle that other researchers usually face, which is negotiating access and establishing a rapport. Being a female researcher was also a benefit to me, as it would be impossible for a male researcher in a conservative Islamic culture to interview women without some tension, or to talk about a sensitive topic such as breastfeeding. Add to that the uncomfortable feeling that would be created by a male researcher observing women breastfeeding and it is easy to understand how the observational data might be distorted.

Jorgensen (1989) suggested that as long as the role to be performed by the researcher is within his or her range of expertise and not in conflict with the researchers other roles it is less likely to be problematic. Bryman (2008) suggests that in some situations "*ethnographers may feel they have no choice in getting involved, because a failure to participate actively might indicate to members of the social setting a lack of commitment and lead to a loss of credibility*" (p. 413).

In practice, any study will be affected by the researcher's values, as the researcher is the main instrument in qualitative studies. However, we cannot avoid having an effect on the social phenomena that we study; we only need to reflect on our roles as an active participant in the research process (Hammersley and Atkinson, 2007), and to acknowledge our influence on the research process and findings.

CHAPTER 5: FINDINGS AND DISCUSSION

INTRODUCTION

The study's findings are divided and organized into four separate sections: a) the description of the research setting and participants, b) observations of the units, c) the mothers' views and experiences and d) the health care team's views and attitudes. This portrays a comprehensive picture of the situation within the two neonatal units from two different viewpoints. Following a description of the two units, I start with my observational data in which I describe the situation in both units, followed by two sets of findings and discussions presented and illustrated with quotes from the mothers' and staff narratives, respectively, supported by extracts from my observation field notes.

The participants' names have all been coded to preserve anonymity. These codes contain three components: setting identification number (the first neonatal setting = NS1 and the second neonatal setting = NS2), category of individual (M = mother, N = nurse and D = doctor), and an individual identification number, where each participant was given an identification number. So for instance, NS1-M2 is mother number 2 in site 1.

THE RESEARCH SETTING

To be able to contextualize the views of mothers and staff who were interviewed and observed, it is crucial to provide some details of the research setting, which is derived from my observation over the 6 month-period.

Research Setting 1

The neonatal intensive care unit at site 1 has a large NICU space with a capacity of 25 incubators. The hospital is a general hospital with a total bed capacity of 650 beds. The unit is located on the third floor of the hospital. This floor is divided into four large wings comprising: the NICU, the labour and delivery unit and two postpartum units. A reception circle is located in the

middle of the four departments along with small waiting areas. There are 29 staff nurses allocated to the NICU, all are with baccalaureate degrees and one with a master's degree. Two of them are male nurses. There are also 2 neonatologists, 4 resident physicians, 1 practical nurse and one escort nurse. The hospital has only two shifts each of twelve hours duration; the day and night shifts and usually there are 7 – 8 nurses working for each shift, making the patient-nurse ratio no more than 3 – 1.

Walking on to the neonatal unit, you enter through open doors into a corridor that has access to a large lecturing room to the left used by medical students and a hand-washing sink to the right, ending with another entrance door that has an automated access control system. Passing the security door, one enters a foyer that has access to the head nurse's office, storage rooms and ending with a large open area that has the nursing station on the left hand side.

The unit has a larger physical space compared to the public hospital's unit, which means it has space for parents to spend time with their infants. The unit is moderately lit with florescent lighting and lined curtains covering the windows most of the time. It is divided into 4 areas, the premature baby rooms 1 and 3 share the open area with the nursing station and are for general admissions of preterm or sick infants who are born at the hospital. Room 2 is for isolated cases from inside the hospital and room 4 is for isolated cases referred from outside the hospital. From the main open area there are entries to the formula room, treatment/medication room, storage areas and nurses' lounge area. It is striking to note that with all the advanced technology in this unit there is a formula room but no room specifically designed for breastfeeding and no pumping facilities or area where this activity could be undertaken privately.

Research Setting 2

Research site 2 is small in size yet comprised 32 incubators and 6 warmers/resuscitation units, resulting in more space restrictions. The unit is under the management of a paediatric hospital, which has 112 beds. However, it is located on the third floor of a maternity hospital that has 98 beds, in between the postpartum, labour and delivery units. The NICU staff consisted of 30 female nurses including 16 staff nurses with Baccalaureate or

diploma degrees and with a master's degree, 4 assistant nurses who have been on a 2 year training course and 10 associate nurses who qualified under an old diploma course, none of these nurses are qualified midwives. There are also 4 neonatologists, 4 resident physicians, and 1 staff member with a Child-Education college degree course, who was responsible for preparation of the infant's formula. The shifts were divided into 3, with a patient-nurse ratio of 8 – 1 on average.

As one enters the unit, it is obviously very noisy and busy. Children are crying, there are loud alarm monitors, doctors and nurses are on duty moving between incubators and parents are visiting their babies. Visitors would also see an area that is well lit with both electric light and natural light coming in through large windows with no curtains, and plastic laminate floors. As you go through the front door there is a small room that serves as the waiting area with two metal chairs, and also a door leading to a very small storage area. Ahead of this room, you enter another area that contains the nursing station. This area has access to the treatment room, a large in-patient room, a small kitchen area and a very small breastfeeding room that has only two seats with no decorations, equipment or windows.

The unit is divided into 4 areas. The main area is the inpatient room that accommodates 25 incubators, and is available for infants who are delivered at the adjacent maternity hospital or are transferred from another hospital immediately after birth. The treatment room (nurses refer to it as the clinic) has 5 resuscitation units and receives preterm or sick infants immediately after birth. In this room, infants get immediate medical care before entering the in-patient room. The outpatient room accommodates 7 incubators and 1 resuscitation unit and is designed for preterm or sick infants who need medical assistance after being discharged from this or any other hospital. The incubators are side by side with no room for seating; visiting parents must therefore remain standing for their entire stay.

The Participants

Mothers

Seventeen mothers of various ages, parity, levels of education and previous breastfeeding experiences (Table 10) were interviewed. All mothers, except one (n=16) were Muslims. Maternal age ranged from 22 to 41, with an

average age of 29.7 years. All mothers were married (n=17) and the majority had caesarean section deliveries (n=11). Nine of them were college or university graduates, while the rest (n=7) had a primary or secondary school education. The majority were unemployed (n=13), low to middle social class, and primiparous (n=12). Two mothers gave birth to twins that made the total number of preterm infants 19. They were born with a gestational age between 29 and 36 weeks with a mean gestational age of 33 weeks. Generally, the mothers at research setting one had a higher level of education and were of a higher social class than the mothers at research setting two.

Table 10: Characteristics of participating mothers

	No.	Code	Mum's age (yr)	Delivery type	Parity	Education	Work	Infant GA (wk)	Infant Wt (g)
Research site 1	1	NS1-M1	28	N.V.D	Multi	Secondary school	No	33	2023
	2	NS1-M2	28	N.V.D	Primi	Baccalaureate	Yes	31	1405
	3	NS1-M3	30	C/S	Primi	PhD	No	29	1700
	4	NS1-M4	25	N.V.D	Primi	Secondary school	No	31	1700
	5	NS1-M5	27	C/S	Primi	Baccalaureate	No	32	1300/1700
	6	NS1-M6	30	C/S	Multi	Baccalaureate	No	33	1800
	7	NS1-M7	28	C/S	Multi	PhD	Yes	32	1600
Research site 2	8	NS2-M1	22	N.V.D	Primi	Baccalaureate	No	35	2200
	9	NS2-M2	33	C/S	Primi	Primary school	No	34	2100
	10	NS2-M3	41	C/S	Multi	Primary school	Yes	34	1700
	11	NS2-M4	27	C/S	Primi	Baccalaureate	Yes	36	2500
	12	NS2-M5	26	N.V.D	Primi	Secondary school	No	36	1800
	13	NS2-M6	35	C/S	Multi	Secondary school	No	33	1700/1800
	14	NS2-M7	29	C/S	Primi	Baccalaureate	No	34	1600
	15	NS2-M8	25	N.V.D	Primi	Secondary school	No	32	1000
	16	NS2-M9	35	C/S	Primi	Primary school	No	35	1100
	17	NS2-M10	36	C/S	Primi	Collage	No	34	2000

GA: Gestational age

Multi: Multiparous.

Primi: Primiparous

C/S: Caesarian section.

N.V.D: Normal vaginal delivery

Nurses and Doctors

The total number of the health care staff at the site 1 was 35, and 38 staff members at site 2. I managed to observe 86% of site 1 staff (n=30) and 84% of site 2 staff (n=32). The participants who agreed to be interviewed in both hospital units consisted of 15 staff members, all were Jordanian, various ages, educational level, work experience and genders (Table 11). At site 1, staff members' age ranged from 23 to 40, with an average of 30.4 years and from 5 months to 15 (mean=6.5) years of experience. Four nurses were female, one was male, and there were two male neonatologists. At site 2, the age ranged was from 27 to 51 with an average of 39.6 years and from 2 – 19 (mean of 12.25) years of experience. All nurses were females (n=5), with three male neonatologists.

Table 11: Characteristics of participating health care team

	No.	Code	Age yrs.	Gender	Job	Education	Marital status	Previous BF experience	Work experience
Research site 1	1	NS1-N1	23	F	RN	Baccalaureate	S	N	5 months.
	2	NS1-N2	26	F	RN	Baccalaureate	M	Y	4 yrs
	3	NS1-N3	28	F	RN	Baccalaureate	S	N	2 yrs
	4	NS1-N4	26	M	RN	Baccalaureate	M	NA	2 yrs
	5	NS1-N5	31	F	RN	Baccalaureate	M	Y	9 yrs
	6	NS1-D1	40	M	Doctor	Neonatology fellowship	M	NA	15 yrs
	7	NS1-D2	39	M	Doctor	Neonatology fellowship	M	NA	13yrs
Research site 2	8	NS2-N1	40	F	RN	Baccalaureate	M	Y	18 yrs
	9	NS2-N2	37	F	RN	Baccalaureate	M	Y	14yrs
	10	NS2-N3	38	F	Practical nurse	Diploma	M	Y	15 yrs
	11	NS2-N4	27	F	RN	Baccalaureate	M	N	2yrs
	12	NS2-N5	31	F	RN	Master	S	N	5 yrs
	13	NS2-D1	46	M	Doctor	Neonatology residency	M	NA	19 yrs
	14	NS2-D2	47	M	Doctor	Neonatology residency	M	NA	10 yrs
	15	NS2-D3	51	M	Doctor	Neonatology residency	M	NA	15 yrs

RN: Registered nurse

Y: Yes. N: NO. NA: Not applicable

M: Married

S: Single

OBSERVATIONS OF THE UNITS

The following section, which comprises a description of the breastfeeding practices and working conditions within the two units, is drawn from data collected by my observations. The subsequent two sections relating to the mothers' and the staff's perspectives are derived from interview data supported by my observational data where appropriate.

As discussed earlier in the method chapter, during my fieldwork I assumed an observer-as-participant role, in which the balance was in favour of observation over participation. This gave me the freedom to observe and reflect on what was observed, thus minimising the risk of '*going native*' (Seale, 2004). I entered the unit as a guest and initially conducted a brief presentation about my study aims and objectives to the staff members in each unit. This presentation and the subsequent discussion eased the tension of the first day of fieldwork.

At the time of commencing this study, the two research settings provided care for both preterm and full term infants with any medical complications. Within the two units, infants were fed according to a schedule feeding, usually every 2-3 hours, and by bottle. Two types of formula were given: Similac Advance a pre-prepared infant formula and Similac Neosure formula for preterm and low birth weight infants. The field notes read:

Babies are fed preterm infant formula milk. The plan is to be fed every two hours, but the nurse explained to me that as a result of the work load and time constraints, they only feed them every three hours. She added "*actually it is impossible for the baby to feed every two hours; he could not tolerate to have a meal every two hours. The shift is only 8 hours and we can't feed them this often especially when we have critical cases*"

Fieldnotes, research site 2. Monday, 21/2, 2011

At the time of the study, only site 2 had WHO/UNICEF Baby Friendly Initiative accreditation. It supported exclusive breastfeeding in its postpartum unit and forbade the use of bottles and formula within these units. In site 1, however, bottles were allowed on the postnatal wards if requested by the mothers.

In the case of normal delivery, both hospitals taught mothers about breastfeeding and provided support after delivery. In the postpartum units in both hospitals, I observed many wall posters that discussed the benefits and other issues regarding breastfeeding. However, within the neonatal units, it was different. There were no posters, no handouts explaining the benefits of breastfeeding and no pumping facilities, the use of formula and bottles was considered totally acceptable, indeed was the norm. Within the two neonatal units, ready-to-use infants' formulas were often provided free of charge by various drug companies.

It has been suggested that, for preterm infants the initiation and protection of mothers' milk supply should start in the hospital (Walker, 2008). In order to achieve that, mothers require a high quality breast pump and need to express milk after each breastfeeding attempt or every 8 – 10 hours per day until breastfeeding at the breast is established (Walker, 2008). My observational data revealed that these recommendations were not followed in either research setting. Although both settings, particularly site 1, involved high technology environments, they both lacked breastfeeding facilities including the essential breast pumps.

Throughout the entire fieldwork, I witnessed only 2 pumping activities in site 1 and none in site 2. Both mothers used an old style manual pumping machine brought by the mothers themselves, and they used privacy screens around them to carry out the pumping; in both cases, the mothers were left on their own without any assistance.

Effective breastfeeding is a major goal for any preterm infant, however, no strategies were observed in either of the two setting in support of this. Besides lacking pumping and storing facilities, there was no private space for breastfeeding, no convenient place around the infant incubator for the mother to stay, and skin-to-skin contact was never encouraged between mothers and their infants. Along with, the high noise levels, especially in site 2, these factors were all potential barriers to promoting and facilitating breastfeeding and a family centred approach. The small breastfeeding room in site 2 was not adequate in any terms, and because it was small and with no windows it was used by the ophthalmologist when retinal examination for preterm infants was required. In such situations, the mothers who came to breastfeed their infants

had to wait for hours for the ophthalmologist to finish his work. In one of these incidences, my field notes read as follows:

It is 12:05 noon now. The mother 'M' was allowed finally to enter the unit to breastfeed her baby inside the main room rather than the breastfeeding room, because the breastfeeding room is still occupied by the ophthalmologist since morning. The mother's baby has been transitioned recently to breastfeeding and he is waiting for the 11 am feed. The mother grasped a chair and searched for a place to sit with some privacy. The nurse handed the baby to the anxious mother. She is a primipara and this is her second time breastfeeding, adding to that the baby was extremely hungry and screaming loudly. She took the irritable baby and tried to make herself comfortable in the plastic chair. However, the chair was high for her, as her legs could not set comfortably on the floor. She uncovered part of her clothes, looked around to see if there is anyone [men] seeing her, and tried hard to get the baby to latch on. She spent much time trying but failed to do that herself while the baby continue crying. She did not ask for any help from the nurses as they were busy with the other babies and with the ophthalmologist. I approached her and offered some help until she was able to get the baby to breastfeed.

Field notes, research site 2, Tuesday, 22/2/2011

And in another occasion:

Since the early morning until now (11:30am) the breastfeeding room is still occupied by the ophthalmologist and his assistants to examine the children. 3 mothers are waiting outside for the 11 am feed. Because of the delay, the nurse agreed to let the mothers do the breastfeeding inside the main room. Each one of them took a chair and placed it against the wall with their backs to the windows and started breastfeeding. Two of them needed help as they were primiparas with preterm infants, while the third is multipara for a full term infant and thus had no problem breastfeeding. Again, I was the only available person to give some help.

Field notes, research site 2, Tuesday, 1/3/2011

Mothers' presence in the NICUs varied during the day. Those staying in the postnatal ward usually visited their infants more often, and may visit during the night shift. Those coming from their home generally visited once a day,

although some only visited once every few days, depending on factors such as distance to hospital, travel costs, other family responsibilities, and their husband's work. The visiting parent, mainly the mother, usually sat beside the infant's incubator on a regular chair (leather or plastic in site 1 and plastic on site 2) if available, which was uncomfortable for breastfeeding purposes. During the visit, mothers were not allowed to take their infants out of the incubator without permission.

As noted:

The nurse told me that there are no specific visit hours for the parents as they can visit at any time. Yet she explained how the crowded unit does not accommodate the presence of many mothers at a time. They restrict the visit to only the parents. Other family members are not allowed to visit.

(Fieldnotes, research site 2. Mon.21.4)

In site 2, visiting was limited to parents only; this contrasted with site 1 where parents and sometimes grandparents were allowed to visit. In both units, visits are only permitted during the day and all visitors to both units are encouraged, via posters that hang over each sink, to wash their hands or use medical gel prior to their entry; however, hand washing was not strictly monitored.

Although there was recognition of the need to involve mothers and to communicate effectively with them by the staff members, the actual involvement of the mothers in their infant's care was minimum in site 1 and nonexistent in site 2.

Minimal interactions were observed between the nurses and the parents. These interactions were usually initiated by the parents and were limited to asking a clarification question, commonly about the infant's condition and feeding. The interaction generally ended once the question had been answered. No active breastfeeding assistance was seen during the entire fieldwork period. The presence of fathers in the unit was rare and when observed they were seldom engaged in any activities. They usually took the lead for asking questions about their infant's health status especially when the

doctor was around. However, answering their questions was not always welcomed by many of the staff members as the following field note highlights:

During the medical round, a doctor resident joined us coming from outside the unit. He made a comment about a father who was standing outside the unit's main entrance and asking the same questions about his infant's condition to every doctor leave the unit. The neonatologist who was leading this round agreed on his comment and added that the father's behaviour is annoying and that he used to avoid this particular father when leaving the unit.

My personal reflection to this event was: I wondered to myself, "Did they think about spending some time with the parents to discuss their infant's conditions with them, answering their questions about their infant's health status? This would certainly decrease the stress and anxiety of the parents and calm them down.

Fieldnotes. Research site 2. Tuesday, 8/3/2011

The two units lacked facilities to accommodate the whole family or even the mothers. Waiting areas were provided outside the units, but longer stays were not possible under the current situations. Only a few chairs were provided in the units for the use of mothers while breastfeeding. As site 1 was a large unit, it could be rearranged to accommodate a seating area for the family. However, in site 2 this was not possible due to the small physical size of the unit and demands on the limited space.

My observations highlighted an institutional influence on the nurses' work and on the interaction between nurses and mothers. Priority was given to the 'task', which the nurses were expected to accomplish. Supporting breastfeeding was not amongst their priorities.

With limited resources, heavy workload and time constraints, nurses attempted to focus on carrying out medical orders for the infants allocated to them. A sense of urgency was exhibited, as nurses wanted to complete their 'tasks' in order to deal with the unpredictability of the infants' conditions. All activities appeared programmed and routine and, when interviewed, none of the nurses referred to any task that concerned the mothers, such as assisting in

breastfeeding or pumping; however, they did offer mothers a verbal explanation if requested.

Nurses had to complete many nursing and official documentations during the shift which added to their busy schedule. This created an almost frenetic environment in which mothers were pushed to the periphery of their infant's care.

During the shift reports and medical rounds that I witnessed, the staff focused on technical details such as monitors and ventilators readings, medical procedures required or undertaken, vital signs, and medications. Breastfeeding related issues were not often communicated in detail; it was only when an infant was transitioned to the breast when this was reported.

The round included 3 resident doctors, a nurse and myself. There are 21 infants in the unit today. During the round, they discussed many issues such as daily fluid recommendations for preterm infants including feeding and fluids calculations. However, they did not mention the breastfeeding or breast milk in any of these 21 cases.

Fieldnotes, Research site 2, Monday, 21/2/2011

Nevertheless, these issues were occasionally communicated in site 1, but staff failed to communicate the presence of expressed milk in the unit's refrigerator.

There are 3 bottles of expressed breast milk in the unit's refrigerator which are labelled by the mother's name, date and time, and the patient file number. However, when the nurses gave the last feed for the babies, they did not use those in the refrigerator; instead they gave these 3 infants formula milk.

Fieldnotes. Research site 1, Thursday, 26/5/2011

On other occasions, nurses ignored the presence of expressed breast milk as the following field note indicates:

I was sitting at the corner of the nursing station observing when a mother entered the unit. She was wearing a sleeping gown and she walked in with slow steps as she had C/S 2 days ago. She was holding a manual breast pump in her hand that contains a very tiny amount of expressed milk. A nurse was sitting at the station desk. She asked her if she could see her baby and if she could leave the milk for the baby. The nurse approved her request and said, "Go see *the baby first and then we will see about the milk*". While the mother was walking in, the nurse added with sarcasm in her tone "*take care of the milk*". The mother spent some time with her baby. She stood up all the time in front of the incubator only watching her infant. She looked tired and decided to leave. When she left the main room passing through the nurses' station, she looked around for someone to ask about her infant's condition and to leave the milk. No one was there except me. She asked me if I knew where the others were, but I had no answer. She left without leaving the milk or having her questions answered.

Fieldnotes. Research site 2. Monday, 28/2

My observation revealed that most of the space within the two units was taken up with the high technology equipment, which created a barrier to implement a family-centred care approach. Family involvement was severely restricted in both units and was only limited to the mothers. In the current situation, both units limited the mothers' abilities to care for their infants and to practice breastfeeding, and staff focused more on the technical and medical aspects of the infants' care. However, a greater involvement of the mothers on their infant's care plan would probably enhance the mother-infant attachment process, promote breastfeeding, improve mothers' emotional status (Kearvell and Grant, 2010) and result in less workload for the staff.

Whilst In the preceding section I have reported findings that emerged from my observational data collection, it is important to consider these in conjunction with the perspectives of those involved to gain an in-depth understanding of the situation. In the next two sections I offer both the findings and a discussion of the mothers' and the nurses' viewpoints respectively. Each section starts with a summary table. Table 12 summarises the finding themes and subthemes of the mothers' account, and table 13 summarizes themes and subthemes of the staff accounts.

THE MOTHERS' STORY

I didn't expect what happened to me, everything was normal, my pregnancy was normal, but when I came to give birth everything has changed, everything became painful....I suffered in the emergency room, and then suffered in the delivery room and then in the operating room....I don't recall what happened, but I remember seeing the anesthesiologist face, I remember his face very well, he was the last thing I saw...in that moment I felt that I will die....I made Shahada¹ repeatedly

(NS2-M4)

The quotation above, from one of the mothers who took part in this study, illustrates the focus of this chapter. This mother described her experience with the unexpected change in her pregnancy path. For most women pregnancy is a time of great expectations, happiness and excitement with the arrival of the new baby. However, not all women experience the glow of the uncomplicated pregnancy. For many, giving birth is just the beginning of another emotional period that of having a premature baby in the NICU. All of the participants of this study shared the experience of feeling of sorrow and pain for having a preterm infant in the NICU.

The mothers' stories begin with an unexpected change in the normal flow of their pregnancy and ends with the birth of a preterm baby in the NICU. Suddenly, they realized that mothering and breastfeeding would be relatively different experiences from what they had expected. Breastfeeding became a complex process for some and impossible for others. Five distinct themes emerged from the mothers narratives and my observations (Table 12): the crisis, the control struggle, the separation, acceptance and adaptation and becoming a mother. Almost all the mothers in this study spoke about going through all these stages during their infants' stay in the NICUs, however, each mother experienced each stage differently according to her previous experience and the amount of support that she had.

¹Shahada – (also Tashahud) is the declaration of the testimony of faith for Muslims. It is the proclamation of Allah's oneness (i.e., I bear witness that there is no true god but Allah and I bear witness that Muhammad (PBUH) is His servant and Messenger). This confession is the first thing a Muslim hears at birth and highly recommended to be the last thing a Muslim says before he dies.

Table 12: Themes and subthemes generated from the mothers' accounts

Themes	Subthemes
The Crisis	• Emotional instability
	• Strategy of not visiting the baby
	• NICU as a stressful environment
The control power	• Lacking control and seeking permission
	• Language as control
	• Giving mothers subordinate roles
The separation	• Difficult to accept
	• Feeling like stranger and not being important
	• Need for physical closeness
Acceptance and adaptation	• Gradual acceptance
	• Spiritual aspects
Becoming a mother	• The special moments
	• Breastfeeding as a turning point
	• Practical and informational needs

The Crisis

The mothers participating in this study considered the birth of a preterm infant a crisis that caused great stress. Most of the mothers were not prepared for a preterm birth, thus the neonatal admission was stressful. During this vulnerable time, mothers experienced feelings of powerlessness, lack of control, not belonging, disorientation and neglect. Many elements were identified that represent being in a crisis including emotional instability, choosing not to visit the baby, infant's shocking appearance, feeling guilty and finding the NICU a stressful environment.

Emotional instability

The birth of a preterm infant has been described by the mothers in this study as a crisis that caused huge emotional upheaval at a time when they themselves were recovering from the birth process. This issue has also been identified by other researchers (Affleck, Tennen and Rowe, 1991; Hynan, 1991; Singer, et al., 1999; Caplan, 2000; Hurst, 2007; Baum, et al., 2012). All of the mothers (n=17) in this study reported being stressed and responding negatively to the birth of their baby as a result of the sudden change in their pregnancy and their infants' admission to a critical care unit. Mothers described having a wide range of negative feelings, such as sadness, fear, anxiety, guilt, anger and oppression.

Mothers described their experiences of having a preterm infant in the NICU as full of strains. A lot of stress was reported as being related to the infant's health status and survival, the environment of NICU, the staff attitudes, their abilities to perform maternal activities and to their identity as mothers. Feelings of sorrow and fear dominated the mothers' narratives. These feelings are understandable and may give emphasis to the feeling of helplessness.

At that night I felt like I was caught in a fire, it was heartbreaking. I decided to go and see them...I went there, I wish if you could saw them... [Crying]....they were both in the same incubator, my other baby [first baby who passed away] was very tired, they connected him to a device, he was not moving at all.

بس بالليل حسيت نار ودارت روحي طلعت قلت بدني ارواح اشوفهم. عمليه عمليه مش راح اموت اللي الله بده ينجيه. ساعدتني اختي...رحمت، جيت. (تبكي) لو انك شفتي. كانوا حاطينهم في نفس الحاضنه بس هذاك كان تعبان تعبان. كانوا حاطينله الجهاز ولا يتحرك ولا اشي.
(NS2-M6)

Mothers talked about feeling angry and oppressed when their babies' condition deteriorated and because they were not allowed to hold or breastfeed their infants:

I asked them if I could carry her or breastfeed her, but they told me that this is not allowed at this stage. I wanted deeply to breastfeed her, but I had to be patient. I used to come with my breasts full of milk. When I came once, I found that she was tired and they connected her to oxygen and they stopped oral feeds for her. I felt helpless and oppressed. The doctor was standing at her incubator side when I began crying hardly.

كنت اطلب منهم ان اقوم بحملها او ارضاعها ولكنهم اخبروني بان هذا ممنوع وان علي الصبر حتى يبدوا هم بارضاعها من الزجاجه والتأكد من قدرتها على الرضاعه...صبرت بالرغم من اني كنت ارجب بارضاعها بشده وكنت اتي وصدري متحجر ممثلي بالحليب. وعندما عدت مرة اخرى، وجدت انها قد تعبت ووضعوها على الاوكسجين ووقفوا عنها الرضاعه. شعرت بالقهر الشديد...كان الطبيب يقف عندها يعالجها...وبدأت بالبكاء.

Fear about the preterm infant's survival was another stressful situation for the mothers. The mothers reported being terrified of losing their babies. This finding confirms earlier work by Affleck, Tennen and Rowe (1991) and Affonso et al. (1992).

I was terrified of losing the baby. I did not worry about myself at all, but about my baby.

كنت اشعر بخوف كبير جدا جدا على الجنين. لم اخف على نفسي مطلقا ولكن على ابني.

(NS1-M1)

I wasn't thinking of my life and my condition, my attention was directed toward his condition and his life.

ما كنت مهتمة بحياتي انا ووضعني مثل ما اهتميت بوضعه هو. اول ما انجبت سألت عنه

(NS1-M2)

Similar to other mothers in previous studies, guilty feelings were reported and were identified as a way that parents used to adapt to this crisis (Affleck, Tennen and Rowe, 1991; Wigert, et al., 2006; Baum, et al., 2012). In the following quotes, for example, mothers felt guilty and blamed themselves for the preterm birth and for not being able to help:

When I came for the first time, I looked at him but I didn't cry. I don't know what my feeling was at that time? I can't describe those feelings. I stood up in front of his incubator and spoke to him. I told him: I don't know what to do for you, and I don't know if I was the cause of what is happening to you!

عندما اتيت لأول مرة الى هنا رأيته ولم ابكي لا اعرف ما هي المشاعر التي تولدت.... لا استطيع ان اصفها...وقفت عنده وتحدثت اليه وقلت له لا اعلم ان كنت انا السبب فيما يحدث معك ام لا؟

(NS1-M1)

I feel that I lost something because I didn't breastfeed him. I don't know whose responsibility is it? May be it is my responsibility because I gave birth prematurely.

اشعر اني خسرت لانني لم ارضعه...لا ادري على من تقع المسؤولية، يمكن علي انا لانني ولدت ولاده مبكرا.

(NS1-M4)

Some mothers started questioning what happened to them, and whose fault was that?

I was thinking: Oh God is it possible that I was not having any medical condition in the first place? Is it possible that my pregnancy was normal and that the doctors did all this to me only for learning purposes? Many thoughts like these came to me.

ولكني كنت اقول: يا الله ايعقل انني لم اكن اعاني من شيء ؟ ايعقل ان حملي كان طبيعيا وبان
الاطباء فعلوا بي هذا من اجل التعلم فقط؟ كانت تدور في ذهني افكار عديدة وغريبة.
(NS2-M6)

Strategy of not visiting the baby

Some mothers used a strategy of not visiting their infants during their initial admission to the NICU in an attempt to lessen the loss if their baby died.

At the beginning I refused to see him. When I was in the delivery room I told them [nurses] that I do not want to see him, I was worried about losing him, may God forbid. I did not want to get attached to him that's why I refused to see him.

في البدايه رفضت ان اراه. عندما كنت في غرفة الولادة كنت اقول لهم اني لا اريد رؤيته فقد
كنت متخوفه من فقدانه لا سمح الله ولم ارد ان اتعلق به لذلك رفضت ان اراه.
(NS1-M1)

Wigert et al. (2006) described a similar situation in which mothers' anxieties about their infants' health status complicated the attachment process, where interaction became subordinate to the infant's health. These mothers had to turn off their emotions in order to handle the possible loss of their infants.

Some mothers talked about being shocked by their infant's appearance and small size, an emotion also identified by other researchers (Baum, et al., 2012).

When I saw them for the first time, I was shocked because of their small sizes. Frankly, there were no feelings toward them because of my extreme fears of their little sizes. I didn't feel that they belong to me....may be because I was scared.

عندما رايتهم لأول مرة صدمت بصغر حجمهم شعرت انهم.. بصراحة لم يكن هناك
مشاعر تجاههم بسبب شدة خوفي من حجمهم الصغير. لم اشعر انهم يخصوصوني...لم
اشعر انهم لي من شدة خوفي.
(NS1-M5)

NICU as a stressful environment

Mothers reported that the NICU environment generated a stressful reaction because they felt scared of the surrounding environment. It was described by parents in another study as like being in an alien world (Hall, 2005a). The initial visit to the NICU and the sight of the medical equipment and machines was shocking for many of them (n=11). The fear of the high-tech neonatal environment added much to the mothers' negative feelings of having a preterm infant. Similar responses have been reported by other researchers (Affonso, et al., 1992; Padden and Glenn, 1997), and it has been suggested that the

distressing sight of seeing their infants wired up to machines may affect the mothers' psychological adjustment and interaction (Affonso, et al., 1992).

I was terrified he was connected to many devices, which scared me. The monitors' alarms scared me too. The alarm sounds became part of my dreams at night. I could hear them while sleeping.

كنت خائفه كثير. الاجهزه اللي محطوطه عليه خوفتني كثير والاصوات. صارت في منامي
اصوات التنبيه، صرت اسمعها وانا نايمة.
(NS1-M2)

It scared me when I saw him for the first time. I was worried of his lungs not being mature enough because he was very tiny, and I felt that he is in serious condition because they brought him to this unit with all this machines attached to his body, the whole unit felt scary with these alarming sounds, his body was tiny and scaly. All these things scared me a lot.

خفت لما شفته اول مره لانه صغير وخفت انه تكون رئته مش مكتمله وحسيت انه وضعه
خطير لانه في الخداج والاجهزه عليه حسيت انه وضع القسم كله بخوف واصوات التنبيه مخيفه
وجسمه كان صغير ومتقشر، هاي الامور كلها اشعرتني بالخوف.
(NS1-M4)

For the preterm infants' mothers, motherhood starts in an unfamiliar and frightening environment, where it is difficult to initiate physical contact between mother and child. The public nature of neonatal units inhibits interactions and bonding processes where the mothers became mothers, physically but not socially or emotionally (Flacking, et al., 2006).

The study findings also showed that mothers of preterm infants experienced overwhelming and different levels of anxiety, stress, sadness, fear, guilt, anger and oppression within the NICUs. Many previous studies confirm that mothers of premature infants have a higher degree of stress compared to mothers of full term infants (Brooten, et al., 1988; Miles, Funk and Kasper, 1992; Younger, Kendell and Pickler, 1997; Holditch-Davis and Miles, 2000; Eisengart, et al., 2003). Singer et al. (1999) found that mothers of low birth weight infants experienced a significantly higher incidence of psychological distress during their babies stay in the neonatal intensive care unit. Their study indicated that the birth of a low-birth-weight infant is a crisis that places a greater strain on the mother's parenting role, thus affecting the attachment process between mothers and their babies. According to Wigert et al. (2006) this crisis comprises three components: the mother's feeling of guilt and shame because she was unable to give birth to a healthy baby, feelings of sadness over the lost dream of having a healthy, full-term baby and the daily worry, hope and satisfaction about her baby's wellbeing.

Mothers of premature infants may experience resentment, frustration and anger during infant hospitalization in the NICU (Lupton and Fenwick, 2001). These findings confirm the current study's findings.

The Control Power

The second main category is the control power in which control relationships existed between staff members and mothers. Many forms of power relationships were observed including lacking control and needing to seek permission from the nurses, using a foreign language and giving mothers a subordinate role.

Lacking control and seeking permission

The results identified a controlling power that placed mothers in a subordinate position to the nurses. In many situations during the study period, there have been incidents, which I observed, that demonstrated the control issue by the nurses. The following is an example from my field notes:

One mother came to ask about her baby. She greeted the nurses, who were sitting at the nursing station and busy with paperwork, but she received no answer. She asked for permission to see her baby, but was told that she could only look at him through the window.

(Fieldnotes, research site 2. Mon.18.4)

The mothers' narratives and actions demonstrated a lack of control as they talked about situations where nurses controlled their interactions with their infants. For example, some mothers described how they had to seek permission to visit and interact with their infants. On other occasions, they gave examples of being very stressed while waiting for the "appropriate time" to get access to the NICU:

This is my fourth Caesarean section, yet never been as tired and exhausted as this time. This time I was so tired I could not leave the bed for two days. When I got out of bed I immediately came to visit him, but she [the nurse] refused to let me in, because, according to her, it wasn't appropriate time for the visit because there was a medical round.

هذه العملية القيصرية الرابعة ولم يحدث لي هذا التعب في عملياتي السابقة. هذه المرة كنت متعبه جدا ولم استطع القيام لمدة يومين. وعندما اتيت لزيارته للمرة الاولى لم تدخلني للوحدة وقالت لي هناك مرور اطباء في الداخل.

(NS2-M3)

Mothers told stories of how they had to seek permission to stay with their infants outside the feeding time. The mothers needed permission from the nurses to visit their infants or to stay with them; this was reported to be a common obstacle in fostering the mother-infant attachment process (Hurst, 2007).

They welcome us only at the feeding times; you are not allowed to enter otherwise. They told me to come at 11 am to feed my baby, but when I came at that time, they did not allow me to enter. They told me that they were giving the medications.

يرحبون فينا عند الحضور. ولكن هذا فقط على موعد الرضعة ولا يجوز الدخول بغير ذلك. اخبروني ان اتي على الساعه 11 صباحا للزياره وللرضعة وعندما حضرت لم تسمح لي بالدخول. قالوا لي انهم يوزعون العلاج.

(NS2-M8)

Similar to Lupton and Fenwick (2001) study, the nurses in this study were acting as gatekeepers rather than carers, as illustrated by the following narrative:

On my first visit, which was after sunset, she [nurse] said: okay you can come in. My second time was at 10 pm, she was not there at that time, so I passed through, but she saw me while leaving, so she said: you just came shortly before, you can't come and go often, when I returned back at 6 am the next morning, she said: isn't you who came last night? Being in-patient does not mean that you can come whenever you want.

اول مره رحنت فيها قالت لي عادي فوتي، ثاني مره ما شافتنني لما فتت، كانت الزياره الاولى بعد المغرب والثانيه الساعه 10 مساء وكانت مش موجوده لما دخلت، وبس طلعت شافتنني وحكتلي ما انتي قبل شوي اجيتي خلص لا تظلي رايحه جايه فما رجعت لليوم الصبح من الساعه 6 الصبح رحنت فحكتلي مش انتي اللي اجيتي مبارح؟ وحكت : مش معناته انك دخول في القسم انك تظلي رايحه جايه.

(NS2-M10)

On a few occasions that I witnessed, mothers were left feeling upset and oppressed by the nurses' action of control. The following illustration from my fieldnotes describes a situation in which the nurse was inconsiderate to the mother's feelings and her presence and was acting as the owner of the infant and the place:

A mother came to breastfeed her baby at the 11 am feed to find that the nurse had just bottle-fed him. She appeared frustrated. I learnt afterwards that she had come early that morning for the 8:30 meal to find that he just been fed. She chose to wait outside for the 11am feed. The nurse forgot that the baby's mother had arranged with her to come and feed her baby, and then she forgot again about the mother's presence at the 11 am feed. The mother, with tremendous patience, expressed her willingness to wait again for the next feed 3 hours later. I felt sorry for her and told her that she could ask to wait inside the unit at her baby's bedside instead of waiting outside. She was pleased to know that this was possible. When she asked, the nurse did not approve her request, but told her that she would give her the baby so she could spend some time with him in the breastfeeding room

(Fieldnotes, Research site 2. Sun.27.2)

Studies were identified elsewhere that detect a power struggle between nurses and mothers over the infant's care (Lupton and Fenwick, 2001; Kenner and McGrath, 2004). The nurses' constant presence in the NICU may create a belief that they own the unit, which results in them excessively controlling the access mothers have to the unit.

Language as control

One mother described how she experienced a lack of control and increased anxiety when the health team were discussing her daughter's condition in English and she could not understand what they were saying. She wanted to know what is going on:

They were [staff] using English language in their discussions and I did not understand what they were saying. Even though I have a university degree in English language but I did not understand what they were saying, because they were using medical terms that I did not understand. They were debating about the existence of something and how to solve the problem. They said that her hand, I do not know what, and that her breathing, I do not know what, and because I did not understand, my fears have multiplied.

كانوا يتحدثون الانجليزية ولم أكن أفهم ما يقولون بالرغم من أن تخصصي الجامعي هو اللغة الانجليزية إلا اني لم أكن افهم ما يقولون فقد كان كلامهم كله مصطلحات طبية لا أفهمها. كانوا يتناقشون عن وجود شيء ما وكيفية حل المشكلة. وقالوا أن يده، لا أعلم ما بها، وأن تنفسها. لا أعلم ماذا، ولأنني لم أفهم، فقد زاد خوفي كثيرا.

(NS2-M4)

The use of jargon and medical terminology during the medical rounds was another feature that made parents feel out of control over their infants' situation. In such cases, mothers commonly felt uncertain and unaware of their infants'

situation because again they could not understand the medical team's discussion. In the previous quote for example, the mother thought that the staff were hiding something about her infant's health status, which intensified her feelings of anxiety. In a quantitative survey of 209 mothers of preterm infants, Bialoskurski, Cox, and Wiggins, (2002) reported that the need for accurate information about their infants' condition was a priority for 93% of the mothers surveyed. In addition the mothers remembered and understood information about the condition of their children if it was given in non-medical terms.

Giving mothers subordinate roles

Mothers were given subordinate roles to the nurses, who became the primary caregiver for all the infants, even those who did not require intensive care. Most mothers of this study preferred staying at their infants' side and wanted to do some mothering activities:

Oh God, if it is in my hand or is my choice, I would prefer to stay here to his side, day and night sitting in this uncomfortable chair, just observing and watching him. I swear to God, every night I begin having feeling of pressure over my chest, as if I am dying. I don't sleep, neither at night nor during the day. Everyone sleep at night except me. I keep praying for his recovery. I am dreaming that I will be able to cuddle him between my hands and leave this unit to my home. I am dreaming that I will be able to change his diapers and his clothes and put him on my breasts and feed him.

والله لو يهملني انا ما بوفر والله والله لو يقولولي نامي هون وعالكوسي واطل طول الليل قباله ما بوفر. لانه والله بس يجي الليل عزرائيل بتقول مسك روعي ما بنامش لا الليل ولا النهار بالليل كلهم بناموا وانا بظل صاحيه انا وربى بدعيه يا من درى والله يشفت لو آخر يوم لو اخر نقطه بدمي بشفت.....نفسى احملة بين ايدي واطلع من المستشفى واغيرله وارضعه.

(NS2-M6)

According to Wigert et al. (2006), interacting with their babies is important for the preterm infant's mothers. They may experience low self-esteem and a sense of not belonging when their child is totally cared for by the health care professionals; however, in cases where sufficient interaction and information was provided a mothers' confidence was maintained (Wigert et al., 2006).

The Separation

The third main category derived from the analysis reduction process was separation. During this phase, mothers reported many negative emotions that arose because of separation from their infants. The following elements were

identified in this category: difficult to accept, feeling like stranger and not being important and physical distance.

Difficult to accept

Most of my participants expressed difficulty in accepting their new situation of having a preterm infant admitted to the NICU and described how difficult it was to be discharged from the hospital without having their babies with them:

After I gave birth, I had to leave the hospital without her [the baby]. This increased my sense of anger and I was asking myself: with all this waiting and suffering, why have I need to leave without her? That increased my pain and suffering, I felt emotionally tired, especially when they told me that her breathing got worse and that she needed oxygen. I was thinking then: all this pain and patience to have a normal child and then this happened to her?

وعندما انجبت وخرجت من المستشفى وحدي دون ابنتي زاد هذا من قهري وقلت : كل هذا الانتظار والتعب ولم تخرج البنت معي؟ ، وزاد المي مجددا وتعبت نفسي أكثر وأكثر عندما قالوا لي ان تنفّسها تعب وانها على الاوكسجين....وقلت في نفسي: كل هذا التعب والصبر حتى تأتي الطفلة سليمة ثم يحدث لها هذا.

(NS2-M5)

When I left the hospital I was crying because he wasn't with me. How bad is it for a mother to leave her baby in a hospital? Every time I hear a baby cry, I start crying.

وعندما غادرت المستشفى، غادرت وأنا ابكي لانه ليس معي. فكم هو سيء ان تترك الأم ابنها في المستشفى. وكنت كلما سمعت صوت طفل يبكي، ابكي كثيرا.

(NS2-M9)

Hutchinson, Spillet and Cronin (2012) also identified that mothers were faced with the difficult feelings of not being a parent when discharged from hospital without their infant.

Feeling like a stranger and not being important

During their infant's hospital stay, mothers reported that they felt like strangers when they were separated from their infants. Similar emotions of not being mothers have been identified elsewhere (Wigert, et al., 2006). Many of the participating mothers described their initial feelings when seeing their preterm infants as not belonging and not feeling like a mother:

I didn't feel that they belong to me. You know, I feel that it is just a dream; I didn't feel that I had given birth to my twins, and I didn't feel like a mother.

لم أشعر بأنهم لي، لم أشعر أنهم لي من شدة الخوف. ولأنني لم أنجب بولادة طبيعيه، لم يحضروهم لي وأخذوهم لقسم آخر. وأنا لا استطيع التنقل بحرية بسبب العملية وبسبب الألم عند الحركة. عرفتني..أشعر بأنه حلم، لا اشعر بانني انجبت أصلا او اني اصبحت أما.

(NS1-M5)

Being unable to breastfeed or offer breast milk made some mothers feel their infants did not need them. Additionally, and depending on which part of the NICU they were in, some mothers did not have a place to stay with their infants. This separation between the mothers and their preterm infants and the inability of mothers to spend as much time as they wanted with their babies signalled an infant focused care, in which mothers were left feeling unwelcomed and unimportant. These findings confirm earlier work by Wigert et al. (2006) and Flacking, Ewald and Starrin (2007) where separation placed the mothers in subordinate roles and made them feeling like visitors.

The visiting policy accelerated the mothers' feeling of being just a visitor. Even though site 2 hospital visiting policy allowed mothers to visit any time, nurses restricted the visit for certain hours during the day, resulting in limited interaction between mothers and their infants. Site 2, on the other hand, had a more flexible visiting policy for the mothers; however, mothers in site 1 also reported feeling unwelcome and not important because of their limited participation in their infant's care:

I feel that my presence here is not important for him. What am I coming to do? The other reason is the unit here, you stay standing up all the time, there is no place to sit down in this room, and you feel like you are not welcomed. If there was a place to sit down, hold him, breastfeed him or touch him I would come every day.

وبحس انه وجودي مش مفيد اله، شو بدني اجي اعمل؟ ثاني سبب انه المكننا هون، مش عارفه، بتظلي واقفه وما فيش مجال تقعد. بتحسي انه مش مرحب فيكي. يعني لو فيه مجال اقعد، ارضعه، المسه، احمله كان ممكن اجي كل يوم.
(NS1-M4)

Breastfeeding was a motivating factor for the mothers to frequently visit and interact with their infants. In addition, it contributed for the mothers' feeling of being important:

If breastfeeding was allowed I certainly would come every day. This is number one reason.

لو كان فيه رضاعه كنت اجيت كل يوم...بس هاي اول سبب، انه ما في رضاعه
(NS1-M4)

If they told me that I can breastfeed her, I would come every day...but because they did not allow me to breastfeed her, I started coming every 2 to 3 days because I feel that my presence is not important.

لو حكولي انه ممكن الرضاعه لها كنت اتيت كل يوم ورضعتها بس لانهم منعوني صرت اجي كل يومين ثلاث لاني حسيت انه جيتي ما راح تفيد في اي اشي.
(NS2-M5)

The above extract suggests that the quality of interaction between mothers and their infants, as well as their feelings of being important, were determining factors in the frequency of their visits. Factors that motivated parents to visit their infant regularly included their willingness to take responsibility for the baby and to have some control of the situation, a welcoming attitude from the unit's staff and a family-friendly environment (Wigert, Berg and Hellström, 2010).

Mothers wanted to be involved in the infant care plan but said they were not always given the chance. They needed to be acknowledged and to be part of their infants care plan in order to make sense of their presence. It was suggested by Griffin, Wishba and Kavanaugh (1998) that failure to involve mothers in infant care provoked anxiety and created a sense of sadness and loneliness for the mothers. Flacking et al. (2006) also suggested similar findings, where separation between mothers and infants generated insecurity in the self and in their maternal role. Researchers identified a delay in maternal identity recognition for the preterm mothers when compared to term mothers; this was triggered by many events including physical contact and interaction with their infants, participating in infants care and feeling of love for the infant (Zabielski, 1994; Shin and White-Traut, 2007).

Need for physical closeness

The need for physical closeness was strongly identified in the mothers' narratives as important in order to feel like a mother. Many mothers wanted to stay with their babies:

I wish if I could have a place available at the unit to stay with him all the daylong, as you see, I am only allowed to stay with him for the breastfeeding, and when I am done, I have to wait outside.

أتمنى أن يكون لي مكان في الوحدة اجلس فيها مع ابني طوال اليوم. فكما ترين اجلس معه فقط وقت الرضاعة على كرسي غير مريح وعندما ينتهي، علي المغادرة والانتظار في الخارج.

(NS2-M9)

Feelings of sorrow and sadness dominated the mothers' narratives because of the physical distance between them and their infants. Mothers experienced enormous distress when separated from their preterm infants. Many studies have proved that keeping mothers and infants together is helpful in lowering the effects of these negative emotions (Lupton and Fenwick, 2001; Wigert, et al., 2006; Flacking, et al., 2012). Similar to other studies (Wereszczak, Miles and Holditch-Davis, 1997; Schroeder and Pridham, 2006; Lindberg and Öhring,

2008), the mothers in this study expressed a need for physical closeness and did not feel like real mothers. Similarly, in Baum et al. (2012) study, mothers reported difficulty grasping that they were mothers because of their separation between them and their infants. As a result of the separation and the limited contact between the mothers and their infants, alienating effects have been identified by some researchers (Padden and Glenn, 1997; Flacking, Ewald and Starrin, 2007).

Acceptance and Adaptation

Acceptance and adaptation is the fourth category that was derived from the data. This study has shown that mothers were greatly helped in the process of accepting and adapting to having a preterm baby if they had a role in the care of their baby and through their religious beliefs.

Gradual acceptance

As discussed earlier, the mothers of preterm infants went through an overwhelming emotional crisis during their infants' stay in the NICUs. Mothers had no control over when they visited or interacted with their babies; however, when they were able to be a 'mother' to their infants in the neonatal units they reported strong positive emotions and showed better acceptance and adaptation to their crisis. During their NICU journey, they described how their negative feelings eased over time. They described how their emotions toward their infants grew and their attachment. Their concerns started to lessen as they watched their infants' health improve:

Day by day I began seeing him improving and getting better, so I started feeling better, even when I had to leave him, I used to call the unit as soon as I arrived home, I used to call late at night or after midnight .I usually talk to them [nurses] and ask about his condition and how he is doing before I go to sleep.

يوم عن يوم بس صرت اشوفه يتحسن صرت ارتاح نفسيا يعني حتى لما اروح ...بكون في الليل هون وبس اروح لازم بين الساعه 11 و 12 او حتى الساعه 1 بعد نص الليل احكي معهم وأطمأن عليه قبل ما انام.
(NS1-M2)

The improved health of the participants' babies was not the only factor that made them felt better, touching, feeding and spending time with their babies also helped. Some mothers described the gradual adaptation by saying:

As for the third time it was different, I had positive feelings that was because I asked them [nurses] to let me touch my babies, so I had these good feelings.

اما في المرة الثالثة فكان الامر مختلف... وشعرت بمشاعر قوية جدا كان ذلك لاني طلبت منهم ان المسهم.... فتولدت عندي هذه المشاعر. اليوم ذهبت منذ الصباح لزيارتهم اجبرت نفسي على الذهاب فقد كنت متعبه جدا.
(NS1-M5)

Other mothers needed repeated visits in order to get used to the infants' appearance which would then strengthen their maternal feelings:

But I tried to repeat the visit more and more because I wanted to get use to their appearance [her twin] and in order not to be afraid of their appearance anymore. Frankly, there was no feeling toward them because of the intensity of my fear of their small sizes.

ولكنني حاولت ان اكرر الزياره لهم لاكثر من مرة يوم امس بالرغم من تعبني بسبب العمليه كي اعود عيني على حجمهم وشكلهم وحتى لا اخاف منهم. بصراحة لم يكن هناك مشاعر تجاههم بسبب شدة خوفي من حجمهم الصغير.
(NS1-M5)

Spiritual aspects

Another element that enabled the mothers to cope with the situation was their religious beliefs and spirituality. Almost all the participating mothers expressed the sense of a spiritual aspect, a force of higher power beyond their control that helped them to cope with their fears. The only Christian mother who participated in this study also expressed issues of faith similar to the Muslim mothers. This suggests that mothers of different religious persuasions turn to a higher power during their vulnerable time. However, references to their faith occurred more often in the Muslim's mothers' narratives. "God's will" or "Allah's will" is a phrase that is culturally pervasive among Muslims and was frequently used by the mothers. This phrase has a religious connotation, which means that everything occurs according to what Allah wants. It acknowledges the Muslim's submission to the Lord, indicating that whatever happens will happen because it was God's plan and that it always happens for a reason. Mothers' concerns were lessened by this belief and by believing that everything in their lives depends on "God's will" and that Allah, the most gracious and most merciful, plans their lives:

Our life is in Allah's hands. I mean "if the nation were gathered to harm you with anything, they would harm you only with something Allah had already planned for you" [she refers to part of a saying of Prophet Muhammad (PBUH)].

هاي الأمور بايد الله يعني لو اجتمعت الأمه على ان يضروك بشيء لن يضروك الا بشيء قد كتبه الله لك.
(NS1-M6)

Another mother expressed her submission to God's will while talking about losing one of her twins:

There is nothing I can do about that, I have no power or control over his death. Everything is from Allah the Lord of the World. He created him. I created neither his hands nor his legs and thus can't put back his soul. And only Allah has the cure for the other.

لا يوجد ما يستطيع عمله، فلا حول لي ولا قوة. كله من رب العالمين. لم اخلق فيه قدم ولا يد ولا يستطيع ان اعيد له الروح. الله وحده الشافي.
(NS2-M6)

They described how they were relying on the will of God and how Allah is the source of power and only He could cure their infants:

I was terrified, but at the same time, I trusted Allah. I was praying to God and asking him for his kindness. I told Him that I accept His judgment. I used to say: thanks for Allah if He chooses for him to live and keeps him for me. And if He takes him from me, then it's His judgment and He will make up for me. I can do nothing. I can't defy the will of the Lord of the World....And praise to Allah, He favoured on me and cured him for me.

كنت في خوف شديد وفي نفس الوقت متوكلة على الله وكنت ادعو الله واقول "اللهم اني لا اسالك رد القضاء ولكنني اسالك اللطف فيه" "شو ما انت كاتب انا راضيه" وكنت اقول الحمد لله ان اراد الله له الحياة وابقاءه لي ، وان اخذه مني فان عوضي على رب العالمين....شو بدني اعمل لن استطيع تحدي ارادة رب العالمين والحمد لله فضل علي وشفاه لي.
(NS1-M1)

My husband was reassuring me and saying: didn't we agree that whatever happens, it is from Allah, and that we will accept whatever Allah has for us? Everything happen according to what Allah has decreed, and we shall accept that.

زوجي كان يشجعني ويقول " الم نتفق انه مهما حدث فانه من الله واننا سنرضى بما كتبه الله لنا؟ انت هكذا تكفرين بقضاء الله وقدره.
(NS2-M2)

Reading the Quran to their infants was, for many participating mothers, a source of comfort:

I was crying and the nurses came and helped me and reassured me and they said that their health is good and they allowed me to touch them and I read Quran on them, thank God, I felt happy and comfortable.

فقد كنت ابكي عليهم وحضرت الممرضات وساعدوني وطمأنوني عليهم وقالوا ان صحتهم جيدة وسمحوا لي بلمسهم وقرأت عليهم شيء من القرآن والحمد لله شعرت بسعادة وراحة.
(NS1-M5)

Muslims believe that the Quran has healing effects. A study, monitoring the physiological changes in participants while they listened to readings from the

Quran, detected stress reducing effects on various organs of the body (Elkadi, 1985), whilst religious identity was found to influence the health beliefs and practices of British Pakistani Muslim patients (Mir and Sheikh, 2010).

As seen above, the mothers reported that physical closeness, frequent visits and breastfeeding made the adaptation process easier for them. They also described how their anxiety and fears of losing their infants made them turn to Allah asking Him for his support and mercy. They talked about Allah being the source of life and death and is therefore the only one who can cure their children.

Becoming a Mother

As discussed earlier, mothers identified many maternal needs that helped them to adapt to the emotional strains of having an infant in the NICU, including physical closeness with their babies, feeling important, needing to breastfeed, participating in infant care and practicing some religious act such as reading from the Quran.

The final category that emerged from the data analysis was “*becoming a mother*”, in which mothers described many elements that made motherhood real for them. This category involves: the special moments, breastfeeding as a turning point and practical and informational needs.

The special moments

It may be assumed that becoming a mother starts from the moment of giving birth. However, this was not supported by the study’s findings. Many of the participating mothers initially reported they did not feel like mothers and described different points, after giving birth, where they started to feel like real mothers. For the first time mothers, the phrase “*becoming a mother*” dominated when they talked about the first time that they felt like a real mother. For mothers who already had children this issue was not a concern, however, they talked about the first time when they had more control of the infant and when they felt that the baby became theirs.

Mothers remembered vividly the moments when they felt like mothers. The first visit, the first time they held their baby and the first breastfeed were significant moments for the mothers that made motherhood more real. The frequency of their visits was linked to the process of transformation into motherhood. Some mothers suggested that they initially felt detached from their infants but after a

few visits they began having different feelings and started to feel that the baby belonged to them:

When I visited him for the first time, I had a strange feeling which I can't describe, may be because I didn't touch him nor hold him. But when I visited him for the second time, it was different; I felt that he is my baby then. Today morning I had a strange but good motherhood feeling, and I can feel that when I touch him, I will feel different. My motherhood feelings toward him will get even better when I breastfeed him.

يمكن اول يوم رحى ازوره كان شعور غريب بقدرش افسره... يعني، خصوصا انى لا مسكته ولا رضعته ولا اشي، وخصوصا انى بعد يومين تا شفته، لكن لما رحى عليه ثانى يوم... لآ، اختلف الامر، حسيت انه ابني... اليوم كمان رحى عليه الصبح وكان شعور غريب وحلو وانا متأكده انه بس المسه راح يتغير كمان ولما اعطيه حليبى كمان راح يتغير.
(NS1-M4)

In addition to the first visit, mothers talked about their experience of the first touch and became very emotional when remembering or talking about it.

A mother came to visit her part twins. She was standing at the incubator's side, crying hard and asking God to heal her baby after losing one of her twins. I approached her and asked her whether she wanted to touch him. She was happy to do that, and said that nobody told her that she could. After washing her hands, I opened the incubator's windows for her and she reached his skin with her shivery hands. This was the first touch since his birth 9 days ago. She continued crying, but this time with a wide smile on her face.

(Fieldnotes, research site 2. Sun.27.2)

Mothers described the experience of holding and touching their babies for the first time as a significant moment that appeared to make motherhood more real. This perception is supported by previous research (Lindberg and Öhring, 2008) that stresses the mothers need for closeness to their infants. Touching and holding a baby is usually the first step toward breastfeeding. One mother described how holding her baby for the first time gave her warm feelings that made her want to breastfeed him even though she had no breast milk:

In my last visit, when I touched him, that was 5 days ago, they took him out of the incubator and I cuddled him. It was the first time to touch him that was 20 days after he was born. [Mother's voice began trembling as she talks] I put him in my lap, and tried to breastfeed him despite the fact that I don't have milk anymore and

he was not hungry because he had already finished his bottle feed. Even though, I felt affectionate towards him. I felt that he is mine, he became my own, especially because he is my first baby.

: آخر زياره لما مسكته. قبل 5 ايام، طلعلولي اياه من الحاضنه وحطيته في حضني ، كانت هاي المره الاولى اللي بلمسه فيها، يعني بعد حوالي 20 يوم من ولادته. [صوت الأم يرتعش وهي تتحدث] حطيته في حضني، وحاولت اني ارضعه مع انه ما في عندي حليب. بس هو كان شبعان كان توه راضع، بس حسيت هيك بحنان. وحسيت انه صار الي وبخضني، وخصوصا انه اول بيبى الي.
(NS1-M4)

Breastfeeding as a turning point

The participants identified breastfeeding as the most important turning point for their experience of becoming a mother. This was evident in their narratives:

Feeling like a mother has started with the first breastfeed, and when I kissed her it increased more and more.

شعور الامومه بلش عندي عندما بدأت ارضعها وعندما قبلتها زاد اكثر واكثر.
(NS2-M1)

Breastfeeding was a cultural norm for all of the study participants. All mothers (n=17) in this study planned to breastfeed their infants for at least the first six months. Of the 17 participants, 14 mothers expressed breast milk in order to maintain their milk supply. The other 3 did not express because they were not told this was possible. Of the 14 who expressed, 9 discarded their milk because they did not know about the possibility of storing it. Only 5 provided milk for their infants, 3 of whom were advised to do so by the staff. Of the 14 mothers who expressed milk, 7 succeeded in breastfeeding later, 9 were still waiting for their infants' conditions to improve before being allowed to breastfeed and one mother's milk dried up within the first two weeks. For all the mothers who succeeded, breastfeeding was a distinct point in becoming a mother, particularly for the first time mothers.

I continued crying until yesterday when my baby breastfed from me. The moment I started breastfeeding, I felt relieved. It was only then when I felt that I have become a real mother. What reassured me is that I knew from them earlier that when the baby starts breastfeeding it means that he is in a good condition and he will soon be ready to go home.

استمر بكائي لغاية يوم أمس عندما رضع مني. مجرد ما رضع مني، ارتحت كثيرا، وشعرت حينها فقط بانه اصبح ابني حقيقة. وما طمئنني اكثر انهم قالوا لي حين يبدا الطفل بالرضاعة من امه فهذا يعني ان وضعه تحسن وانه قارب على مغادرة القسم.
(NS2-M8)

Another mother described how her maternal feelings started and developed over time, but it was with breastfeeding when it increased and motherhood became real:

When I gave birth, my feeling of happiness has increased and I experienced the beautiful motherhood feelings. These feelings have increased and became real when I breastfed him, I felt at that time I actually become a mother [smiling]. The feeling of motherhood started earlier, but increased with breastfeeding. It starts with pregnancy, and develops with time and increases when you see your baby and breastfeed him. Breastfeeding connects a mother to her child.

وعندما انجبت زادت سعادتي وشعرت بمشاعر الامومه الجميله وزادت هذه المشاعر واصبحت حقيقه
عندما ارضعته مني ، شعرت وقتها اني فعلا أم [تبتسم]...كانت مشاعر الامومه موجوده من قبل ولكنها
زادت مع الرضاعه. فمشاعر الامومه تبدأ بمجرد الحمل وتتطور هذه المشاعر مع الوقت وتزيد عند
رؤيه الطفل وارضاعه فالرضاعه تقرب بين الام وطفلها.
(NS2-M7)

Mothers talked with joy about their first experience in breastfeeding and how it was nothing like anything they had ever felt before, it was an “*indescribable*” event according to them:

Thanks God I felt so happy, I start feeling like a mother. [smiling] because this is the first time for me to breastfeed, it was only yesterday and today when they allowed me to hold him, when I put him on my chest I felt like a mother. I felt nothing like this before.

الحمد لله انبسطت حسيت اني أم. [تضحك] عشاني اول مره برضع...مبارح واليوم بس اول
مره بمسكوني اياه. عشنه على صدري حسيت اني أم. ما كنتش اشعر باشي بالاول.
(NS2-M9)

The feeling was indescribable. It was only then when I felt that I became a mother. I felt happy, extremely happy. But at the same time I felt resentful because I will be leaving soon without him. But, thank God, what I care about now is that he started breastfeeding from me. This was a relief for me. Motherhood feeling is a very beautiful feeling, it is something hard to describe. I only want to put him into my breast and feed him.

كان شعور لا يوصف. شعرت حينها فقط بانني اصبحت اما. كنت سعيده جدا...في قمة سعادتي.
ولكن في نفس الوقت اشعر بالاستياء لانني ساتركه بعد قليل واعود للمنزل بدونيه. ولكن والحمد
لله ما يهمني الان انه اصبغ يرضع مني. فهذا اراحني نفسيا بشكل كبير. شعور الامومه جميل
جدا....شعور يصعب وصفه. انا على استعداد ان ابقى معه طوال اليوم، فقط اريده ان يمسك
صدري ويرضع. ولكنه ما زال يجد صعوبه في ذلك. اشعر انه يعاني وهو يحاول ان يمسك
صدري.
(NS2-M8)

The mothers' milk itself is connected to the transformation into a mother. Mothers referred to “*my milk*” in a way that highlights its importance and significance for their infants' health:

I felt so happy when they increased the amount of his feeds from my expressed milk. I felt so happy because I am seeing him improving and I felt that it is because of my milk.

أكثر شيء شعوري تحسن لما زادت كمية الحليب اللي بيعطوه اياها لانها من حليبي كنت سعيدة كثير. وانا شففته بعيوني انه عم يتحسن ويزيد وزنه شعرت انه حليبي هو السبب في هذا التحسن.
(NS1-M2)

Those who were unable to give their breast milk to their infants, talked with sorrow about how they might be feeling if they had the chance to do so:

My breasts were engorged all the time. I used to pump my milk and throw it away. I felt so bad about that. I wish if I could bring it for him. I wish if they could give it for him, I would be feeling much better.

والله كان صدري هيك (واشارت انه مليء بالحليب) وشفطته واكبه. يا ريت لو انه اجيله الحليب ويرضعوه اياه يا ريت، كانت نفسي تتي تحسنت كثير.
(NS2-M6)

They asked for my milk just once, so I pumped it and brought it for them. They took it from me, I felt happy because I brought my milk and that they will give it to my baby. If they asked me to bring milk every two hours I would do that.

جبت حليبي لهون مره واحده وشفطته وجبتلهم اياه واخذوه. كنت مبسوطة لما جبتلهم الحليب، وانهم راح يعطوه لابني. لو طلبوا مني اجيب حليب كنت مستعدة اجيب لو كل ساعتين.
(NS2-M9)

Despite the powerful connection between breast milk and becoming a mother, most of the mothers in this study did not express their milk immediately after the birth of their babies. That was because, for some, their main concern had shifted toward the health of the baby, and many were unaware that they could give their milk to their infants. The medical staff did not encourage early initiation of expressing breast milk and mothers who decided to use a pump were mostly encouraged to do so by family members:

At the beginning my breasts were engorged and tender to touch. When I asked them here about breastfeeding, they answered that during their first period of life, preterm babies can't tolerate breastfeed. And I asked them again by phone and they told me that he still having milk through a tube. So my milk starts diminishing by time until it ceased. Nobody here told me what to do to maintain my milk production. My mother and my aunt told me to pump it. I did for a while, but I don't have milk anymore. I tried to pump but had nothing...every time I asked to come and breastfeed, the answer was not yet, still on the feeding tube.

اول فتره صدري صار يوجعني وصار فيه تحجير، وهون لما اسالهم يقولولي انه اول فتره ما بيرضع البيبي. سألت الممرضات بالتلفون وحكولي انه هسه ما بيصير يرضع لانه بياخذ الحليب عن طريق انبوب عن طريق الانف وصار الحليب يخف في صدري شوي وهسه راح كله ما ظل اشي...لم يخبرني احد بما علي القيام به ولكن امي وخالتي قالوا لي: اشفطيه! الان لا يوجد حليب

بالمرة...حاولت اني اشفط بس ما فيش، كل ما كنت اسال : آجي ارضع؟ كان الجواب لأ بعده عن طريق الانبوب.
(NS1-M4)

Another participant talked about her decision to use a breast pump:

It was my decision to pump for him, and when I told them about my decision they encouraged me. I used to pump and store the milk in the freezer, and then bring it for them in the next morning. But my milk starts diminishing by time because every time I used to come and find him sick and then leave the unit without him I feel resentful. I began to bring very little amount of milk, so they had to help him by formula milk.

كان القرار قرارى وعندما اخبرتهم به شجعوني على ذلك فكنت اشفطه واضعه في الفريزر واحضره لهم في الصباح. ولكن حليبي بدء يخف مع الوقت لانني كنت اشعر بالاستياء كلما حضرت لزيارته وغادرت الوحدة دون ان يخرج ابني معي فلم اعد احضر لهم ما يكفي من الحليب فاضطروا ان يساعدوه بحليب اصطناعي.
(NS1-M1)

It has been suggested elsewhere that mothers felt that they would cope with the crisis better if they had received support from the hospital staff and if they had been given the appropriate knowledge and training related to the care of a preterm infant (Lindberg and Öhring, 2008). The mothers in this study have identified many areas where support was needed.

Practical and informational needs

All the mothers in this study said that they were delighted to become mothers. However, they went through different levels of anxiety. Some were faced with the fear of the unknown in terms of the responsibilities for the new arrival. Mothers wanted the unit to be a learning environment to ease their fears and to increase their self-confidence. They wanted a more cooperative relationship with the nurses, to learn from them about how best to deal with their infants at home. Confidence in looking after preterm infants at home is an important aspect to becoming a mother. Some mothers talked about being frightened of taking their infants home because they did not feel confident in looking after them:

I feel that I have a lack of information, which I should have so that I can take care of him. For this reason, I wrote down any single information I heard them [staff] saying. I wish if there are any educational sessions here in the unit that I can attend about the care of premature babies. When I leave with him to my house, I will have to deal with him on my own. I will not have them [staff] around to assist. I want to know everything; his immunity, is it good or not? How should I deal with him in certain situation? And whether my relatives can see or hold him? I do not want my fears to be exaggerated. That's why I want to get the largest amount of information possible before he

leaves the hospital in order to have the ability to deal with any possible situation.

أشعر بوجود نقص كبير في المعلومات عندي التي ينبغي أن تكون موجوده عندي حتى اتمكن من العناية به. من أجل ذلك أقوم بتسجيل أية معلومه أسمعها منهم. أتمنى ان تكون هناك دورات تثقيفيه هنا في المستشفى عن العناية بالأطفال الخدج . لأنني بعد فتره سوف اغادر معه الى البيت وسوف أضطر للتعامل معه لوحدي. ولن يكونوا موجودين عندي للمساعدة. أريد أن اعرف كل شي عن مناعته، هل هي جيده أم لا؟ وكيف يجب علي التعامل معه، وهل يستطيع الاقارب ان يروه او يحملوه؟ لا أريد ان يكون خوفي عليه مبالغاً به، لذلك أريد الحصول على اكبر كميّه من المعلومات ممكنه قبل ان يغادر المستشفى من أجل أن يكون لدي القدرة على التعامل مع أي حاله يتعرض لها.

(NS1-M2)

I am frightened of the idea that I will go home with both of them. I don't know how I am going to deal with them...I asked them [staff] if they can stay longer here until they gain more weight. They told me that this is not in their best interest to stay longer as they will be exposed to germs in the hospital more than the house and that I will get used to them quickly.

اشعر بالخوف من التفكير بانني سوف اذهب بهم للبيت لوحدي وكيف سأتعامل معهم وقلت لهم هل يجوز ان ابقهم عندكم حتى يزد حجمهم؟ فاخبروني بان هذا ليس من مصلحتهم وبانه عندما يقرر الطبيب لهم الخروج يجب اخراجهم وبانه يكونون معرضين لتلقي اي جرثومه في المستشفى اكثر من البيت وبان البيت افضل له وبانني سوف اتعود عليهم سريعاً.

(NS1-M5)

These findings are congruent with a recent Jordanian study by Obeisat and Hweidi (2012), in which a descriptive correlation design was used to identify the perceived needs of parents of critically ill infants admitted to the NICU. Parents ranked the need for assurance and information about their infant's progress as the two most important needs. Ranked next to these was the need to be in close proximity with their infants.

Hutchinson, Spillet and Cronin (2012) identified similar results where interactions with staff had a major impact on the parent's experience. Moreover, Kenner and Boykova (2007) put more emphasis on the informational needs for Russian parents on their transition from the NICU to home.

To conclude, this study has shown that the transition into motherhood for mothers of preterm infants was not what they expected. They missed the joy of having a full term healthy baby; instead, they had to deal with a crisis filled with stress and anxiety. Mothers had periods of vulnerability and adjustment throughout their transition to motherhood. These findings were not unique for the Jordanian mothers, similar findings have been identified in many other cultures, for example, for Swedish parents (Jackson, Ternstedt and Schollin, 2003), Korean mothers (Shin and White-Traut, 2007) and for parents from diverse racial

backgrounds with the majority being Caucasian (Hutchinson, Spillet and Cronin, 2012). The transition into motherhood is a key concept for this study that will be developed in a subsequent chapter.

In order to overcome the crisis that mothers of preterm infants experience, it is important to help them make the transition into motherhood with minimal pain. The mothers themselves identified many things that helped them make the transition, including physical closeness with their babies, feeling important, needing to breastfeed or provide breast milk, participating in infant care and some practical and informational needs. Physical and emotional closeness have been identified as essential to the physical, emotional and social well-being of both the infants and their mothers (Flacking, et al., 2012).

With appropriate support, a mother's role as the primary care giver can be restored while they navigate their way through the NICU's environment. Nurses within the NICUs play an important role in empowering mothers in order to facilitate bonding and attachment (Kenner and McGrath, 2004; Herbst and Maree, 2006). However, nurses often find the process of empowering mothers within the context of NICUs difficult. This will be the topic for the next section where the findings of the health care professionals' views will be discussed.

THE STAFF'S VIEW

Nurses play a crucial role in supporting breastfeeding in hospitals generally and in neonatal units specifically, their attitude and knowledge in support of breastfeeding is essential for its success. Any effort, therefore, intended to increase rates of breastfeeding of preterm infants must consider the knowledge and attitudes of the health care professionals who are working in the neonatal units. The findings of this study suggest that while nurses and other health care professionals agree with the benefits of breastfeeding for preterm infants, the actual implementation of a breastfeeding policy within the neonatal units is more problematic.

The findings are presented as three interconnected themes that emerged from the analysis of my observations and discussions with the health care team (Table 13). The first describes the contradiction that exists between the health care professional's beliefs and behaviours in relation to breastfeeding and supporting the mothers. Elements that comprised this theme are "breast milk is best", perceiving the promotion of breastfeeding as a nicety not a necessity, lacking the mothers' support and the abdication of responsibility. The second theme relates to their working conditions was a perceived lack of hospital support for the health care team and barriers to breastfeeding. The final theme relates to the existing power differential among the nurses and the mothers.

Table 13: Themes and subthemes generated from the staff accounts

Themes	Subthemes
The contradiction	•Breast milk is best
	•Breastfeeding promotion as a nicety not a necessity
	•Lack of mothers' support
	•Abdication of responsibility
Working conditions	•Lack of institutional support
	•Barriers to breastfeeding
The power differential	•Control relations

Although providing support for mothers in the NICUs is crucial for the wellbeing of both mothers and infants staff, in both neonatal units, felt implementing this

support was difficult. They identified many barriers that prevented them from providing the appropriate guidance and support for the mothers.

The Contradiction

'Breast milk is best'

Discrepancies were seen between what the health care team believed was right in terms of breastfeeding support and what they actually did to support women during their infants' admission in the NICUs. When the health care team members were interviewed they spoke of their beliefs about the superiority of breast milk. The majority of them felt it was important to promote breastfeeding within their unit. They stated they believed "*breast milk is best*", and they were aware of the importance of supporting mothers to achieve exclusive breastfeeding within the NICU. However, there was a contradiction between their stated beliefs and their actual behaviours. During this study infants were fed pre-prepared infant formula with very minimal use of mothers' milk. One nurse at the research site 1 revealed her belief of the importance of breast milk by saying:

I believe that breast milk is best but it is not easy to implement this in the unit.

قناعاتي الشخصية انه '*breast milk is best*' بس مش سهل اطبق هذا في القسم.
(NS1- N5)

Another nurse at site 2 recognized the importance of implementing a breastfeeding strategy in their unit; however she gave a list of barriers to achieving this:

Yes I wish to implement a breastfeeding strategy, but I think it is very hard. We have seen that when the mothers came from a distant place, they face difficulties in attending every day, and if they want to pump and collect their milk, we do not have the possibility to store it, we have no particular refrigerator for breast milk. We just have a refrigerator for the medications. Even though, there are some mothers who brought their milk and we keep it in the medication's refrigerator.

انا قناعاتي انه يا ريت.....ولكن كم يكون بالامكان تطبيق الرضاعة الطبيعيه هنا قليل وقليل جدا. وقد رأيتي ان الامهات حين تأتي من مكان بعيد اشعر بانها تستصعب الحضور كل يوم الى هنا وان ارادت ان تجمع حليبها، فنحن ليس لدينا امكانيه بتخزينه فليس لدينا ثلاجة خاصه بالحليب. لدينا ثلاجه خاصه بالعلاجات. وهناك بعض الامهات التي تحضر حليبها نقوم بوضعه في ثلاجة العلاجات.
(NS2-N1)

Nurses were also aware of the importance of supporting and educating mothers of preterm infants in terms of breastfeeding; however, they felt this was not part of their role:

Health education for the mothers is very important even before they gave birth. I mean covering certain topics in the health centres, for example watching video on the benefits of breast milk and so on ... this will reduce the burden on us, and we don't need to teach them everything from the beginning. I assume that health education for mothers should occur in the postnatal unit. Mother should come to us to breastfeed her baby, not to receive education.

التثقيف الصحي للامهات مهم جدا حتى قبل ان تتجب، يعني في المراكز الصحية طرح مواضيع فيديو مثلا عن فوائد الرضاعة والحليب وغيرها... هكذا تخفف العبء علينا عندما تكون لديها معلومات ولا نضطر بتعليمها كل شيء من البداية. من المفروض ان يتم عمل تثقيف صحي في قسم ما بعد الولادة عن الرضاعة الطبيعيه وان تأتي الام الينا الى هذا القسم تطلب ان ترضع ابنها وليس ان نقوم نحن بتثقيفهم عن ذلك.
(NS2-N3)

Health care professionals were aware of all the benefits of breast milk and breastfeeding in comparison however, technology was more highly valued.

Breastfeeding promotion as a nicety not a necessity

Despite the strong scientific evidence of the superiority of breastfeeding and breast milk for preterm infants, breastfeeding promotion continues to be viewed as a nicety instead of a necessity in both units; staff members relied more on technology to save the infants' lives. Nurses and physicians focused more on the technical details of the infant's treatment, which demonstrates the perceived inferiority of breast milk within the NICU. They would frequently post reminders of technical information or treatments for infants on the unit's board, to facilitate communication between each other, whereas on several occasions they forgot to communicate the existence of expressed breast milk in the unit's refrigerator. One participant specifically talked about this issue:

Nurses could tell each other about the availability of breast milk in the fridge, but this is rarely occurs. I think, this is because they do not give considerable attention to the breastfeeding issue. You may tell a nurse about the availability of expressed mother's milk in the fridge for a baby, but she often forgets that and she may also forgets to communicate that to the other nurses. This is, I think, because they do not consider it [breast milk] important.

لما يكون في حليب مشفوط، الممرضات ببسملوا بعض انه في حليب للبيبي فلان في الثلاجة. ولكن نادرا ما يكون في حليب. اعتقد انهم ما بيهتموا كثير بموضوع الرضاعة الطبيعيه، يعني ممكن احيانا بتحكي للممرضه انه في حليب ام في الثلاجة للبيبي الفلاني وبتنسى انها تعطيه وبتنسى انها تسلمه للممرضه اللي بعدها. ممكن لانهم ما بيعتبروه شيء مهم.
(NS1-N1)

While the majority of participants felt that it was important to support breastfeeding mothers, some nurses did not feel that supporting breastfeeding was their responsibility, whilst saving the baby's life clearly was. According to them, breastfeeding was not an issue of significance and was not linked to the baby's wellbeing. Breastfeeding has also been seen as a minor health issue by health care professionals in other studies (Dillaway and Douma, 2004).

One participant perceived breastfeeding as inferior because she considered helping and supporting mothers in this way as a kind of social interaction with them that was not as important as the "medical part":

Frankly, our attention is on the medical part. We try our best to work on the social side with the mothers, but at the end you need to carry out the medical part of care more than the social part.

بصراحه التركيز كله على الجوانب الطبيه بتكون اكثر، يعني الواحد بيحاول قدر الامكان انه يشتغل على ال social work مع الامهات بس بالنهايه بيهمك انك تنجز الجزء الطبي اكثر من الجزء الاجتماعي.
(NS1-N5)

A doctor talked about the priority of the physical health of the babies:

The problem is that when you talk about a child in critical condition the vast majority here do not put the breastfeeding matter at the highest degree. The issue of breastfeeding takes a medium or even a lower degree of priority and importance after the health status of the child. Thus, you do not find any of the medical and nursing team who gives this issue its required attention and, therefore, no one thinks about how to implement and develop this topic.

المشكلة انه عند التحدث عن طفل في وضع صحي حرج فالغالبية العظمى هنا لا يضعون لهذا الأمر أهميه في الدرجة العليا. فموضوع الرضاعة يأخذ درجة متوسطة ان لم تكن متدنيه من حيث الاهميه بعد الوضع الصحي للطفل. فلذلك لا تجد من الكادر الطبي والتمريضي من يولي هذا الموضوع الاهتمام المطلوب وبالتالي، لا يفكر في كيفية تطوير هذا الموضوع.
(NS1-D1)

Another nurse emphasized their priorities within the NICUs:

We do not have educational brochures or something like that, this is not our responsibility. After the will of Allah, saving the baby and keeping him alive until being able to feed and return to his home, is our responsibility. Frankly, breastfeeding is not in our agenda.

لا يوجد لدينا نشرات تثقيفيه ولا شيء من هذا القبيل...هاي مش شغلتنا...فبعد ارادة رب العالمين، شغلتنا هي انقاذ الطفل وابقائه حيا وايصاله لمرحلة يستطيع فيها الرضاعة والعوده الى بيته؟ اما الرضاعة الطبيعيه فهي ليست في الاجندا، فلا يوجد لها اي برنامج عندنا.
(NS2-N2)

Mothers of preterm infants need teaching and support to initiate breastfeeding but because breastfeeding was perceived as insignificant, along with other barriers such as time constraints and heavy workloads, formal teaching was replaced by incidental (serendipitous) teaching:

Some mothers show interests on breastfeeding...you may encourage them to breastfeed, but there is no formal teaching. It's up to you and according to your time. When you feel that the mother is really interested and asks questions, you may explain to her and may help her, new mothers are often who need more help.

فيه امهات بتحسوها انها هي مهتمه وحابه تعطي *breastfeed*...ممكن انك تتصحيتها بالرضاعه الطبيعیه، ما في تثقيف رسمي طبعا حسب فضاوتك انت بتحكي مع الام ، وممكن انها تيجي ام بتحسوها انها عن جد مهتمه وحابه تعطي *breastfeed* وممكن تساعديها وتشرحيلها عن وضعية البيبي. وغالبا البكرات هم اللي بيحتاجوا مساعده.

(NS1-N3)

Lack of support for mothers

Although aware of the importance of supporting breastfeeding mothers, nurses recognized the lack of it in their units:

There is not enough support to breastfeeding. No motivations for mothers to breastfeed, it is only our verbal encouragements for them. No posters on the benefits of breastfeeding for example, and there is no breastfeeding room, this would encourage them to breastfeed. There is also no breastfeeding consultant in the unit, many mothers need help to start the process of breastfeeding and to know how to deal with the premature child, thus the presence of breastfeeding consultant is crucial.

لا يوجد محفزات الا تشجعينا للامهات على الارضاع شفويا فقط...غير ذلك لا يوجد اي حوافز. لا يوجد لافتات عن فوائد الرضاعه مثلا ولا يوجد صور ولا غرفة مكتوب عليها غرفة الرضاعة الطبيعیه مثلا فهذا لوحده يحفز الام على الرضاعه. لا يوجد ايضا خبيرة للرضاعه الطبيعیه في القسم...حبذا لو تكون موجوده فالكثير من الامهات بحاجه للمساعده في البدء في عملية الرضاعه وفي كيفيه التعامل مع الطفل اثناء الرضاعه.

(NS1-N4)

They justified their failure to provide support by pointing to the lack of facilities within the two units:

You have seen that there are no available facilities for pumping and storing breast milk in the unit, and you have seen the breastfeeding room available here [referring to its small size]. We do not have any facilities for the mother to come and breastfeed here. But in spite of all of that, we do encourage them to come and breastfeed.

اعتقد انك رايتي بعينيك انه لا توجد امكانيات متوفره في الوحده ورايتي غرفة الرضاعه المتاحه هنا. لا يوجد لدينا امكانيات تستطيع فيها الام ان تاتي وترضع هنا. وبالرغم من ذلك نحن نشجعها فعليا على ان تاتي وترضع حتى مع عدم توفر الامكانيات لذلك.

(NS2-N1)

According to some participants, there were no appropriate storage facilities for the mothers' milk in their units. They felt uncertain about the appropriateness of using the unit's medication fridge for milk storage and even questioned the appropriateness for mothers to pump and store at home:

For the mother to leave her milk here, as you can see, our fridge is not appropriate for the milk storage. This is my opinion. I think it has to be stored in certain temperature and certain methods. And even at home mothers do not know how to store the milk; they use their freezer that contains chicken and meat.

ومن جهة ان تترك الام حليبها هناالثلاجه هنا غير مهيأه لتخزين الحليب....هذا توقعي ورأبي يعني لازم يكون درجة حرارة معينه وطريقة تخزين الحليب بطريقة معينه. وحتى في المنزل فالامهات لا تعرف كيف تخزن الحليب يعني عندها الفريزر فيه دجاج ولحوم.
(NS2-N5)

The previous examples from the nurses' accounts indicated a presence of cognitive dissonance (Festinger, 1962) between what they believed was right and what they actually did. A detailed discussion about these contradictory beliefs and behaviours follows in Chapter 7.

The nurses' attitudes and behaviours could be detrimental for the breastfeeding outcome within the NICUs. In many situations that I witnessed nurses were judgmental about the mothers' abilities to satisfy their infant's nutritional needs:

We are usually worry about the baby not getting enough milk from his mother, so we do offer him a satisfying formula feed, therefore he will love the bottle more than breastfeeding, because it is easier for him.

بتكون الممرضه نفسها خايفه على البيبي انه ما يكون رضع من امه وبتكون بدنا نعطييه وجبه مشبعه فبيك بالتالي هو بده يصير يحب الحليب الاصطناعي اكثر من حليب امه كونه بيشبعه اكثر واسهل له في الرضاع.
(NS1-N5)

Negative feelings from the nurses about the nutritional adequacy of breastmilk affected the mothers' confidence in their abilities to breastfeed. The following extract from my field notes demonstrates this effect.

While the mother X [primipara] was trying to breastfeed her preterm baby, the nurse Y, directing her speech to me, expresses her resentment of the mother by saying: “she took the baby in the morning and could not satisfy him; so, after she left, I had to feed him again!”

During the day, I met the same mother while she is trying to breastfeed her baby. She is having a hard time getting him to latch on her breast. I am standing at her side looking at how she is struggling with the feed. She says: “he is not getting enough milk from me, I think I don’t know how to breastfeed him properly” I reply: why do you think like that? She says: the nurse told me that.

It strikes me to what extent nurses could be influential to the mothers’ beliefs. What if the nurse Y sits with this woman for only 5 minutes a day to teach her how to breastfeed her tiny baby and to reassure her that she is doing well, what could this do for this mother?

(Fieldnotes, research site 2, Tues. 01/03/2011)

Even though this mother was complaining of her engorged breasts, along with her milk dripping while she was trying to breastfeed her baby, these facts meant nothing to her under the influence of the nurse’s comment; she felt uncertain about the adequacy of her breast milk and her ability to breastfeed properly.

In a second incident, when the same mother came to breastfeed another nurse prepared a formula bottle for the baby, “*just in case*” as she suggested, because according to her “*When I saw her, I knew that she won’t be able to feed him well*” (Field work, research site 2, 01/03/2011). Nurses at research site 1 showed some judgmental behaviour as well:

The baby was crying during the medical round when one of the nurses commented: “*this baby is on breastfeeding. The problem is that mothers do not give them enough*”. She looked at me, smiled and added: “*those who are on breastfeeding got hungry in less than 3 hours*”. My sense was that she is kind of telling me: do you see why we give bottles?

(Fieldnotes, research site 1, 18/05/2011)

This finding is supported by results from other studies that indicate the influence of health care professionals on breastfeeding behaviours (Dykes and Williams,

1999; Bernaix, 2000; Ekström, Widström and Nissen, 2005; 2006, Ekström and Nissen, 2006; Brown, 2011).

Another participant talked about the absence of any formal teaching and identified time restrictions and busy schedules as barriers for giving such teaching. Encouraging mothers to breastfeeding was generally a onetime event:

Usually mothers do not have formal educational sessions at the unit. We usually ask them: would you like to feed him? Or would you like to pump your milk for him? You know, we are too busy with the other babies, we can't have enough time to sit there with the mothers and give them appropriate teaching. And there is no specialist nurse to do this job.

في العاده لا تتلقى الامهات أي تثقيف صحي في الوحده، احنا كنا نحكيلهم: شو رايك انك ترضعيه، شو رايك انك تجيبيله حليب وتشفطي؟ في العاده احنا بنكون مشغولين مع البيبيات هون وما بنلحق نقعد مع الاهالي بالمره وما في واحد خاصه تعمل هيك تثقيف.
(NS1-N1)

Mothers at site 2 received even less support as a result of the greater work load on the hospitals' nurses. Mothers were handed the responsibility of deciding whether or not to breastfeed without being given the appropriate support. Minimal education was given and only if mothers asked for it:

If the mother asked and wanted to breastfeed her baby we will give him to her if he is feeding from bottle without difficulties. As you saw, any baby needs, at least, 4 days until he can tolerate direct breastfeeding, therefore, it's not that we don't want to; it is hard to encourage breastfeeding. The situation here does not facilitate promoting breastfeeding, and the mother, as I told you before, is not always available here.

وان سألت الام ورغبت في ارضاعه نعطيها اياه... فكما رايتي، الطفل على اقل الاحتمالات بحاجه الى 4 ايام حتى يستطيع الرضاعه عن طريق الفم... فمن الصعب ان نشجع، مش بدناش نشجع الرضاعه الطبيعيه، بس وضع القسم هنا لا يسمح بتشجيع الرضاعه. والام كما قلت لك مش دايم متوفره دايم عندي.
(NS2-N2)

We do not keep an eye on the child when he is breastfeeding from the mother, because we do not give him to her until we make sure of his ability to handle feeding well without asphyxia or cyanosis. Sometimes when they come they may ask for help and may ask about how to do something. Those who do not ask, they do not receive any education.

نحن لا نراقب الطفل عند ال breastfeeding فقط نعطيهِ للام لترضعه حين نتأكد انه يرضع بشكل جيد دون اختناق او ازرقاق. احيانا عندما تاتي تطلب المساعدة وتسال عن كيفية القيام بشيء ما. اما من لا تسأل فلا تتلقى اي تثقيف.
(NS2-N5)

Even though it was not done, the majority of the health care teams felt it was important to promote breastfeeding for the sake of the preterm infant's health. Nevertheless, they felt that this was not their responsibility.

Abdication of responsibility

Nurses at the two neonatal units were aware of the importance of supporting the mothers however, they abdicated their responsibilities of teaching and supporting these mothers to other health care professionals, including nurses in other wards and family members. The following extract from my field note demonstrates this abdication of responsibility:

A primiparous mother came to breastfeed her baby girl (IUGR and PROM). The grandmother came with her. They sat on the small breastfeeding room. The mother found it very difficult to initiate breastfeeding and the baby suffered as she was unable to latch on. None of the nurses offered her help nor did she ask for any. It was only the grandma who was attempting to help.

(Fieldnotes, research site 2, 24/02/2011)

Such abdication of responsibility is linked to many reasons, among them a lack of knowledge and consequently a lack of confidence, time restrictions, heavy workloads and the lack of any continuing educational programmes.

As a result of their own inadequate knowledge about breastfeeding preterm infants, nurses felt uncertain and lacked confidence in teaching mothers. They therefore abdicated the responsibility of teaching and providing support to others:

I do not have personal experience with breastfeeding, as this is my first pregnancy, but I do have some information and knowledge about breastfeeding from my educational background and from mothers who I met. This information may not be accurate or up to date. I also obtained some knowledge from my experience at this unit. Frankly we did not expose to any kind of continuing educational programs related to breastfeeding issue. The hospital has a continuing education committee, however, the breastfeeding related issues is not displayed in their agenda. That's why our information about this topic is a personal effort only and may not be accurate.

لا يوجد لدي خبره شخصيه مع الرضاعة الطبيعيه، فهذا أول حمل لي. ولكن لدي معلومات عن الرضاعة الطبيعيه وأهميتها للأم والطفل حصلت عليها من خلال دراستي ومن ثم من الأمهات اللواتي القاهن. ولكن هذه المعلومات قد لا تكون دقيقة في كثير من الأحيان. وايضا احصل على معلومات من خلال عملي في هذا القسم. بالرغم من وجود لجنة تعليم مستمر هنا في المستشفى الا انه لم يتم عرض موضوع الرضاعة الطبيعيه في وحدة الخداج كأحد

المواضيع المطروحة فيها. فلذا، معلومات الكادر التمريضي عن هذا الموضوع هو جهد شخصي فقط، لذا قد تكون هذه المعلومات غير دقيقة.
(NS1-N2)

It is clear from the quote above that the nurse considered not having a personal experience of breastfeeding as one of the barriers to educating mothers. Having this personal experience was seen by other researchers to make health care professionals' feel more knowledgeable (Simmons, 2002; Battersby, 2006). This view is also congruent with the findings of Dillaway and Douma (2004, p. 424) where health care professionals felt "inadequate" as "supporters" or "educator" because they did not have personal breastfeeding experiences. Nelson (2007), suggested that the health care professionals who had personal experience of breastfeeding often felt a connection with these mothers and they were happy to share breastfeeding tips that had worked for them when they had breastfed their own children.

Nurses within the two settings repeatedly emphasized their lack of confidence about the knowledge they could provide to breastfeeding mothers:

We are relying on our background and our experiences for giving any teaching. So our teaching is not based on any up to date courses that we took or on any training we had. Therefore, many contradicting points of view will arise.

حتى احنا الممرضات هون معتمدات على خلفيتنا العلمية فقط سواء من الجامعة او خبرتنا. حتى احنا لما بدنا نعطي للام لما بدها تسأل نعطيها تثقيف بكون مش بناءا على *course* ماخذينه او على تدريب ، فيصير فيه اختلاف في وجهات النظر حسب خبرة كل واحد فينا.
(NS1-N5)

Nurses depend on their background for breastfeeding information, we don't expose to any educational courses. There is a continuing education department in the hospital, but to be honest with you, the topics that have been introduced to us did not cover breastfeeding for preterm babies' issues. Therefore, nurses depend on their educational background and their experiences as mothers and as neonatal nurses.

ال *background* تاعت كل الممرضات بالنسبة للرضاعة الطبيعيه. ما في تثقيف صحي عنها او *continuing education* . احنا في عندنا في المستشفى *continuing education* بس المواضيع اللي بتتطرح احنا اللي بنختارها ومش خاصه بموضوع الرضاعة الطبيعيه فالأغلب انه بنعتمد على الخلفيه الدراسيه تاعتنا وعلى خبرتنا كامهات وممرضات في الخداج..... بصراحه ما صار في طرح لمواضيع بتخص الامهات اللواتي ينجبن مبكرا او الموضوعات الخاصه بموضوع الرضاعة الطبيعيه للأطفال الخدج.
(NS1-N3)

Because nurses considered themselves unqualified to teach and support mothers they relied on the mothers' families and nurses within other departments to give such support:

Mothers depend on themselves in gaining such knowledge and some rely on their mothers or their social network. There is also a breastfeeding nurses at the postnatal department who is responsible for giving teaching for mothers about breastfeeding before they leave the hospital. While here at this unit, there is no special nurse who is responsible for teaching.

غالبا تعتمد الامهات في مثل هذه المعلومات على انفسهن وعلى امهاتهن والشبكة الاجتماعية الخاصه بهن. ويوجد ايضا في قسم النسائيه (postnatal unit) ممرضه مسؤوله تعطي تثقيف عن عملية الرضاعه الطبيعيه. ولكن هنا في هذه الوحده فلا يوجد ممرضه خاصه من اجل هذا.
(NS1-N2)

Nurses expressed the need for a breastfeeding consultant to take up this role:

We are in the process of having a breastfeeding consultant. Not specifically for this unit, but she will be based on the postnatal unit and she will give teaching for both preterm and full term babies' mothers.

ممکن...يعني هاي بيحوز على المستشفى. احنا حاليا في خطه انه يكون فيه ممرضه منخصصه بالتثقيف للامهات عن موضوع الرضاعه الطبيعيه. في الخداج مش موجوده بس هاي راح تكون موجوده في قسم النسائيه سواء للامهات ال premature او ال full term وانها تعطيهن teaching عن breastfeeding .
(NS1-N5)

The danger of employing a breastfeeding consultant, however, is that the staff may use her as a means to further abdicate their responsibilities.

The Working Conditions

Lack of institutional support

The health care team participants repeatedly described how demanding it was working with limited resources, under a heavy workload and to tight schedules. They argued it was difficult to perform well under these working conditions and felt there was a lack of support from their institutions. During the period of my field work I never witnessed any active assistance for a breastfeeding mother from a nurse, although research site 1 did offer verbal advice when mothers asked for it.

Most of the nurses recognized the importance of evidence-based continuing educational programs to enable them to update their knowledge regarding breastfeeding issues and increase their ability to support breastfeeding mothers. However, this was vocalised more often among research site 1 nurses, maybe because they had a lighter workload:

And they [the hospital management] do not offer any continuing educational programs for us, it's only our previous knowledge that we had from our university education or gained from experience.

وبعدين ما بيعملولنا دورات تثقيفيه ولا اشي، لأ لأ خالص هي معلوماتنا اللي موجوده عندنا من ايام الجامعه او الخبره.
(NS1-N1)

Many nurses expressed their need to have more opportunities for updating their knowledge about breastfeeding, but it was mainly a personal effort:

When I have small number of patients, I usually open the internet and try to update my knowledge. But I am always running out of time, the moment I sit and open the computer, something happens forcing me to stop reading. I wish if we can have some sort of training courses to update our knowledge

بس انا بحاول اني لما اكون مستلمه عدد قليل اني افتح عالنت واعمل update بس يعني يا دوب تفتحي الكمبيوتر الا ببصير اشي وتقومي بسرعهلا ما فيه دورات يعملولنا اياها.
(NS1-N2)

When asked about the possibility of arranging continual educational sessions for the nurses, a key informant doctor talked about previously unsuccessful morning meetings. These were arranged to discuss various issues related to the NICU however breastfeeding was not among them. He pointed to the busy schedule during the day of the health care team:

Most of the information obtained by the staff is from the Internet. We tried also arranging meetings here in the unit every Thursday with the nursing staff where we discuss multiple topics such as resuscitation, nutrition, and thermal regulation, this is very important. But it did not continue because the nurses come to work from seven o'clock am to seven o'clock pm and start working with their patients immediately, so they did not have enough time to continue these meetings, nor doctors have enough time to follow it up.

أغلب المعلومات يحصل عليها الكادر من الانترنت. حاولنا ايضا عمل لقاءات هنا في الوحدة كل يوم خميس مع الكادر التمريضي نناقش فيه مواضيع متعدده مثل *resuscitation, nutrition, and thermal regulation* فهذا مهم جدا. ولكن لم يستمر الامر لان التمريض يأتون للعمل من الساعه السابجه صباحا وحتى الساعه السابجه مساءا ويبدءون العمل مع مرضاهم مباشرة فلا هم لديهم وقت كافي ولا نحن الاطباء لدينا الوقت الكافي لمتابعة هذا الامر.

(NS1-D1)

The medical community may still have inadequate knowledge to support breastfeeding mothers and to minimize breastfeeding problems because allied health schools such as nursing, nutrition and public health have failed to integrate appropriate breastfeeding education in their curricula (Battersby, 2006; Batterjee, 2010). Studies indicated a lack of knowledge and negative beliefs

among health care professionals surrounding issues of breastfeeding preterm infants (Spicer, 2001; Siddell, et al., 2003; Bernaix, Schmidt and Arrizola, 2008). Educating health care professionals and updating their knowledge regarding breastfeeding are essential to provide appropriate support for mothers. Adequate knowledge among health care professionals has been found to be a strong predictor of supportive behaviours for breastfeeding (Bernaix, 2000; Bernaix, et al., 2006; Bernaix, Schmidt and Arrizola, 2008). In fact, breastfeeding education was documented to be the key to increasing the nurses' confidence in supporting mothers (Smale, et al., 2006).

Even though, the research participants recognized the need for providing appropriate support for breastfeeding mothers, they described barriers and difficulties they believed prevented them from providing such support.

Barriers to support breastfeeding

There are many challenges facing nursing in Jordan including budget cuts, staff shortages, increased workloads and restricted resources (Al-Maaitah and Shokeh, 2009). Health care staff identified the impact of these challenges as constraints and barriers to the effective implementation of a breastfeeding policy within the NICUs. The barriers described were varied, but all participants agreed that lack of facilities, the distance to hospital for mothers, unavailability of mothers, infants' compromised physical status, heavy work load, time restrictions and the units' design all contributed towards restricting their ability to give sufficient support.

The most frequently reported barrier to breastfeeding was the lack of facilities. Medical staff reported various shortages among the NICUs that are crucial for the breastfeeding to be successful including: facilities for pumping and storing breast milk and the need for a private breastfeeding room. Participants within both settings talked about the lack of pumping facilities in their units, and stressed the need for making them available for the mothers because, according to them, it is safer for mothers to pump at the unit so that nurses can control the environment in which pumping takes place:

Pumping machines are also not available, I expect that by providing some pumping machines, we will facilitate and encourage pumping breast milk. They will save mothers who are using the manual pumping machines much effort and time. We suppose to make these devices available, as we do provide more expensive devices. When mothers pump here, we can ensure the

cleanliness of the environment....we can't be sure of the mothers' degree of cleanliness at home. Some mothers do not know how to clean or disinfect them [bottles], or may not do it well.

ايضا من المعوقات عدم وجود *pumping machines* فانا اتوقع بانه ان وجدت سوف تسهل علينا الامر وعلى الام فسوف يوفر عليها الكثير من الجهد والوقت في استخدام الشفاطه اليدويه. من المفروض وجود هذا الجهاز مثله مثل باقي الاجهزه التي تكلف الكثير هنا. ومن ناحية اخرى نكون مطلعين على عملية الشفط والتأكد من نظافة المحيط فنحن لا نعلم ما هي الضروف التي تشفط فيها الام في بيتها ودرجة النظافه المتبعه هناك. وحتى الشفاطات اليدويه التي تستخدمها الامهات لا نعلم عن مدى نظافتها او تعقيمها فقد لا تقوم بتعقيمها جيدا ومن الممكن انها لا تقوم بغليها ايضا.

(NS1-N4)

Another participant discussed the storage conditions in their unit, suggesting that it is inappropriate to use the medication refrigerator for the milk storage:

There is another obstacle from our side here; as there are no suitable conditions to store breast milk in this unit, therefore, the expressed mother's milk is stored in the medicine refrigerator and this is not an appropriate method for storage, of course.

هناك عائق من قبلنا هنا، فلا توجد ظروف مناسبة تماما لتخزين الحليب في الوحدة ويتم تخزين الحليب في ثلاجة الادويه وهذا غير مناسب بالطبع.

(NS2-D1)

Another reported barrier was the distance to hospital and the unavailability of mothers. This was more of a problem for research site 1 staff because of the hospitals greater geographical distance from the city centre:

May be the unavailability of the mothers and the distance to the hospital are among barriers. Some mothers say that she can't come because her husband is working and won't be back until late at night, because of that she can't come during the day time.

بس ممكن عدم وجود الام بشكل متواصل مع الطفل. وايضا المسافه وبعد السكن عن المستشفى. هناك امهات عندما نطلب منها القدوم لارضاع الطفل تقول بان زوجها في العمل ولا يعود للمنزل قبل التاسعه، ولذلك فهي لا تستطيع القدوم الا بعد عودته. غير هذا لا توجد معوقات.

(NS1-D2)

Others considered the distance to hospital and unavailability of mothers as the number one challenge:

There is a geographical distance between mothers and their infants. This is number one challenge. After giving birth, mothers leave the hospital early and usually most of them live far away from this hospital. As a result, when we ask them to provide milk for their infants, they find it difficult and may cause distress and hardship to them. It is not easy for them to come every day and offer their milk constantly.

هناك بعد جغرافي بين مكان وجود الام ومكان وجود الطفل، هذا رقم واحد. بعد الانجاب، الكثير من الامهات يغادرن المستشفى مبكرا ويكون سكنها بعيدا، فعندما نطلب منها ان توفر

الحليب ترى فيه صعوبة ففيه نوع من الشده عليها، فليس من السهولة ان تأتي كل يوم وتوفر الحليب باستمرار.
(NS1-D1)

Although closer geographically to the city centre, nurses in site 2 also reported the distance to hospital to be a barrier:

I feel that when mothers come from far away they find it difficult to attend every day.
ان الامهات حين تأتي من مكان بعيد اشعر بانها تستصعب الحضور كل يوم الى هنا.
(NS2-N1)

An infant's compromised physical status was another barrier to breastfeeding mentioned by many staff members in site 1:

Barriers are usually related to medical part of the baby. Also if the baby is on the NGT for long period of time, the mother's milk will cease by time. Some babies may stay for as long as 4 months.

المعوقات على الاغلب في الخداج تكون *related to the medical part* ، الاطفال الخدج اذا كان البيبي متعود على ال *NG tube* وعلى المدى الطويل الام يبيطل عندها حليب تظل تشفط. وكل ما طال بقاء الطفل هون يبصير الحليب قليل جدا. فيبعد شهر ما يبيطل حليب. في اطفال بيقدوا عنا 4.
(NS1-N5)

In research site 1:

It is rather a technical problem now. When it comes to preterm infants, they are at risk for developing various health problems and complications such as RDS, which means that the baby will be NPO for a few days, with the possibility of developing sepsis or any other complications that prohibited the ingestion of oral feeding either breast or artificial milk. This leads to a period of interruption of the baby-mother relationship which will has an effect on the baby's health as well as the mother's ability of producing milk.

المشكلة مشكلة تقنيه الان، انه الطفل في الخداج معرض لمشاكل وعدد من المضاعفات الطبيه وعلى رأسهم ال *RDS* فممكّن يقعد يوم يومين بدون اي *NPO* , *feeding* وممكن يتعرض لل *sepsis* او اي *other complication* تمنعه اصلا من الحليب سواء الصناعي او الطبيعي فهذا بيعمل فترة انقطاع بين الام وبين البيبي وهذا يؤثر على البيبي نفسه ويؤثر على الام بحيب يحدث *decreased of lactation* رغم انه ننصح الامهات انهم يعملوا دائما *suction to increase the lactation* .
(NS2-D2)

One of the most important barriers that were frequently reported by almost all the health care participants was the heavy workload and its consequent time constraints. Nearly all staff members described this lead to mothers not receiving the support they needed. Nurses in the public hospital had a heavier workload when compared to the nurses at research site 1 because of staff shortages. At

the time of this study, the number of the nurses at the research setting 1 was 29; covering two shifts with a maximum capacity of 25 infants. In comparison, research setting 2 employed 32 members of staff who covered three shifts, with a capacity that occasionally exceeded the 38 designated infants incubators and warmers. The staff to baby ratio at the two hospitals was far below the UK recommended standard for intensive care units of a 1:1 ratio (DH: Department of Health, 2009). In other studies, a ratio of 1:2 due to staff shortages was reason enough to prioritize technical aspects of care over family considerations (Cooper, et al., 2007; Johnson, 2008).

In the research site 2, many times during the course of my research I witnessed more than 31 infants per shift with an infant to nurse ratio of approximately 10:1. This extremely heavy workload puts excessive pressure on the nurses leading to negative manners and to more task oriented practices, as reflected in my field notes:

I can feel the intensity of nervousness of the staff members while communicating with each other or with the mothers. It is obvious that this is due to the extreme busyness of the unit. Each nurse has 5 infants to care for. One nurse accompanied one of her infants for his Echo. It was the feeding time for the other infants, so one of her colleagues has to be responsible for feeding them. This brought the number that the nurse had to feed to 9, which caused her to rush through the feeding to finish on time. She was literally, pushing teats into baby's mouth, forcing infants to feed with no break or time for burping. I was thinking then, if the mothers are part of this, they could at least take up this role.

(Fieldnotes, research site 2, 21/02/2012)

An unacceptably high workload in the public hospital did not necessarily cause the nurses to work harder; on the contrary it led to a failure in providing proper care for both mothers and infants:

The units' capacity is full today, there are only two nurses available at the moment as one nurse accompanied an infant to the OR, but I am not sure where the others were. The 'formula responsible lady' commented on this: *"I don't know why I need to prepare formulas for the babies, who is going to feed them anyway?"*

(Fieldnotes, research site 2, 24/02/2011)

Working under such conditions is likely to have a negative impact on the quality of care provision and the support offered to mothers. On the other hand, the workload in research site 1 unit was more comfortable, reflecting a better nurse – mother interaction:

The unit is quiet. Nurses are working with their infants. Each has 3 infants for today. I can sense a relaxed working manner and communications with the mothers. Nurses seem to perform much better under such conditions.

(Field notes, research site 1, 02/05/2011)

The nurses at research site 2 recognized this heavy workload as a huge barrier to the promotion of breastfeeding as they were forced into management and nursing activities.

The work load is a huge barrier to help with breastfeeding especially when we have critical cases. Usually, we have 8 – 9 nurses per shift, where the number of babies sometimes reaches 40. If they want us to help with breastfeeding they have to hire more nurses. We can't give more. At the morning we have to check the infants' files and then morning care followed by morning feed. Then the medical round starts and after that we have to give the second feed and to go through the infants files again to check for any changes on their care plan.

عبي العمل من اكبر العوائق، يومياً يكون عندي 8 ممرضات على الشفت واحياناً 9 وقد يصل عدد الاطفال الى 40 في بعض الاحيان....ان ارادوا ان تساعد في الارضاع، عليهم احضار كادر لي. لا نستطيع اعطاءهم اكثر من ذلك، ففي فترة الصباح يتم تفقد الملفات وتقوم الممرضات بالعنايه الصباحيه ومن ثم وجبة الصباح، بعدها يقوم الاطباء بالمرور وبعد المرور يتم اعطاء الوجبة الثانيه مع تفقد التغيير في الاوامر الطبيه.
(NS2-N1)

Another nurse identified the heavy workload as a barrier to communication with the mothers:

The heavy workload hinders our ability to communicate with the mothers. For example the ratio would be 7-8 babies per nurse during a shift which may increase to be 11 infants sometimes. If I am left with 11 infants on my own, this prevents me from even just talking to the mothers. And if I have the time to talk to her, it will be quick.

ال workload يمنع ال communication مع الامهات. فمثلاً نقوم باستلام حالات تكون ال ratio فيها من 7 – 8 اطفال لكل ممرضه واحياناً يصل العدد الى 11 طفل عندي انا وحدي، وهذا يمنع حتى ان تأتي الام وتتكلم معي وان حدث هذا فيكون بسرعه.
(NS2-N5)

Although having a more relaxed working environment, the nurses at research site 1 also recognized the heavy workload as a barrier to communication with the infant's families:

You know, we are too busy with the other babies, we can't have enough time to sit with the family and give them appropriate teaching.

في العاده احنا بنكون مشغولين مع الببيبات هون وما بنلحق نقعد مع الاهالي بالمره عشان نعلمهم.

(NS1-N1)

The results of this study, supported by previous studies such as Furber and Thomson (2007), suggest that the health care team believe that giving support to mothers puts extra work on them and consumes more time, which contributes to their increased pressure of work:

We don't have waiting room for the mothers, if they stay here, they will put additional burden on us.

الامهات بيعملوا علينا عبي اضافي. ولا يوجد غرفه لهن.

(NS2-N1)

It [teaching/supporting mothers] is just an extra work for them [the nurse] without incentives.

فهو عبيء اضافي عليهم (الممرضات) دون حوافز.

(NS1-D1)

The health care professionals recognized that not only was the mothers' presence in the NICUs extra work, but also that helping them in pumping and storing their milk exacerbated the situation. They clearly acknowledge that the use of formula was much easier and less time consuming:

Another problem with the process of milk storage is that it increases the burden on nursing staff as they should always make sure of the validity period, the name of the mother and the child and so on, which is considered as an extra work for them. Compared to the easiness of formula preparation where they can use the same can for several infants or they may use the ready to use fortified formula which does not require any effort. But then I can say that "it is an extra work but worth doing".

ايضا هناك مشكله اخرى ان عملية تخزين الحليب يزيد من العبيء على التمريض فعليها التأكد دوما من مدة الصلاحية واسم الام والطفل وغيره مما يشكل عمل اضافي بالنسبة لها بخلاف تحضير الحليب الاصطناعي حيث تستخدم العلبة لعدة اطفال او قد يستخدم الحليب المحضر مسبقا وهذا لا يحتاج اي مجهود. ولكن اقول بانه

(NS1-D1)

The previous quote also demonstrated the cognitive dissonance that I referred to at the beginning of this chapter, and which is discussed in-depth in Chapter 7.

Another barrier to breastfeeding is the design of each unit. As described earlier (page 69), the two units lacked appropriate preparations to accommodate the presence of mothers. This was particularly apparent in the research site 2 in which more than 32 incubators were squeezed into a relatively small area. Some participants felt that the physical size and the layout of the NICU did not promote breastfeeding. One participant in site 1 stated that:

The main challenge is with the design of unit as its design is not suitable for breastfeeding preterm infants in general.

تصميم وحدات الخداج بشكل عام للطفل القابل للرضاعة ومولود مبكرا.
(NS1-D1)

A participant in research site 2 referred to the unit's cramped facilities:

The unit cannot tolerate the presence of all mothers at the same time, the place will become crowded. I have no breastfeeding room. As you can see, it's only this small room. So I don't have enough space to accommodate all mothers.

لن يتحمل القسم ان تأتي اليه جميع الامهات لترضع...سيصبح المكان مكتظا "crowded"
ثم لا يوجد عندي غرفة رضاعه...فكما ترين لا يوجد الا هذه الغرفه الصغيره "متر بمتر" فلا
يوجد عندي المساحه المناسبه التي تستوعب جميع الامهات.
(NS2-N2)

Because of the crowded nature of the NICUs, a lack of privacy was seen as part of the barrier to breastfeeding. Participants described the NICUs as public places, where mothers do not feel comfortable while breastfeeding:

In the NICU culture it's hard to implement a breastfeeding strategy. It's a public place, doctors and medical students are going back and forth all the time, if a mother needs to breastfeed she won't feel comfortable, and there is no private room to do that. Pumping also needs facilities and electrical pumps which are not available here.

الثقافه اللي موجوده هنا، بتحسي انه مكان عام، الاطباء رايحين جايين يعني اذا الام بدتها
ترضع ما يتاخذ راحتها ، وما فيه غرفه خاصه، حتى الشفط بالشفاطه بيكون في اجهزه اليه
غير متوفره عندنا.
(NS1-N3)

One participant supported this further by adding:

There is no privacy here and there is no breastfeeding room.

اولا لا يوجد هنا privacy فلا يوجد عندنا غرفه خاصه بالرضاعه الطبيعيه.
(NS1-N4)

The units' design, along with the other barriers identified by the staff in both settings caused a lack of support for breastfeeding mothers. Their heavy workload meant that staff were under pressure to complete their duties and they

became more task oriented. It also led to a more fragmented approach to care (Dykes, 2006). Workload, time constraints, staff shortages and limited resources inhibit successful breastfeeding support for mothers. A heavy workload was identified as one of the major stresses for Jordanian nurses (Hamaideh, et al., 2008). This was brought up by other researchers (Furber and Thomson, 2007; Collins, et al., 2010), indicating that health professionals feel under pressure to deal with their workload. Other studies have also identified insufficient time as a major barrier for breastfeeding promotion in other hospitals (Dykes, 2005; 2006; Nelson, 2007).

The Control Relationships

The analysis of the study findings indicates the existence of power relations between the nurses and the mothers in the two neonatal units. Power struggles between nurses and parents of hospitalized children have also been identified in other settings (Lawlor and Mattingly, 1998; Lupton and Fenwick, 2001). The nurses often placed themselves in the middle of a hierarchy of power. Nursing staff were controlled by their institutions because they were working in difficult conditions with limited resources and staff shortages. Yet at the same time, they acted and talked as if they were the controller. In terms of their relationships with the mothers they were in a position of power in that they talked and acted as though they owned the place and the baby. As discussed earlier (page 83), the mothers were in a subordinate position to the nurses, who controlled their visits to, and interactions with, their infants. Nurses' accounts also demonstrated their perceived ownership of the place and the infants. For example, the following quote shows how the nurse acted to protect the baby from his own mother:

We don't allow the mothers to breastfeed not until we become 100% sure that the child is feeding well and does not get tired during the breastfeeding. I mean, it's not like we don't give the baby to his mother as being abusive!
 ولا نسمح للام بارضاعه الا عندما نكون قد تاكدنا بنسبة 100% ان الطفل يرضع جيذا ولا يتعب أثناء الرضاعه يعني احنا مش تعسفا ما بنعطيه للام.
 (NS2-N2)

These results are similar to the results of Lupton and Fenwick (2001), which identified the nurses as placing themselves as protectors of the infants and inadvertently branding the mothers as being harmful to their infants' health.

The nurses were doing all the caring activities for the infants as part of their daily care plan. Activities such as bathing, changing nappies or feeding which could

have been undertaken by the mothers were included within the nursing activities. In many instances, the nurses' bottle-fed babies who had already started breastfeeding just minutes before the mothers' arrival. Nurses also behaved as though they owned the unit when they controlled who entered it. From my field note:

A father came accompanied by his mother [the infant's grandmother] to visit the baby. The head nurse refused to let them in, arguing that the rule is that only the father and the mother are allowed to visit. The father started arguing loudly with the nurse saying that his mother came from a distance to see her grandson. At the end, the nurse won the argument and did not give the permission for the grandmother to enter the unit.

(Fieldnotes, research site 2, 08/03/2011)

This type of power was recognized by Hewison (1995) as an institutional influence that determines the language and the nature of interaction between nurses and patients, in which nurses take control and give orders based on the "unwritten" rules of their institutions (Hewison, 1995, p. 79). This form of interaction between health care professionals and mothers may generate a true barrier to effective communication patterns.

To ensure that all breastfeeding mothers in neonatal intensive care units are properly supported is a real challenge. It is time consuming and requires preparation, changing policies and providing facilities and space. However, recognition of the weaknesses is the first step toward change. As one of the health care team put it:

We must first acknowledge the existence of limitations and weaknesses from our side, and to start working on improving the current situation. We now recognize and acknowledge the existence of such failure in our system, the importance of breastfeeding, and the importance of continuing education for nursing staff. This situation needs to change for better.

يجب قبل كل شيء ان نعترف بوجود تقصير وانه من الممكن العمل على تحسين الوضع الحالي. اننا ندرك ونعترف بوجود تقصير وبأهمية الرضاعة الطبيعية وبأهمية وجود تعليم مستمر للكادر التمريضي وهذا الوضع يجب ان يتغير للأحسن.

(NS1-D1)

The knowledge and attitude of the units' staff was detrimental, yet they are crucial to the success of supporting and promoting breastfeeding for preterm infants. The health care team in the two settings recognized changes that could

lead to an enhanced health care system and better breastfeeding support such as; good working conditions, improved resources, continuing educational programmes, enhancing their autonomy and the availability of a breastfeeding consultant.

The next chapter addresses the main theme that emerged from the mothers' account and provides analysis and interpretations of their experiences.

CHAPTER 6: 'SUSPENDED LIMINALITY': THE TRANSFORMATION INTO MOTHERHOOD

This research started with the intention of exploring breastfeeding patterns and experiences in two Jordanian NICUs. I did not initially intend to explore the experience of mothering preterm infants and the importance of breastfeeding to this experience, but because breastfeeding was linked to the process of becoming a mother, this topic has emerged as a consequence of the data analysis.

The study considered the experiences of 17 mothers of preterm infants and 15 health care staff in two neonatal intensive care units in Jordan. Analysis and interpretation of the mothers' accounts' shows that they experienced an unexpected change in their pregnancy path that led to their infant being admitted to the NICU. The birth of a preterm infant itself is a crisis that places a great strain on the mother's role (Singer, et al., 1999; Lindberg and Öhrling, 2008). Mothers are not prepared for becoming a mother because everything happens quickly and unexpectedly, and they lose the anticipated delivery of a full term healthy infant (Stern and Bruschweiler-Stern, 1999). Mothers may experience a sense of failure because unable to complete the pregnancy (Griffin, Wishba and Kavanaugh, 1998). They are unable to perform their role as mothers because of the unexpected early birth and their infant's vulnerability. Many mothers experience uncertainty about their role as a mother and of their infants' health status (Holditch-Davis and Miles, 2000). Having a preterm infant places great stress on many mothers, such as being separated from their infant (Baum, et al., 2012), the high-tech environment of the NICU (Padden and Glenn, 1997), and the critical illness of their preterm infant (Affonso, et al., 1992).

In this study, the mothers' transition into motherhood was not without psychological distress as they experienced feelings of powerlessness, a lack of control, not belonging, disorientation and being neglected. These feelings are not unique to the Jordanian mothers but have been identified in many previous studies in a variety of cultures (Hurst, 2001b; Lupton and Fenwick, 2001; Flacking, et al., 2006; Aagaard and Halls, 2008).

THE THRESHOLD OF MOTHERHOOD

The threshold of motherhood is one of many that most women cross at some point during their lives. Some of these thresholds are connected with biological events such as life and death (Teather, 1999). Others are associated with social development such as adolescence and adulthood, or a change in economic role such as retirement. Others mark unexpected events such as accidents and illnesses. Motherhood is a rite of passage, a concept originating in the work of the French anthropologist Arnold Van Gennep (1873 – 1957). It is about a transformation process, a turning point in a person's life where they move from one state to another and enter a new status group. Van Gennep defined rites of passage as "*rites which accompany every change of place, state, social position and age*" (as cited in Turner, 1967, p.94).

Van Gennep developed an archetypal model of change that illustrates the phases of transformation process. A rite of passage consists of three phases, where each has its associated rituals:

- The separation or detachment rites (preliminal): begins with an end to something in our lives. It indicates the detachment of the person from an earlier state.
- The transition rites (liminal): this is the middle stage where the individual passes through and the transition to the new identity take place.
- The incorporation rites (postliminal): here the new identity has been established (Van Gennep, 1960).

The second stage of liminality is the one that has the greatest analytical importance for this research. The term liminal relates to a transitional or initial stage of a process or, occupying position at, or on both sides of a boundary or threshold (OED). Liminality is a phase of ambiguity and uncertainty, of being "betwixt and between", the person no longer belongs to the old state and not yet to the new (Turner, 1987). During this liminal period, Turner described the subject of passage ritual as "*invisible*". The "*transitional-being*" or "*liminal persona*" is "*at once no longer classified and not yet classified....neither one thing nor another....neither here nor there; or may even be nowhere*" (Turner, 1987, pp. 95-97). A person in this state often feels isolated or disconnected from the before and after states (Turner, 1987), and this creates feelings of inadequacy

and uncertainty which arise from the feeling of not fitting in or not belonging (Wendling, 2008).

Liminality as a rite of passage has been applied to many transitional periods within health related contexts to understand and interpret human behaviours. For example, women with Lupus (Mendelson, 2009), initiation of dialysis dependent life for kidney disease patients (Martin-McDonald and Biernoff, 2002), immigrant mental wellbeing (Simich, Maiter and Ochocka, 2009), women and breastfeeding (Mahon-Daly and Andrews, 2002), the experiences of loss and grief associated with AIDS dementia (Kelly, 2008), and living and dying with frailty in old age (Nicholson, et al., 2012). Only one study identified liminal properties with parenting transitions in parents of very preterm infants (Watson, 2011). This model has not previously been applied to mothers of preterm infants and breastfeeding within the context of an NICU.

Pregnancy and childbirth are transitional periods for women. The beginning of the pregnancy is the starting point for rites of passage into motherhood. A pregnant woman at this point separates herself from her formal social identity. For her,

The first days of beyond a doubt pregnancy will be ones of inner turmoil [.....] Already her conception of self is being tested – her body is doing things on its own, and she must cope with her total lack of control over these changes. By the time she has fully accepted the reality of her pregnancy and gone public with the news, neither she nor those close to her will see her quite as they did before (Davis-Floyd, 1992, p. 22).

The length of this separation phase depends on the time required to confirm the pregnancy status and on the pregnant woman to fully accept her pregnancy (Davis-Floyd, 1992).

Childbirth is “*intended to reintegrate the woman into the groups to which she previously belongs [in the case of multiparous] or to establish her new position in society as a mother*” (Van Gennep, 1960, p. 41). Giving birth is a transition that many women go through and normally transforms women into mothers in a very predictable way.

During the periods of pregnancy, childbirth and the immediate postpartum period, the woman is in the transitional liminal phase. At this stage, cultural

transformation may overlay the pregnant woman's experience of the physiological process of becoming a mother (Davis-Floyd, 1992).

CULTURAL RITUALS ASSOCIATED WITH PREGNANCY AND CHILDBIRTH

In Islamic cultures, such as Jordan, there are shared rites and rituals associated with pregnancy and childbirth that are directed towards having both a healthy mother and a healthy baby. These rituals are also seen as spiritual acts. Women get a lot of attention and support from their family members during pregnancy and the postpartum period. Generally, there is help with the housework and a desire to ensure the mother has a healthy diet. During these periods, ingestion of any harmful substances, such as cigarette smoke, is forbidden.

Although it is much shorter in terms of time when compared to the pregnancy period, the birth process itself is a very important rite of passage to becoming a mother. A woman is usually separated from her normal daily life and the people around her (Kitzinger, 2006). She lacks control over the whole situation; her body is exposed and under the control of the health care team, her movements are restricted and she may be connected to a foetal monitoring device and an intravenous drip. She is on the peak of the transformation process. Childbirth *"brings each mother into a dramatic and sometimes distressing encounter with her own body as it undergoes astonishing changes, in a matter of minutes passing through the metamorphosis of delivery to experience an empty body"* (Kitzinger, 1987, p. 172). Although the birth process is modified and changed elsewhere, it is still the norm in many Jordanian hospitals.

An Islamic birth is a desirable and a spiritual event. Many religious and cultural rituals are directed toward the new arrival. Once a child is born, the Adhan (call to prayer) is whispered into his/her right ear and the Iqamah (call for commencing the prayer) into the left, which is usually done by the father or the grandfather of the baby. These prayers include the declaration of faith and ideally take place soon after birth, so that the first word a baby hears is words of Allah's praise. A piece of softened date, if available, is then gently rubbed against the baby's palate just after the birth and before the first feed. This ritual is known as Tahneek.

Around day seven of the birth a single sheep is sacrificed for a girl and two for a boy in a ceremony called Aqeeqah, and the meat distributed to the poor. Aqeeqah is a parent's way of expressing their happiness and showing their gratitude to God. Another way of showing thankfulness to God is by shaving the baby's hair and an equivalent weight in gold or silver is donated to charity. The baby may be named on the day of his/her birth or, in some Islamic cultures, on the seventh day when the Aqeeqah is performed. It is important to choose a meaningful, lovely and good name, as it is believed that a name will have an impact on the newborn's personality. When the baby has a name, people start referring to the parents after his/her name "Kuniyah". For example, 'Um Hisham' means the mother of Hisham, and 'Abo Hisham' is the father of Hisham. Parents choose a single first name for their baby. Middle names indicate the family's ancestry; following the first name is the father's name, followed by the grandfather's name and finally the family name. Moreover, all Muslim male babies have to be circumcised within a few weeks after birth. In Islam, circumcision has no specific rituals, but is a matter of health and hygiene.

Breastfeeding is another important ritual in raising a baby, and is considered the norm in Islamic countries; it is recommended by the Quran that breastfeeding continue for two years. Islam also values the breastfeeding relationship between mother and baby and in cases where the biological mother cannot breastfeed her baby a wet nurse is employed. The wet nurse in Islam is considered a mother and thus her biological children become the baby's brothers and sisters and her husband becomes a father; future marriages between the two families is forbidden. This signifies the level of importance that Islam has for a mother's milk.

All of these Islamic rituals regarding pregnancy and childbirth are well recognised and commonly practiced by the majority of Muslims around the world. Hence, if this expected pattern of rituals has been disturbed mothers may experience great distress.

IMPORTANCE OF BECOMING A MOTHER

Women need to become mothers not only because they are biologically capable of doing so, but also because of the many social and cultural expectations and a lack of other opportunities (Oakley, 1974; Khalaf and Callister, 1997). This is true

in Arab cultures where having children is the primary motivation for marriage. Jordanian women experience personal, social and marital adversities when they are diagnosed as infertile (Obeisat, et al., 2012). They are socially stigmatized as being useless, and people may consider the infertile woman “a tree without crops, which must be cut off from roots” (Obeisat, et al., 2012, p.11). Moreover, one of the most important arguments for a man to practice polygyny and have a second wife is if his first wife is infertile, which makes Jordanian women anxious about having children:

I was extremely happy with this pregnancy as I have been waiting for it 5years to happen. I knew that I will suffer because it was not a normal pregnancy [IVF], but I accepted that with pleasure. I followed all the instructions and the guidelines that the doctor advice me to do. I had to lay down for a long time on my back.

(NS1-M5)

Being acknowledged as a mother is very important for Muslim women because mothers have the highest order of human relationships in Islam

We were very excited with the pregnancy. I had a wonderful feeling and thoughts that I will become a mother made me so happy. I couldn't wait to see the baby.

(NS1-M2)

Allah describes in the Qur'an how parents should be treated. He refers to the recognition of one's parents after the recognition of Allah himself:

Thy Lord hath decreed that ye worship none but Him, and that ye be kind to parents. Whether one or both of them attain old age in thy life, say not to them a word of contempt, nor repel them, but address them in terms of honour. And, out of kindness, lower to them the wing of humility, and say: "My Lord! Bestow on them Thy mercy even as they cherished me in childhood" (Qur'an: Al Isra', 17: 23-24).

Mothers are given a higher status because of their suffering and hardship in their role as mothers.

And We have enjoined on man (to be good) to his parents: in travail upon travail did his mother bear him. And in year twain was his weaning: (hear the command), "show gratitude to Me and to thy parents: to Me is (thy final) goal (Qur'an: Luqman, 31: 14).

This hardship was even deeper and more intense with the women in this study, where most of them went through complicated pregnancies that led to the preterm birth:

This pregnancy was different; it was the hardest. I had a really bad morning sickness. I was admitted to the hospital more than once because of the vomiting and dehydration. They gave me fluids many times. I also fell down once and I had a broken leg, and then I had to deal with infection that leads to the preterm birth. Praise be to Allah, the Lord of the Worlds for helping me going through all of that.

(NS1-M1)

In this study the expectation of the mothers of a happy pregnancy and a healthy baby were totally lost, which increased their suffering:

After I gave birth, I had to leave the hospital without her [the baby]. This increased my sense of anger and I was asking myself: with all this waiting and suffering, why have I need to leave without her? That increased my pain and suffering, I felt emotionally tired, especially when they told me that her breathing got worse and that she needed oxygen....I was thinking then: all this pain and patience to have a normal child and then this happened to her?

(NS2-M5)

THE TRANSITION PROCESS FOR MOTHERS OF PRETERM INFANTS

While in most cases passing through the rites of passage into motherhood occurs in a very predictable way, for mothers of preterm infant's it is completely unpredictable. Normally a woman gives birth to a normal full-term baby, with minimum or no complications. She then returns home to begin her role as a mother until she reintegrates into the society of mothers or gains her new identity as a new mother. The very predictability of this transformation into motherhood is precisely what generates a mother's stress when the predictable becomes the unpredictable.

Giving birth to a preterm infant is a deviation from what is expected at the beginning of a new emotional period. The difference between giving birth to a full term versus a preterm infant might be the duration the mother spends in the liminal space. In the case of full term, normal births mothers cross the threshold into motherhood very quickly however, for mothers of preterm infants being held

in the liminal period often creates a sense of vulnerability. The duration of this liminal period varies according to the infants' condition, the duration of infant's hospitalization and the degree of the mothers' participation in the care of the infant. A state of ambiguity and uncertainty regarding their role and their infants' health during this phase was clearly experienced by most women.

Liminal individuals share common emotional experiences (Turner, 1967). Women in this study shared many components of being in a liminal phase, such as powerlessness, lack of control, being detached and ignored. Women reported that they continually felt confused and detached from being mothers. They were placed in liminal positions because of these components, and were inhibited from progressing into motherhood by the health care system within the neonatal units. What the theory "rites of passage" failed to address therefore, is what happens when a person in the liminal phase cannot move on but is held in this phase. The women in this study were starting their transformational passage into motherhood, but instead of passing through they were held, indeed encouraged to be even deeper, into their liminal phase. I refer to this as being 'suspended in liminality'. Women are suspended in a liminal position until their infant's health status improves, and then they are able to move on and become transformed into mothers.

Maternal feelings started in pregnancy but were placed in a state of suspension after birth because of the infants' critical condition. The admission of a newborn baby to the NICU causes disruption in the mothers' transition to motherhood, thus delaying their identity recognition (Zabielski, 1994; Nelson, 2003). Feelings of physical separation voiced by the mothers and the restricted contacts between the mothers and their infants further suspended mothers in their liminal positions and delay the formation of their identity as mothers, and thus prolonging their in-between status. This separation prevented mothers from achieving many of their expected motherhood experiences such as caring, cuddling, touching and breastfeeding. Caring in general and breastfeeding in particular are important rites of passage into motherhood, not only for preterm infants' mothers but also for all mothers. Therefore, hindering mothers from participating in their infants' care and from breastfeeding will have a negative impact on establishing the women's new identity of becoming a mother. For a mother to establish a maternal identity is very important as it contributes to a women's psychosocial development, leading to an increase in her adaptive behaviours (Mercer, 2004).

Part of the work of the health care professionals may be seen as maximizing mothers' engagement with their babies whilst they are in the NICU unit, in order to make an earlier transition to motherhood (Shin and White-Traut, 2007). However, their use of English during the medical rounds adds to the mothers' experience of being in a liminal space as it provokes feelings of uncertainty and disorientation. All mothers in this study spoke Arabic, with some having limited English skills. More significantly, mothers were not able to understand the health team's English which contained many medical terms. This made mothers feel disorientated and uncertain as they were not engaged, which caused a lack of awareness regarding their infant's care plan.

The use of medical language generally is a source of problems and poor communication for many patients (Bourhis, Roth and MacQueen, 1989), and can easily lead to incorrect interpretations of information given, which may have an adverse effect on patient health. In fact, the US Centre of Disease Control reported that nine out of ten adults have difficulty following medical advice because it is incomprehensible to the average person (Landro, 2010).

Communication will be even more difficult and likely to prove a source of conflict and stress for patients who do not speak the same language as the health care team in addition to the barriers of medical terminology. English is the language of higher education in Jordan, in many courses including those for medical training. Learning English is considered important by Jordanians because it is an international language that is essential for acquiring knowledge and communication between cultures (Al-Haq and Al-Masaeid, 2009). However, the use of English as the means of communication between physicians and nurses in Jordanian hospitals was seen to present barriers to clear communication with parents and to hinder parents' participation in their children's care plans.

English, as the dominant global language, is considered the language of power and professionalism for Jordanians. Therefore, for many Jordanians anyone speaking English is regarded as prestigious and knowledgeable. Bearing this in mind, speaking English in the mothers' presence may build the self-esteem and self-satisfaction of the medical health care team, but at the same time, it may also intensify the mothers' feelings of powerlessness and uncertainty and distance the mothers from the health care team. In this study, the mothers were seen to interpret the use of English by the health care team in front of them as an attempt to hide unpleasant information about their children's health, which

accelerated their anxieties and feeling marginalized, heightened their suspension in their liminal position.

BREASTFEEDING AS A LIMINAL STATE

Whilst this study identified how the NICU environment and the nurses' behaviours contributed towards holding women in a liminal position by inhibiting their caring for their baby, it has been recognized that the act of breastfeed itself may also be viewed as maintaining mothers in a liminal state (Sachs, 2005). Breastfeeding positions women in liminal states as they "*struggle to keep their milk, their breasts and their relationships with their babies in their socially ordained right place, well out of sight*" (Kirkham, 2007, p. 2), in recognition of the potential for social embarrassment when breastfeeding in public place (Condon et al., 2013), such as the NICU. Additionally, breastfeeding women may have to modify their diet and alter their habits to ensure the suitability of their milk (Sachs, 2005), all of which may enhance their experience of liminality.

The use of liminality as a framework to understand the experience of breastfeeding was first introduced by Davis-Floyd and Sargent (1997), and further elaborated by Mahon-Daly & Andrews (2002). Breastfeeding mothers experience liminality as the boundaries between themselves and their infants remain blurred (Schmied and Lupton, 2001). Breastfeeding marginalises women from their everyday life and, according to Mahon-Daly & Andrews (2002), engender three different levels of liminality. The first is concerned with the physical aspect as breastfeeding women's bodies differ from their normal non-breastfeeding state. The second develops through the emotional aspect of breastfeeding, as changes occur that enable the transition of a breastfeeding woman to a new understanding of herself, irrespective of whether the breastfeeding experience was empowering or unsuccessful. The third level relates to the woman's perception of the actual act of breastfeeding as an unacceptable practice in many situations including the public place. Mahon-Daly & Andrews (2002) also suggested that the medicalisation of breastfeeding may contribute to lengthening the liminal state of the breastfeeding women, causing early cessation of breastfeeding.

Sachs (2005) elaborated on the Mahon-Daly & Andrews' three levels of liminality, noting how the physical breast changes and the embodied sensations that

accompany lactation are initially unfamiliar to the breastfeeding woman. Furthermore, she described breastfeeding as a life passage, which could be visualised as a literal passage, with the choice of opening two doors at the birth of the baby; bottle feed or breastfeed.

Developing the problematic aspect of breastfeeding, in Mahon-Daly and Andrews (2002) third level of liminality, Sachs (2005) suggested that breastfeeding women's normal mobility was challenged as they may need to accept limitations of movement in order to respond to their infant's feeding needs. She also highlighted how the concerns voiced by the mothers about breastfeeding in public, expressing breast milk, and returning to work, all demonstrated how breastfeeding is experienced as a marginal and liminal practice. A breastfeeding mother occupies a temporary and unusual phase (Sachs, 2005).

The liminality considered in these two studies related to women whose passage from womanhood into motherhood was clearly recognized by the presence of the baby and care provision by the mother. This movement and recognition, both personal and public, had not yet occurred for the women observed and interviewed in this study. Mothers whose preterm babies were being cared for in NICUs were seen to be held in a state of suspension, with minimal of any acknowledgement of motherhood, despite having delivered a baby. Their contribution towards the nourishment of their baby was also denied. Unfortunately, both issues hold the potential for detrimental effects on maternal and infant wellbeing.

Breastfeeding is a deep human experience which encompasses mothers' perceptions of themselves as women and mothers, and therefore their relationship with their infants and family (Spencer, 2008). When this is desired but not 'allowed' or supported in the NICU situation, the potential for serious and fundamental maternal distress becomes apparent. In such situations, mothers may develop a variety of coping mechanisms to assist them through this difficult passage. In this study, it became apparent that many of the mothers found comfort through their religious beliefs and practices. Whilst this may be specific to Jordanian or Moslem societies, it highlights the importance religion holds for some people living through difficult situations, suggesting this is worthy of recognition and understanding by staff caring for such individuals.

SPIRITUALITY DURING THE TRANSITION PHASE

During difficult situations and periods of uncertainty, spiritual and religious perspectives can provide a context where anxieties and stress may be faced (Yuen, 2011). During the stage of transition, it is often considered that a person comes to believe in the protective powers of the divine (Turner, 1969). Almost all the participating mothers expressed a sense of spiritual awareness, a force or a higher power beyond their control that helped them to cope with their fears and anxieties.

Some research reifies spirituality and religiosity as important components of health and well-being for many (Baumiller, 2002; Callister and Khalaf, 2010; Yuen, 2011). Pregnancy and childbirth have been particularly perceived as spiritual events throughout history and across cultures because of the miraculous processes involved (Obeidat and Callister, 2011; Linhares, 2012).

The discovery of pregnancy is a life-changing event; it initiates an ontological process of transformation, which, all being well, culminates in the birth of a child, a mother, a family. Yet even if the pregnancy does not continue to term for whatever reason, something has changed forever in the life of that woman. She can never return to her pre-pregnant state. To be pregnant is to be touched by the creative power of something infinitely greater than self and such proximity with the divine is transformational.

(Moloney, 2007, p. 122)

Callister and Khalaf (2010) identify childbirth as a time to get closer to God and the use of religious beliefs and practices as powerful coping mechanisms. In the current study, issues of faith dominated the mothers' narratives. Mothers regarded what happened to them as the will of Allah. During this vulnerable time, "*connecting with a spiritual source for insight is essential to activate the deeper powers of a rite of passage,*" (Wendling, 2008, p. 3) and, for many mothers, to reduce their fears of the unknown. Mothers concerns were lessened by the belief that everything in their lives was pre-planned by Allah, and that He, the most gracious and most merciful, is taking care of their infants:

Our life is in Allah's hands. I mean "if the nation were gathered to harm you with anything, they would harm you only with something Allah had already planned for you.

(NS1-M6)

THE INCORPORATION PHASE

The final phase of rites of passage is the incorporation phase, the rites of childbirth deemed to reintegrate women into the groups to which they previously belong as mothers, or to generate their new identity as new mothers (Van Gennep, 1960). The experience of having a preterm infant in the NICUs delayed incorporation and affected mothers differently. For first-time mothers, the rites of passage were most acute, as mothers were facing the challenges without previous experiences. This passage is also a major transition in the women's roles; it is moving from one status into another, a more honoured one. A woman is becoming a mother, and this can only happen once. For experienced mothers, however, it is a matter of extending the family and accommodating their preterm infants into this family. Their transition is from mother to mother, which is an enhancement of an already gained status. For both, first-time mothers and experienced mothers, during the integration phase, liminality is replaced by moving into the new identity and/or having confidence in their mothering roles with the preterm infants. This phase comprises the true feeling of and acting like a mother.

What might be gained at the end of this transition process however may be quite different than what was initially expected (Wendling, 2008). For some mothers of preterm infants, the transition ends with the infant's death, and thus the transition to motherhood will never be achieved with this particular pregnancy. For such women, the liminal stage may become a way of life rather than a transitional period, as they will never proceed to the next stage of what Van Gennep called postliminal or incorporation. Turner (1987) argues that some people may not move beyond this liminal space. In fact, these women will return back into their preliminal state, as just women. They are grieving for the loss of their infants, but also for their lost status. This situation is devastating for the first time pregnant women, because the long period of the pregnancy and the short period of being mothers is not acknowledged by their community.

The women's stories about their time in the two NICUs supported the argument that they experience being suspended within their liminal positions. This study argues that while these women were going through their transition into motherhood, their infants' admission to the NICU held them in a liminal position. Being suspended in their liminality may have an impact on the mothers' psychological status and on their relationship with their infants. Nurses and

midwives at the NICUs play an important role in helping mothers throughout their transition to motherhood. Making nurses and midwives aware of the different stages that mothers go through may develop a greater understanding of the mothers' needs while they are trying to adjust to their new roles as mothers in the stressful situation of having a preterm infant.

CHAPTER 7: ATTITUDES, INSTITUTIONS AND POWER

With the teaching of Islam and the cultural characteristics of the Arab, it is difficult to explain some of the nurses' negative attitudes toward the presence of the preterm infants' mothers in the neonatal intensive care units; as well as their unsupportive attitude towards supporting and promoting the breastfeeding of preterm infants within these units. This chapter analyses the views of healthcare staff in the two neonatal intensive care units, it considers the inconsistencies in their attitudes and beliefs, the presence of institutional control and the power struggle between mothers and nurses.

Islam teaches Muslims the proper way of dealing with others and of maintaining good relations with each other. Islam considers believers to be brother and sister and stresses the need of treating each other with mercy and kindness. Allah said:

The believers are but a single brotherhood, so make peace and reconciliation between your two (contending) brothers. And fear Allah, that ye may receive mercy. (Qur'an: Al Hujurat, 49:10).

Prophet Muhammad (PBUH) also emphasized this further, stating: "*None of you truly believes until he loves for his brother what he loves for himself*". On another occasion he said: "*The likeness of the believers in their mutual love, mercy and affection is that of the body. When one limb of it complains, the rest of the body reacts with sleeplessness and fever*". These statements by the Prophet show the humanity that Islam commands. One cannot be a true believer until he loves for others what he loves for himself, and when treating others the way he wishes to be treated.

Culturally, generous hospitality is highly valued in the Middle East and has been one of the distinctive features of Arabian culture throughout history. It is because of these religious and cultural beliefs, that health care providers' attitudes, mainly the nurses, appear so strange.

COGNITIVE DISSONANCE

It was clear from their discussions, that health care professionals believe that “*breast milk is best*” for both full-term and preterm infants. However, they did not support breastfeeding because of all the perceived barriers they mentioned, and because these barriers were out of their control. An insight into such contradictory beliefs and behaviours is offered by Leon Festinger (1962). Festinger suggested that people try to find cognitive consistency in their beliefs and attitudes in any situation where two conflicting cognitions (knowledge, opinion or belief) exist. He noted:

Persons sometimes find themselves doing things that do not fit with what they know, or having opinions that do not fit with other opinions they hold (Festinger, 1962, p.4).

An example is a person who may know that smoking is bad for his health and yet continues to smoke. This person will try to achieve consistency, “*consonance*”, by rationalizing his inconsistencies, “*dissonance*”, to himself on the basis that smoking is also an enjoyable behaviour, the chances of suffering from health problems are not serious, and that he would put on extra weight if he stopped smoking which is as bad as smoking itself. Thus to continue smoking is consonance with his ideas about smoking (Festinger, 1962, pp.2-3).

When dissonance is present, the person will feel uncomfortable; he/she will try to reduce or eliminate it and will avoid situations that may increase dissonance in order to achieve consonance (Festinger, 1962). Many approaches could be used by someone trying to eliminate feelings of dissonance (Pickens, 2005, p.47);

- Eliminating responsibility or control over an act or decision.
- Denying, distorting, or selectively forgetting the information.
- Minimizing the importance of the issue, decision or act.
- Selecting new information that is consonant with an attitude or behavior.

The health care team’s attitude toward supporting breastfeeding in NICUs indicates cognitive dissonance, as they are aware of what should be done, but do not do it.

My personal belief is that breastfeeding is the best way of nutrition, but what is the possibility to apply such strategy here? I think is a very low possibility.

(NS2-N1)

Their belief that breast milk is the best food for preterm infants is dissonant with the unsupportive behaviours they display to the mothers. In order to achieve consonance, they are trying to eliminate their sense of dissonance either consciously or unconsciously.

Considering the health care team's behaviours in the light of the cognitive dissonance theory it suggests that they are rationalizing their behaviours and justifying their continued unsupportive behaviours by:

1) Eliminating their responsibilities *"We do not have educational brochures or something like that... this is not our responsibility"* (NS2-N2). They are abdicating their responsibilities to others *"You know, we are too busy with the other babies, we can't have enough time to sit there with the mothers and give them appropriate teaching. They need to have a breastfeeding specialist nurse to do this job"* (NS1-N1).

2) Denying and distorting certain information such as, for example, that the breast milk is superior to the formula: *"frankly, I did not feel any difference. After the baby survives the first critical period of his life, either he takes formula or breast milk, he will gain weight and discharge from the unit"* (NS2-N2).

3) Minimizing the importance of the issue of breastfeeding within their units; *"saving the baby and keeping him alive until being able to feed and return to his home, is our priority. Frankly, breastfeeding is not in our agenda"* (NS2-N5).

4) Selecting information that is consonant with their behaviours, such as finding new knowledge or information that is consistent with their beliefs. Someone with dissonance will seek information that decreases dissonance and avoid any information that may increase dissonance (Festinger, 1962). They may rationalise, for example, that formula is as good for the preterm infants as the breast milk, as the previous quote indicated, or that it is more convenient to use than the breast milk, at least under the current arrangements.

we accept the idea of implementing a breastfeeding strategy...but if each mother wants to come and breastfeed her baby and wants to stay at the unit for 24 hours a day, then it is not acceptable, because preterm babies as you know have low immunity.

(NS2-N3)

Another nurse said:

We prefer for the pumping to take place at her house because we worry a lot about infections and sepsis if she pumps here. As you know, most patients here are premature babies who have a compromised immunity and may get infections so easy. Mothers may themselves carry certain bacteria.

(NS1-N2)

In these quotes, nurses used a well-recognized fact about the low level of immunity for preterm infants to justify their unsupportive behaviours. This reminded me of a famous Arabic statement: “كلمة حق أُريد بها باطل” which is best translated as “A truth told with a bad intention”. This may imply that they are not motivated to change the existing arrangements for better breastfeeding practices.

The health care team also tried to eliminate their sense of dissonance by convincing themselves, and the others, of the existence of many barriers that interfere with the achievement of successful breastfeeding. They rationalise why they are not doing it by giving a list of reasons that, they believe, make it impossible to implement such strategies within their units. Once they have established there are barriers to breastfeeding, then there is no point encouraging mothers to come and breastfeed because of the existence of those barriers.

You have seen that there are no available facilities for pumping and storing breast milk in the unit, and you have seen the breastfeeding room available here [referring to its small size]. We do not have any facilities for the mothers to come and breastfeed here. But in spite of all of that, we do encourage them to come and breastfeed their babies.

(NS2-N1)

There are other ways of reducing dissonance, such as preventing its occurrence in the first place (Baker, 2003). This, according to Baker, requires the person to ignore, avoid, or refuse to accept any new information that is dissonant from what is already known. Finally, another important way to deal with cognitive dissonance is by changing the environmental cognitive element by changing the situation to which that element relates; i.e. changing the NICU's environment, so that it will become facilitative rather than inhibitive. This option, however, is not always possible and is much more difficult to achieve than the other strategies, because they must have a sufficient degree of control over their environment (Festinger, 1962).

INSTITUTIONAL POWER

What the theory of cognitive dissonance failed to cover was what happens when someone is forced to behave in a way that is contrary to his/her opinion or belief. This may be an institutional power that forces a person to behave in such way. Large institutions, like hospitals, develop strategies to keep everyone under control (Kitzinger, 2006). The characteristics of such hospitals and their health care professionals correspond with many of the characteristics of Lipsky's work of street-level bureaucracies.

Michael Lipsky (1980) coined the term "*street-level bureaucracies*" to indicate public service agencies whose workers "*interact directly with citizens in the course of their jobs, and who have substantial discretion in the execution of their work*" (p.3). The workers deemed to be "street-level bureaucrats" , are teachers, police officers, social workers, judges, public lawyers, health workers and many other public employees, who tend to have much in common because they experience similar work conditions . Lipsky (1980) suggested that street-level bureaucrats often perform contrary to their own goals, and this is what Festinger's theory failed to cover. Although nurses are expected to act as patients' advocates, this can be incompatible with their organization's expectations. Commonly they work under conditions of limited resources, tight schedules and unclear objectives that force them to develop certain work routines to manage their workload.

Among strategies that large institutions, such as hospitals, develop to keep their staff under control are the nurse-ratio and time restriction (Lipsky, 1980). My research mirrors Lipsky's theory in that most of the health care professionals stated that it was difficult to perform their jobs well with the limited resources they had, including a lack of breast milk pumping machines and storage facilities and with their excessive workload. Working under such conditions was described as a "*wounded workplace*", where "*relationships are dysfunctional and people are hurting from overwork and under appreciation*" (Lynch, 2002, p.183). Hunter and Deery (2005) have suggested that dealing with the organizational demands while caring for women presents a key source of emotion work.

The struggle between the organizational needs and the mothers' needs was seen as fundamental for street-level bureaucrats who "*must find a way to resolve the incompatible orientations towards client-centred practice on the one hand*

and expedient and efficient practice on the other" (Lipsky, 1980, p.45). This meant that, the health care team had to respond to the mothers' requirements with very limited information, time and resources; therefore, they developed routines in order to feel that they were doing their job properly. Staff members performed routines in the work place to give them a feeling of being in control and to help them manage their time (Dykes, 2005). As neatly summarised by Hunter in her consideration of emotional labour at work:

"The prevailing 'production-line' approach requires conformity, task orientation and suppression of emotions in order to ensure that institutional goals are reached. Care becomes reductive and fragmented, and the work of the midwife becomes goal oriented rather than client focused". (Hunter, 2010, p. 257).

Such working conditions generally restrict the development of any form of relationship between health care providers and mothers, as health care providers will tend to make rapid judgments and rapid actions, leaving the mothers' actual needs unmet (Dykes, 2005). This relationship is not a balanced one; it is "*a relationship of 'unidirectional' power*", [in which] *street-level bureaucrats sometimes....dominate their interactions with clients....they....teach clients to behave 'properly'. They structure work patterns to maximize control over clients independent of any policy objectives.*" (Lipsky, 1980, pp. 58-59).

Hunter (2001, 2004, 2005, 2006, and 2010) provided important insights into the midwives' experiences of emotion in work. She suggested that emotional labour is primarily the dissonance generated by the co-existence of conflicting ideologies of practice. Midwives experience a tension between the women's demands on them and their institutional workload, a tension between the ideal and the reality. The resultant conflict between the two; 'being professional' and 'being with woman' is a key source of emotion work which leads to a variety of negative emotions such as anxiety, anger and frustration. Such emotions will affect the emotional wellbeing of the midwives and consequently the quality of care provided by them (Hunter, 2005).

When considering the emotion work of midwives, three significant and interconnected key areas exist: the impact of context and organisation of maternity care, midwife-woman relationships and collegial relationships (Hunter, 2010). This means that the context in which care is provided impacts on the

quality of relationships between midwives and women and between midwives themselves.

Working in a NICU with preterm infants is even more charged given their vulnerability and preciousness. Nurses in this study faced a conflict between the need for providing a critical care for both vulnerable infants and their mothers, while maintaining an institutional work demand. With the limited resources and time restriction, nurses perceived the family and mothers' needs as less important than the specialist care needed for the preterm infant.

The results of this study emphasised issues of concern for the medical health care team which correspond with other studies, describing how issues such as shortage of resources, case loads and space and time restrictions have a negative impact on the quality of care provision and support for mothers (Dykes, 2005; Furber and Thomson, 2007). Nursing shortages caused an increase in workload, which was found to be one of the most common stresses among Jordanian nurses (Hamaideh, et al., 2008). Nurses in Jordan are faced with many challenging working conditions including heavy workloads, limited autonomy, an unsupportive working environment and feelings of inadequacy (Oweis, 2005; Jordan Nursing Council, 2008; Al-Maaitah and Shokeh, 2009), which contribute to job dissatisfaction, burnout and high rates of turnover (Al Ma'aitah, et al., 1999; Jordan Nursing Council, 2008). Almost all the participating staff raised these issues. Their comments were full of resentment:

Our shift is 8 hours; each infant has to have a feed every 3 hours during the shift. The work load is a huge barrier to help with breastfeeding especially when we have critical cases. Usually, we have 8 – 9 nurses per shift, where the number of babies sometimes reaches 40. If they [managers] want us to help with breastfeeding they have to hire more nurses. Today, for example, I have 5 nurses for 25 babies, 5 babies for each nurse. Today is considered a picnic for the nurses when compared to the regular working days.

(NS2-N1)

While this high patient to nurse ratio was found in the research setting 2 NICU only, the nurses within the research setting 1, who had a patient to nurse ratio of no more than 3 – 1, described having the same difficulties in coping with the heavy work load and time pressure. This may be explained by what Dykes (2006, p. 129) has suggested that practitioners often adopted a “*busy mode*” regardless of the ward's state. This was mainly because of the unpredictable

working conditions for the practitioners, and once they developed a certain way of communicating with women it becomes a pattern of behaviour (Dykes, 2006).

There were other factors seen to interfere with the nurses' performance. According to Widaningrum (2006), the performance of health care providers within the health care system depends also on their knowledge, skills and motivation, which can have a major influence on care provision. In a recent study, lack of incentives and inadequate information for Jordanian nurses were seen as contributory factors for inefficient operations (Ajlouni, 2011). This was confirmed by one participant:

The problem with our Jordanian hospitals is that they do not give nurses leadership roles for decision making. There is also no incentives, either moralistic or materialistic, in order to increase their assertions on the success of the breastfeeding. It is an extra work for them without additional incentives; they may thus question the benefits that may be acquired from their cooperation in this matter. I believe that the lack of such incentives reduces the chance of gaining the nurses support for this process.

(NS1-D1)

Nurses believe that their hospital institutions undermine their autonomy, which places them in a subordinate position to the administrators and the physicians, with very little support for their profession (McParland, et al., 2000). Such a perception was mirrored in this study where nurses within the two units frequently pointed out that they receive very little support from their institutions:

And they [the hospital management] do not offer any continuing educational programs for us. The administrative side should have the desire to create a breastfeeding program because the presence of breastfeeding consultant alone is not enough as she can't do the job alone.

(NS1-D2)

While the health care providers at the two neonatal units were trying to provide good quality of care for infants, the nature of their institutions restricted their attempts in providing more holistic family care. This led to more insincere work and to display of controlling behaviour over the infants' mothers. Staff with a lack of motivation to work will pass on their feelings of oppression and under-appreciation to their clients, and their work will resemble early factories (Dykes, 2006). This resonates with Freire's ideas of "*pedagogy of the oppressed*" where "*during the initial stage of the struggle, the oppressed, instead of striving for*

liberation, tend themselves to become oppressors, or sub-oppressors” (Freire, 1972, p. 22). The oppressed groups are believed to adopt the traits of their oppressor and become oppressors themselves. Nurses in the two units were seen to be oppressed by their institutions as they were devalued; there was no investment in them and no recognition of their worth. As a result, they become oppressors themselves over the mothers, so they had no recognition of the mothers’ worth and invested nothing in the mothers. They did not help the mothers to become the mothers they could be. Part of this view resonates with Michel Foucault’s ideas of power relations. Although Foucault (1972, 1980) believed that power is not something that institutions possess and use oppressively against individuals, he did believe that power establishes a network through which it freely circulates in our day-to-day interactions and that “*the individual which power has constituted is at the same time its vehicle*” (Foucault, 1980, p. 98).

According to McParland et al. (2000), nurses often use language to exert power over patients, or the mothers in this case. In many situations in this study, interactions between the nurses and the mothers were by way of giving instructions and orders

One nurse noticed her [the mother] long nails and said to her: you got to trim your nails otherwise I won’t allow you to hold your baby. The mother smiled and replied that she just get used to the long nails.

(Fieldnotes, research site 2. Tues.22.2)

The following example from the mothers’ accounts also demonstrated the power of language that nurses used over them:

I returned back the second day at 2 am, and then at 3 am, the nurse said to me: you come to the unit so often, why you are doing that, you suppose to come once a day. I do not have an answer. I just replied: I do not know, I do not know. The nurse said: go to your room [as she was still in-patient] and come back in the morning only, eight o’clock will be good, just after cleaning up the unit.

(NS2-M6)

In everyday life, Bourdieu (1991) argued that language is not only used as a way of communication, but also as a mechanism of action and power. Through the

use of a certain language an individual can exercise his/her social power and impose his/her authority; *"utterance are not only...signs to be understood and deciphered; they are also signs of wealth, intended to be evaluated and appreciated, and signs of authority, intended to be believed and obeyed"* (Bourdieu, 1991, p. 66). The symbolic relation of power and authority depends not only on the linguistic properties, such as in this case the use of English, but also on the non-linguistic properties such as characteristics of the voice, social qualities of the speaker for example his/her aristocratic and academic titles, uniforms and his/her institutional attributes (Bourdieu, 1991, p. 70). The medical health team, in this study, imposed power over the mothers by carrying out certain behaviours including using incomprehensible language.

OTHER FORMS OF POWER

Another consideration in the power differential observed between mothers and the health team providers was their perceived knowledge and expertise. The health care professionals' specialized knowledge and expertise placed them in position of authority over mothers. According to Bourdieu (1990), there are many forms of power that can be used to rank ourselves above others in our interaction with them. In his theory of practice, Bourdieu tries to explain individual and group actions within the social world through the connections between structure, power and agency. He discussed the interactions between people and social structures. He concluded that, the actions of social groups include influences from cultures, traditions and objective structures within their society. He developed concepts of field, capital and habitus to represent these influences within the social world.

A field for Bourdieu, is an accumulation of specific social positions controlled by given power relations through which individuals struggle over desirable resources (Bourdieu, 1990). Habitus is the basis for the person's regular mode of behaviour. It includes the person's beliefs, dispositions and personal orientations, which does not emerge spontaneously from the individual mind and character, rather through the persons growing interaction with various 'fields'. A person's range of positions in their social fields is displayed by the distribution of forms of capital. Fields, therefore, are sites for power over capital. Capital can take a variety of forms: economic, cultural, social or educational. These forms

represent the means of power that someone uses to improve their position within the field.

What is relevant here is Bourdieu's idea of the presence of symbolic power in social relations that gives more authority for some over the others. Behague et al. (2008) suggests that hospitals are loaded with habitus of employment, kinship and productive social fields through which social, economic and healthcare conflicts and power struggles emerge, causing patients to react in a subordinate passive way. The health care teams within the two hospitals occupy different social positions to the patients and their families, which categorize them as separate class entities. They occupy a position of authority based on their cultural capital such as expertise, knowledge, uniform, gender, age, and the use of medical terminology and English that puts them in a position above the mothers.

Despite the institutional differences between the two hospitals' NICUs, the issue of power differential emerged strongly in both, although, this may be due to different reasons. Differences exist between the staff at the two hospitals in relation to the forms of power that they have. For example, in research site 1, age proximity between the staff members and the mothers, as well as their shorter years of experience as nurses reduced the authority imposed by them over the mothers. Whilst at site 2, the staff members are generally older than the mothers and have more experience, which gave them more power and authority. However, although younger and less experienced, the staff members at site 1 have a higher social class than members of site 2, mainly because they are working in a higher social class and more advanced hospital, which may contribute to their imposed, yet lower, level of authority. While these differences may demonstrate different forms and levels of symbolic power among the staff at the two hospitals, it did not change the fact that there exists a level of power and authority within these units.

In terms of the hierarchy of hospital staff nurses occupy a position in the middle, indicated by the various lines of authority between the nurses and other hospital personnel, where physicians occupy the highest level in the hierarchy of authority. In Jordan, most health care institutions place nurses in a subordinate position to administrators and physicians (Al Ma'aitah, et al., 1999). Nurses represent the hospital administration by implementing the hospital policies, and represent the physicians by following their instructions in treating patients.

However, their interpretation of either policy or patient treatment is limited. Nurses with less authority have a correspondingly reduced level of control of their practice. Gaining control is very important because it relates to a persons' desires and needs to feel in control in order to maintain predictability. Low levels of control are related to occupational stress with expected consequences on patients and their families and increased staff burnout (Dykes, 2006).

Nurses generally, and in Jordan specifically, need to be able to have an active role in decision making and require adequate resources to meet the needs of patients and their families (Oweis, 2005). It is crucial to increase our understanding of the mechanisms and manifestation of power that exist in the hospital setting. Efforts can then be made to develop effective communication skills between nurses and families, as well as on maintaining appropriate professional attitudes.

To Conclude

To sum up, both the mothers' and the nurses' experiences within the NICUs can be likened to the whirlwind of a storm (Figure 3), in which the baby is the centre of attention, the nurses are caught up within the institutional care model and the mothers are pushed to the periphery. It is a whirlwind of emotions for both mothers and nurses. Whilst the preterm babies rest in the calm eye of the storm from admission to discharge, the nurses and the mothers are caught up in the whirlwind with their emotional burdens whirling around them. These burdens make the nurses more task-oriented and cause them, inadvertently, to push the mothers to the periphery of their infant's care. Consequently, the mothers suffer tremendous emotional upheaval that entraps them in a suspended liminality. The more difficult the working conditions are, in terms of staff shortage, limited facilities and time constraints, the stronger the whirlwind will be, not only for nurses, but also for the mothers and their infants.

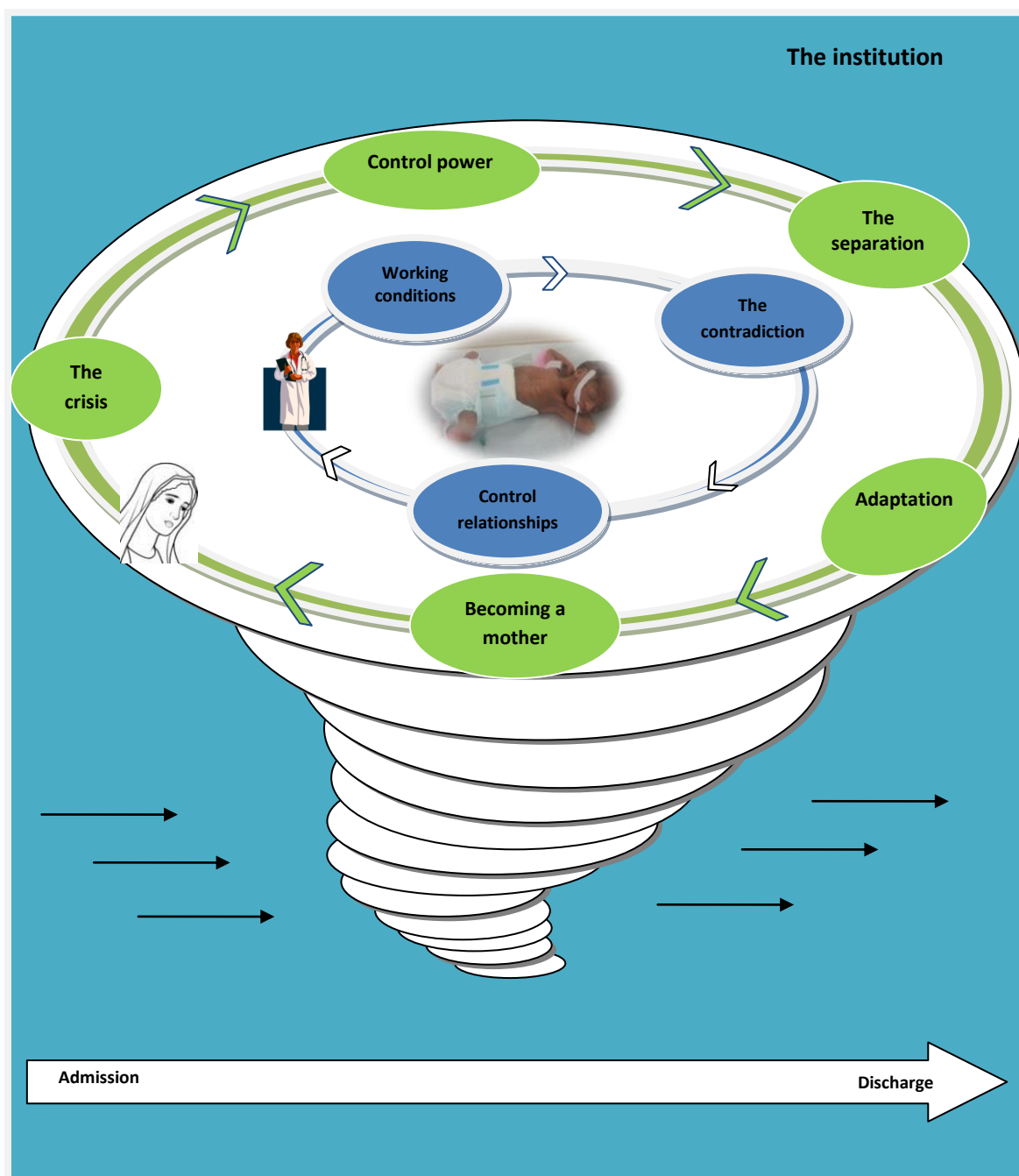


Figure 1: The storm model– image of the baby taken with permission. Source: personal collection

CHAPTER 8: IMPLICATIONS AND CONCLUSIONS

This study explored both mothers' experiences of breastfeeding preterm babies, and health care professionals' attitudes and practices in supporting and promoting the breastfeeding of preterm infants, in two Jordanian NICUs. This chapter will address the implications for practice, future research, the research limitations and the conclusions of the research findings.

SUMMARY OF FINDINGS

The study adopted an ethnographic research design that involved two hospital-based neonatal intensive care units in Northern Jordan. It aimed to provide a description, and to understand attitudes and behaviours towards breastfeeding practices within the two units. The study sought to identify factors that promote or interfere with early initiation of breastfeeding premature infants, observe and describe the practices of breastfeeding preterm infants and identify any variation between the medical staff and the mothers' perceptions of breastfeeding support within these neonatal intensive care units. It is my understanding that this is the first ethnographic study in Northern Jordan to highlight these important topics.

By carrying out participant observations for a period of 6 months, I was able to observe social processes such as breastfeeding activities, nursing interventions, and parent participations that took place in the NICUs. To gain more insight into the mothers' and the health care professionals' beliefs, semi-structured interviews were undertaken. The data from the participant observation and interviews was analysed using an inductive approach, in which themes emerged to generate a picture of the different experiences.

Although my initial aim was to explore the breastfeeding practices within the two NICUs, other significant issues emerged. Observational data indicated how, in the sites studied, the nurses caring for the preterm infants assumed total responsibility for the baby, effectively marginalising the mothers. Two main areas were then explored: the first highlighted the mothers' experiences of having a preterm infant cared for in a NICU; the second concerned the nurses' experiences of caring for infants in NICU with particular regard to feeding practices. Both issues were considered with regard to the influence the

institutional care model for preterm infants and their mothers impacted on the way that these mothers could look after their children. I argued that the mothers were held in suspended liminality and that this may be significant for their long term parenting abilities.

For the last few years, efforts to increase the awareness of Jordanian mothers' of the benefits of breastfeeding were seen to be successful (Mubaideen and AL-Saraireh, 2006). In this study, all the mothers were aware of the importance of breastfeeding and wanted to breastfeed. However, they faced many obstacles that prohibited them from practising breastfeeding or other maternal activities such as cuddling or sometimes even touching their babies within the neonatal units. There was little evidence that mothers were assisted by the nurses to build meaningful relationships with their infants. Nurses were the primary carers of the infants doing even the simple activities that mother could do such as changing nappies. Under these conditions mothers did not feel themselves to be real mothers; rather they experienced feelings of being unimportant and unwelcome, feelings that placed them in suspended liminal positions because they had not yet become independent mothers.

Mothers in this study spoke of a struggle with the NICUs' staff as they lacked control over their infants. Their visits were guarded and controlled by the neonatal units' staff. They wanted to spend more time with their infants, to be actively involved in their care and to be able to use a breast pump and store their milk at the hospital.

Nurses also spoke of a struggle when working in the NICUs. The two neonatal units were viewed as institutions in which many inhibitive caring behaviours took place, not only for the mothers, but also for the nurses. The institutional model was seen to generate task oriented activities that caused the nurses to work in an unsupportive way to the mothers. Some of the identified institutional barriers included: staff shortages, time restrictions and busy schedules, which contributed to a stressful environment for the nurses. Stress levels among nurses are known to increase when they have to look after an increased number of patients in the same number of working hours (AbuAlRub, 2004; AbuAlRub, Omari and Al-Zaru, 2009). Other barriers included lacking pumping facilities, space restrictions and a lack of continuing educational programmes. Limited space in the NICU units meant that the parents were only encouraged to come in certain times. These barriers restricted the nurses' abilities to support and interact with the mothers,

and increased their burnout. Burnout among nurses is generally considered a major problem and has been linked to reduced job performance, increased tardiness and absenteeism, loss of productivity, increased turnover and many physical and psychological health problems (Wright and Bonett, 1997; Hall, 2005b; Jennings, 2008). Yet interaction with mothers can make a task meaningful that can mitigate burnout (Stevens, 2003). Although babies need an enormous amount of care, the mother-baby dyad needs an emotional element of support, which is an important part of the care process. Thus, supporting mothers may help nurses and midwives to achieve a high level of job satisfaction, less stress and decrease burnout (Stevens, 2003).

The study findings support previous research that indicated that the health care professionals play a significant role in the mothers' behaviour and decision to breastfeed. Staff behaviour can have an important effect on the mothers' confidence in their abilities to breastfeed their preterm infants. Therefore, actions that provide a supportive environment, not only for mothers, but also for the health care professionals is essential to improve the overall quality of patient care.

Although Jordan has seen gradual improvement in breastfeeding promotion practices, the progress rate still below the universal recommendations (UNICEF, 2008). It was noted that the Jordanian hospitals in this study follow the western model of care, which is seen to have succumbed to similar detrimental effects of an institutional model of care. This regime portends further deterioration in breastfeeding rates in Jordan. Adding to that is the negative impact it imposes on the psychological wellbeing of the vulnerable mothers. The results of this study suggest an urgent need to target breastfeeding programmes in the NICUs in Jordan. As was noted before, breastfeeding in Jordan and in other Islamic countries has a religious basis, therefore incorporating religious teaching in the feeding policies may increase both the mothers' and the health care professionals' commitment to breastfeeding success. The following section will discuss in more details the implications and recommendations of the study findings for practice.

IMPLICATIONS FOR PRACTICE

As discussed earlier, the findings of this study provide insights into mothers and nurses experiences of breastfeeding in NICUs. If addressed, these findings will help improve the practice and nursing care for preterm infants and their families. It could be used to guide the policy maker in the two Jordanian hospitals to develop appropriate strategies to improve mothers' experiences and help them in their transition to become mothers. While the study findings are supported by previous studies related to breastfeeding a preterm infant in other cultures, this work brings to light new understanding of how breastfeeding is connected to the process of becoming a mother within the context of the two Jordanian NICUs. It also highlighted issues related to the nature of nursing work undertaken within the two NICUs. These institutions promoted the task oriented approach and reduced the professional identity of nurses, who became task oriented and put less effort into developing their professional knowledge with up to date evidence based practices.

These issues are important to consider when providing good quality of care. On one hand, mothers need to be able to look after their babies. This is significant not only for the mothers' identity and psychological wellbeing, but also for the preterm infant's wellbeing, which relates to the function of neonatal intensive care units. On the other hand, this is also significant for the nurses who are required to work according to their professional standards of care, which is difficult within the existing working conditions.

The insights gained from this study can be used to enhance staff understanding of the mothers' journeys within the two neonatal units. This study found that for the mothers delivering prematurely, the rite of passage to becoming a mother is suspended in the liminal phase. Although this suspended liminality is about mothers within the two studied settings, there is the potential that this may be experienced by any mother having an infant in a neonatal intensive care unit, which relates to their abilities to look after their babies within these units or once they are discharged.

Moreover, the understanding gained from this study indicated that the initial stage of transition into motherhood was a time of vulnerability. In order to support them and to help make the transition to motherhood with minimal distress, nurses and midwives need to understand and recognize the vulnerability that

these mothers experience. This vulnerable time, the mothers came closer to their religious and spiritual beliefs and practices, which, if facilitated within the NICUs, may promote their adaptation process and thus made the transition into motherhood less stressful.

Staff training is useful if offered regularly to provide them with an understanding of the mothers' experiences. If the health care professionals are aware of the transitional periods that mothers undergo during their infants' presence in the neonatal units, they may develop greater appreciation and understanding of the mothers' experience. It is also important for nurses and midwives to keep in mind that each mother experiences the transition differently. Some mothers may adapt easier and make the transition in a shorter time while others may take longer to make the transition. Thus an individualised care plan is recommended.

This study has identified breastfeeding and offering breast milk as central to the experience of becoming a mother. To feel like a real mother, mothers need to have unlimited access to their infants and to be empowered to take control and improve their experiences by breastfeeding their preterm infants. Therefore, it is useful for nurses and midwives to develop strategies that enhance the mothers' participation in the routine care of infants' by allowing them to practice breastfeeding and pumping breast milk whenever possible. To include the mother-infant dyad, health care professionals at the NICUs may need to modify their practices and environment. This could be addressed by substituting the infant-focused care approach with the family-centered care approach, which aims at improving parents' competence in their infants' care before discharge from hospital (Axelin et al., 2010). In a family-centered care approach, parents are expected to take some responsibilities and to participate in their infant's care plan. It increases the mothers' competency in understanding their infants' cues and behaviours, which proved to give greater confidence in their role as a mother (Broedsgaard and Wagner, 2005).

The use of the family-centered care approach has been very well received by NICU's staff in different settings (Westrup, 2005) and was seen to have a positive influence on the mother-infant relationship (Davis, Mohay and Edwards, 2003), it would therefore appear to be appropriate to implement it within the Jordanian NICUs. Providing more opportunities for mothers to make contact with their infants by holding, touching and spending more time at the NICU, is beneficial because it encourages nurturing relationships between the mothers

and their infants. This provides the basis for the development of self-confidence, security, emotional stability, readiness to learn and social competence for the infants' mothers (Talmi and Harmon, 2003). This relationship is also important for the preterm infants because it is central to their development (Bowlby, 1965). When mothers lose the opportunity to develop meaningful relationships with their infants, they are likely to carry on feeling powerless and helpless, and may engage in avoidance and distancing behaviours which restrict their ability to interact with their infants (Fenwick, Barclay and Schmied, 2001a; Lupton and Fenwick, 2001), and thus impact on the child's developmental process.

More flexible hospital practices would help to involve mothers in their infants' care plan. Some modification of the spatial orientation of NICUs such as providing comfortable seats beside the incubators, offering leaflets to mothers welcoming them and indicating what they can and cannot do and arranging welcoming sitting areas, with drinks machines, where parents can relax might be helpful. This will allow a more nurturing environment that may facilitate stronger mother-infant relationships.

Staff attitudes and behaviours toward breastfeeding are also important to mothers because they provide input into the mothers' decision to breastfeed (Bernaix, 2000; Ekström and Nissen, 2006; Brown, 2011). Therefore, health care professionals working in NICUs may need to focus on strategies for putting available research into practice and for using the research to establish guidelines for breastfeeding preterm infants. Health care professionals also need to identify barriers from the mother's side that may hinder the future continuation of breastfeeding. This may be achieved by providing individualised, research-based teaching strategies to assist the breastfeeding mothers in developing a sense of competence. If mothers do not feel comfortable with their infants, their anxiety can have an adverse effect on sustaining breastfeeding. In addition, protocols should be established for breast pumping, proper milk collection and storage, and the initiation of feeding during an infant's stay in the NICU and management of common breastfeeding problems.

In the NICUs, further educational efforts and support are needed to address the specific breastfeeding needs of mothers with preterm infants. Mothers would benefit from emotional, educational, practical and follow-up support. Nurses who are unqualified to provide breastfeeding support for mothers may need to refer these mothers to a skilled lactation consultant. Providing a certified lactation

consultant who is trained to help mothers and staff at each unit is important for successful breastfeeding (Walsh, Pincombe and Henderson, 2011). A lactation consultant can bridge the gap between theory and practice and can communicate effectively with the mothers thus ensuring adequate and holistic care (McInnes and Chambers, 2008). The availability of a lactation consultant in the NICU does not only enhance the quality of breastfeeding support, but also encourages mothers to be actively involved in decisions about their infant's feeding.

Despite their awareness of the benefits of breastfeeding and breast milk for preterm infants, the majority of the health care team studied recognised their lack of knowledge relating to issues that would enable them to support preterm infants' mothers properly, and showed an interest in developing such knowledge. However, this was not possible for most of the nurses because of the busy schedule and time constraints. As a result, many nurses relied on their personal breastfeeding experiences to give advice for breastfeeding mothers, which could not be assumed to be sufficient. Research suggests that the NICU staff knowledge and attitudes can influence the mothers' decisions to breastfeed (Kavanaugh, et al., 1995; Jaeger, Lawson and Filteau, 1997). In order to increase the staff knowledge, policy makers may need to consider activating the role of the continuing health educational programs' committees and to encourage a better learning culture by facilitating access to more learning resources. Studies showed that educational interventions have potential to change knowledge and influence the attitudes of nurses working with breastfeeding mothers (Siddell, et al., 2003). The neonatal units' staff should be closely involved in the development of such continuing educational programs that is sensitive to their learning needs in the light of the mothers' needs.

Providing staff with knowledge is necessary to give support to mothers, but it is not sufficient to create the changes sought (Gennaro, 2010). A combination between knowledge and other motivation factors are essential to implement change. These include creating guidelines and rules, giving feedback on practice, reminders and rewards (Gennaro, 2010). This can be transferred to the NICUs in Jordan where a mixture of such strategies may improve the breastfeeding rates and the support given to mothers.

Ethnographic studies have a well-recognized role in changing health care practice (Sharkey and Larsen, 2005). Witt (2011) identified many elements of

change that are necessary to take place in NICUs in order to have an improved quality of care. Among these is the need for nurses to keep updating their knowledge and to look for the latest techniques instead of doing things in the traditional way. Witt also suggested the facilitation of a family-centered care approach. She stressed the importance of involving parents in the decision making process of their infant's care plan. She also pointed to the difficult issue of when supplies run out within these units, suggesting that nurses need to speak up about the deficiencies and try to bring this issue to someone's attention. Witt's suggestion could be applicable in any neonatal intensive care setting including the Jordanian settings.

Among other strategies for change is the Baby Friendly Hospital Initiative (BFHI), which introduces ten steps for successful breastfeeding in hospitals (Table 2, p. 7). The implementation of BFHI has been proven to increase breastfeeding rates in many different settings all over the world (do Nascimento and Issler, 2005; Vincent, 2006; Nyqvist, 2008; Abrahams and Lobbok, 2009; Thomson, Bilson and Dykes, 2012), and in some Jordanian hospitals (UNICEF Press centre, 2007). UNICEF UK has established ten steps to maintain breastfeeding in neonatal intensive care units (Table 6, p. 22). It requires the NICU to have a written breastfeeding policy, to educate staff members on how to implement this policy, educate parents on the benefits of breastfeeding, facilitate Kangaroo Care, support mothers to initiate and maintain milk expression, and encourage and support exclusive breastfeeding. Milk expression needs to be a priority in the NICUs because it is crucial to the health of preterm infants and is considered to be life-saving (Hilton, 2010). Mothers need to receive information about the benefits of their milk for their infants with practical support with long-term milk pumping until their infants are able to progress to direct breastfeeding.

Applying change may necessitate modifications that could be beyond the nurses' control such as changing spatial orientation or providing more resources and workforce. Collaboration of all parties is vital for the success of breastfeeding outcomes within NICUs. Hospital management needs to be part of this change and may start with creating breastfeeding policies across all hospital settings that could be applied under the current situation. Furthermore, to enhance the quality of care within NICUs, administrators could recruit adequate nursing staff to help eliminate stress related to heavy workloads. However, there has been a recognized female nursing shortage in Jordan for the last few years (Al-Maaitah and Shokeh, 2009). Breastfeeding creates a gender problem and there are

increasing numbers of unemployed male nurses in Jordan. One of the strategies that the hospital in site 1 used to overcome staff shortages was hiring male nurses in their NICU. This strategy could be extremely helpful if applied in other hospitals, including the research setting 2 in which staff shortages is one of the greatest barriers in promoting breastfeeding. Whilst hiring male nurses in the NICUs may appear inappropriate to support breastfeeding mothers in a highly conservative culture, they could be used to free up the female nurses who could support breastfeeding mothers.

With an institutional model that creates a task oriented care of approach with limited resources, staff shortages and time constraints, there is a tendency for minimal professional development. This could be addressed by the application of the Jordanian Nursing Council (JNC) recommendations regarding professional development for nurses and midwives. JNC developed a strategy that has two domains: education and practice. The educational domain focuses on dimensions such as the efficiency of graduate nurses and midwives, faculty members and the development of educational legislation. The practical domain focuses on practice legislation, professional issues, safe environments, professional performance and manpower and databases (JNC, 2011). The JNC strategy stresses the need for professional development as a continuous and comprehensive process, which could be established by persons or institutions.

The JNC has developed standards for general nursing and midwifery practice. Appendix L gives some examples of the standards for the professional development of nurses and midwives and how they would be monitored in Jordan. In many Jordanian health care settings, these standards are not incorporated into their workplace (JNC, 2008), which, if followed, could positively enhance the quality of care in Jordanian hospitals.

THE STUDY'S CHALLENGES AND LIMITATIONS

The use of the ethnographic approach is seen to offer great possibilities to describe and interpret both the mothers' experiences of breastfeeding, and the health care professionals' attitudes and behaviours toward the support given. However, the use of this approach raised important methodological issues for this study and, as with all other studies; there are a few limitations inherent this research.

A particular challenge of this study was the dual nature of my nurse-researcher roles and the need to maintain a balance between being an insider and outsider to the Jordanian culture. This was a challenge that needed an awareness of my own perceptions and experiences, and that they could influence my interpretations of the participants' realities. Maintaining an open-minded approach through continuous self-evaluation (Hanson, 1994) through the process of critical reflexivity during the entire research process helped in the recognition of how my own views and experiences could influence the research findings. Other strategies that were used to maintain the research rigor are discussed in Chapter Four, page 58.

Another consideration of the dual nurse-researcher role is the fact that the data collection was undertaken by a known practitioner to the staff which, as in any other research, may have skewed the responses and observed behaviors. Although we cannot avoid having an effect on the culture that we study (Hammersley and Atkinson, 2007), we only need to reflect on our role as an active participant in the research process by being transparent in detailing the choices that were undertaken during the research process.

As a novice interviewer, my initial interviews may be lacking further probing or paraphrasing for some topics, which are important to ensure that sufficient data is obtained. The duration of my interviews ranged from 30 -40 minutes and might be considered a potential limitation to achieving more in-depth discussions. However, 30 - 40 minutes was considered appropriate by others who suggested that 20 – 60 minutes was the average duration for a qualitative healthcare interview (Gill, et al., 2008).

Another important methodological issue in conducting a cross-cultural research was the translation from one language to another. For this study, maintaining a cultural equivalence in translation is a challenging process. I learned that the choice of a phrase while translating the participants' accounts could alter the cultural meaning of their discourses and thus influence the final representation of their reality. Cultural equivalence was maintained through cross-checking of some transcripts with the research participants, in addition to presenting some of the complex portions of the translated findings to a knowledgeable bilingual nurse researcher. A detailed description of the translation process can be found on page 60. There is, however, a lack of published studies on the cross-cultural translation issues, which necessitate more considerations for such issues.

A major challenge in this study was writing up the research in a second language. The ability to write well is not a naturally acquired skill, but rather a challenging experience that requires a conscious effort and a great deal of time in composing, developing and analysing ideas (Myles, 2002). This is particularly difficult when it comes to writing in a second language. Although still developing, my written English has reached an acceptable level when compared to my spoken English. This may be partly because I lacked confidence in speaking English rather than in writing it, because when writing I have time to think, write, and then edit and amend, which is clearly not possible when you are speaking. My greatest struggle was with the grammar and it took a lot of effort to overcome this concern. Extensive reading, not only for the sake of study-related knowledge, but also to learn how others wrote, helped develop my writing technique. Feedback from supervisors was also very useful in developing my writing and enhanced my academic style.

This study is conducted in only two Jordanian neonatal units in one geographical area. Therefore, the care provided for preterm infants and their mothers may not be the same in other Jordanian hospitals, and therefore the breastfeeding experiences and the staff attitude may be different. This means that the study findings may not be directly applicable within other hospital settings. Although, the insights uncovered may be transferred to similar situations. To facilitate that, an in depth description of all elements of the study process has been provided.

The duration and timing of the study fieldwork presented another potential limitation. Although a large amount of data was collected, a longer period of fieldwork (more than the 6 months of this study) may have provided more insight and given a more complete picture of breastfeeding preterm infants. In addition my observations and interviews took place only during the day shifts. Although most of the nurses rotate through the shifts covering the 24 hours, it is possible that the nurses I did not meet had different perspectives or attitudes towards breastfeeding within their units. However, I managed to observe 86% and interviewed 20% of the total workforce at the NICU in the research setting 1, and observed 84% and interviewed 21% of the total workforce at the NICU in the research setting 2, which offered a significant understanding of the situation.

RECOMMENDATION FOR FUTURE RESEARCH

As with other research, this study created more questions than it answered. Building on the study findings, future research may include an examination of Jordanian hospital policies and practices of promoting breastfeeding for preterm infants. Mothers of preterm infants in the NICU context face many challenges and barriers with breastfeeding and providing their breast milk, as well as with their transition to motherhood. These barriers have a negative influence on the initiation and breastfeeding rates for preterm infants', who are the most in need of breast-milk (Ayton, et al., 2012). More focused studies are needed to investigate suggested strategies of support for preterm infants' mothers that may help them to overcome the stresses and challenges that they face, particularly in Arab countries where research has failed to cover these issues.

Research could also examine the efficiency of newly proposed interventions that are culturally sensitive to the Jordanian population, and look at their effectiveness on breastfeeding outcomes and study the health care professionals' attitudes toward such interventions. An example of these interventions is the introduction of family-centered care, an approach that has been proven to enhance the quality of NICU care resulting in less stress and more confidence among parents in neonatal intensive care settings (Cooper, et al., 2007), and the introduction of banking donor milk in a way that is appropriate to the Islamic instructions. Additional studies may focus on the father's experience of having a preterm infant in NICUs, and the impact of preterm delivery on the family as a whole.

Many studies looked at the influence of the care environment on the patient outcomes, but little attention was paid to the influence of this environment on the nurses themselves, which will inevitably impact on the patient outcomes. More attention is needed to explore the NICU staff experiences of working in these critical care units, their struggle working in difficult conditions in some hospital settings, working relations, job pressure, job satisfaction and to examine some strategies that are intended to overcome such challenging situations, such as the recruitment of male nurses. This, however, may require more investigation of their roles within a predominantly female NICU culture in an Islamic society.

Although this study did not aim to investigate issues of power and control, these emerged as strong themes during the data analysis process. This would warrant

further investigation utilising a critical ethnography approach that would enable researchers to investigate in more depth the power relationships and how these relationships may shape the social processes within NICUs.

FINAL CONCLUSIONS

Interventions to improve the breastfeeding of preterm infants in NICUs are likely to improve the wellbeing of this vulnerable population and thus to have a significant impact on neonatal and infant mortality rates. Identifying factors that influence the utilisation of such interventions is important as a starting point as it provides the basis for change.

Providing breastfeeding support for preterm infants in the NICU in Jordan is a challenge. Efforts for change should begin. These involve, changing hospital policies regarding breastfeeding in the NICU, providing NICU staff with breastfeeding literature and training, adding a lactation consultant to the NICU health care team and implementing breastfeeding protocols that enhance the mothers' experience and facilitate early breastfeeding.

This is a study at Doctorate level, which is demonstrated by my ability to look at a situation where knowledge is limited, to undertake a substantial systematic investigation into it and to follow the norms of the ethical requirements for research. Then to analyse the findings and to come up with new insights and a new understanding that will contribute to the overall body of knowledge.

This research contributes to that body of knowledge by providing an awareness of the patterns and experiences of breastfeeding within two Jordanian NICUs. In particular, this research has:

- Provided a description and understanding of the attitudes and behaviour as regards breastfeeding practices in two Jordanian NICU units.
- Identified factors that promoted or interfered with early initiation of breastfeeding within NICUs in Jordan.
- Identified variations in the staff and mothers perception of support given within the two units.
- Created a model (the storm model, page 155) that reflects both the mothers and the nurses' experiences within NICUs.

It is important that these contributions are recognized because understanding the breastfeeding practices experienced within NICUs allows for the identification and planning of more positive strategies to support mothers and breastfeeding within these units. It is anticipated that these contributions will lead to improvements within the NICUs environment in Jordan and thus to the preterm infants' wellbeing.

Personal Reflections on my PhD Journey

Looking back at my PhD journey, I realised that I have spent more time with this thesis than with my own children. The metaphor of "my child" when referring to my thesis became so true to me. Despite all the difficulties and the combination of emotions during this journey, it has been a joy for me. This journey was a rite of passage in my life, a personal transformation that had a profound effect on my research capabilities and personal growth.

The ethnographic approach corresponds well with my personality, as I always enjoyed talking to strangers, interpreting human actions and analysing types of personalities. Ethnography strengthened my decision making abilities, as I needed to decide on matters such as what to observe, when to observe, whom to talk to, what to ask, what to believe, what to question, what information to record and how to record it (Anspach, 2003). It taught me the importance of interpersonal qualities when interviewing people, how to get them to speak about their struggles and feelings, how to observe and analyse data from an outsiders perspective in one's own culture, how to find patterns and connections between multiple types of data and how to interpret human behaviour.

This research is, then, not only a scientific study to acquire a degree, but also a lifetime experience. It led me to a deep appreciation of what mothers of preterm infants face during their babies stay in NICU, in which they encounter "*an environment with a constantly shifting set of people, who were seemingly forever preoccupied, spoke a strange language, and used unfamiliar equipment*" (Anspach, 2003, p. 191), along with the overwhelming distressing concern of their infant's wellbeing. Moreover, it deepened my understanding to what nurses and other health care professionals encounter while trying to do their best in delivering care to the preterm infants and their families.

This study has indicated how important a welcoming and supportive environment is for parents of infants admitted to NICU, both to support the successful

development of breastfeeding and also the skills so essential for the mothers while they are trying to adjust to their new roles as mothers in the stressful situation of having a preterm infant. The mothers experiences of being suspended within liminal positions during their infant's stay in the NICUs, may have an impact on the mothers' psychological status and on their relationship with their infants, thus on the infant's wellbeing.

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APPENDICES

APPENDIX A: Ethical approval/ Anglia Ruskin University

29 July 2010



Anglia Ruskin
University

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Int: +44 (0)1223 363271
www.anglia.ac.uk

Khulood Shattnawi
34 Ashbury Close
Cambridge
CB1 3RW

Dear Khulood,

Re: Application for Ethical Approval

Project Number: 09/055
Project Title: Patterns of Breastfeeding of Preterm Infants in Two Jordanian Hospitals
Principal Investigator: Khulood Shattnawi

Thank you for resubmitting your documentation in respect of your application for ethical approval. This has been considered by the Chair of the Faculty (of Health and Social Care) Research Ethics Panel (FREP) in advance of the scheduled meeting in September.

I am pleased to inform you that your research proposal has been given approval under the terms of Anglia Ruskin University's *Ethics Guidelines for Research*. Approval is for a period of three years from July 2010 and is subject to random monitoring by the Research Ethics Subcommittee (RESC). Please note that, if your research has not been completed within three years, you will need to apply to FREP for an extension of ethics approval. Similarly, if your research should change significantly in any respect, or if risk of harm or breach of confidentiality becomes likely, you will be obliged to submit a new application.

Yours sincerely,

Dr Leslie Gelling
For the Faculty (of Health and Social Care) Research Ethics Panel

cc: Andy Stevens (Supervisor)
Julie Smith (FREP Sponsor)
Beverley Pascoe (RESC Secretary)



APPENDIX B: Ethical approval / Ministry of Health



م ب ا / لجنة اخلاقيات / ٤٦٦١

الرقم

٢٠١١/٣/١٥

التاريخ

الموافق

مدير تطوير الموارد البشرية

تحية طيبة وبعد ،،،

اشارة لكتابكم رقم تطوير / متدربين / ١٧٦٣ تاريخ ٢٠١١/٢/٢٢ بخصوص البحث المقدم من طالبة الدكتوراه / خلود كايد شطناوي .

بغضون :-

" انماط الرضاعة الطبيعية في قسم الخداج / [REDACTED] / اريد "

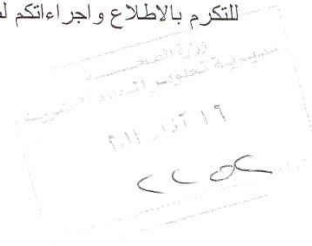
يرجى التكرم بالعلم بأنه تم عرض البحث على لجنة اخلاقيات البحث العلمي وقد قررت اللجنة موافقه على اجراء البحث المشار اليه اعلاه ، بعد تعديل Time table حيث ان مشروع الدراسة يبدأ في ايار / ٢٠١٠ وينتهي في نهاية عام / ٢٠١٠ ونحن الان في شهر اذار / ٢٠١١ وعلى ان يقوم الباحث بتزويدنا بنسخه من نتائج الدراسة لاحقا .

للتكرم بالاطلاع واجراءاتكم لطفا .

واقبلوا الاحترام

رئيس لجنة اخلاقيات البحث العلمي

الدكتور عبد الهادي البريزات



ص ب / رس

البريزات

المملكة الأردنية الهاشمية

عالم: ٠٢٢٠ ٥٢٠٠٩٦٢ ٦ ٥٦٨٨٢٧٢ ٦ ٩٦٢٢ ٦ ص ب: ٨٦ عمان ١١١١٨ الأردن الموقع الإلكتروني: www.moh.gov.jo

APPENDIX C: Ethical approval / MOH – Research site 2



الرقم ٧٤٠ / ٢٠١١
التاريخ ٢٠١١ / ٢ / ١٧
الموافق

February 17, 2011

Khulood Shattnawi
Irbid 21110
P.O. box 2813

Re: Application for Ethical Approval

Project Title: Patterns of Breastfeeding of Preterm Infants in Two Jordanian Hospitals

Dear Khulood,

Thank you for your application for ethical approval which was considered by the hospital Ethics Panel at their meeting on 15 February 2011.

I am pleased to inform you that your research proposal has been approved. Please note that, if your research should change in any respect, or if risk of harm or violation of confidentiality becomes likely, you will have to submit a new application

I wish you well in your study

Yours sincerely,

Dr Mohammad Jafar AL-Ajlony MD



APPENDIX D: Ethical approval/ Reseach site 1

لجنة البحث على الإنسان Institutional Review Board	
Ref.:	الرقم: 9/ 2011/ جنة 31 تاريخ 2011/4/21
Date:	التاريخ: هـ الموافق: ٢٠١١ / ٤ / ٢٧ م
الأستاذ الدكتور عميد كلية التمريض المحترم جامعة العلوم والتكنولوجيا الأردنية	
تحية طيبة وبعد،،،	
إشارةً إلى كتابكم رقم ت/283/22 تاريخ 2011/3/16 والمتضمن عرض البحث المقدم من الطالبة خلود كايد شطناوي بعنوان:	
أنماط الرضاعة الطبيعية لأطفال الخداج في اثنتين من المستشفيات الأردنية في منطقة أربد	
يرجى إعلامكم بموافقة لجنة البحث على الإنسان على إجراء البحث العلمي المشار إليه أعلاه، على أن يتم التقيد بالشروط التالية:	
1. الحفاظ على سرية المعلومات وأن لا تستخدم إلا لغايات البحث العلمي.	
2. تزويدنا بنسخة من نموذج التفويض الخطي للمشاركين في البحث (أولياء الأمور)، والاحتفاظ بنسخة أخرى مع الباحث لإبرازها عند الحاجة.	
3. تزويدنا بأسماء المشاركين في البحث.	
4. تزويدنا بنسخة من نتائج البحث.	
وتفضلوا بقبول فائق الاحترام،،،	
رئيس لجنة البحث على الإنسان	
الأستاذ الدكتور محمود الشيايب	
ش.إ. سلق الجان قداسة	
٢٠١١ / ٤ / ٢٧	

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APPENDIX E: Participant information sheet/ English

PARTICIPANT INFORMATION SHEET

Title of project: Pattern of Breastfeeding of Preterm Infants in Two Jordanian Hospitals.

Introduction

Dear participant, you are invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or you would like further information, please contact me or one of my academic supervisors, using the details provided below. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

I am a PhD student at Anglia Ruskin University/ Cambridge/ UK, supervised by Dr. Andy Stevens and Dr. Trudy Stevens. This research is exploring the patterns of breastfeeding experiences, and support provided to preterm infants' mothers in two Neonatal Intensive Care Units (NICU) within Irbid catchment area in Jordan. By watching what goes on, talking with individuals and participating in breastfeeding activities, it is hoped to gain an understanding of the culture of breastfeeding shared by this group and the reasons behind why some women do not breastfeed their preterm infant at all, or only breastfeed for a limited time. An appreciation of these issues will help health professionals to identify how they may better support breastfeeding in the NICU and understand constraints to breastfeeding that women might encounter.

The study will:

1. identify factors that interfere with early initiation of breastfeeding premature infants in NICU.
2. observe and describe the practices of breastfeeding preterm infants in NICU.
3. identify variation in professionals' and mothers' perceptions of breastfeeding objectives.

Who is organising the research?

Anglia Ruskin University is overseeing this research study.

What will happen to the results of the study?

The results of the study will be used in my PhD thesis. The material will be presented at academic and professional conferences and in academic journals. The findings will also be shared with professional groups who work in NICUs.

Findings from this study will contribute to developing a better understanding of barriers of breastfeeding preterm infants in Jordan

Source of funding for the research

This research is being funded by Jordan University of Science and Technology/
Jordan

Contact for further information

Researcher: Khulood Shattnawi

Mobile number:

Email: [khulood.shattnawi@student\(anglia.ac.uk\)](mailto:khulood.shattnawi@student(anglia.ac.uk))

Shattnawi@yahoo.com

First Supervisor: Dr. Andy Stevens

Email: [Andy.Stevens2\(anglia.ac.uk\)](mailto:Andy.Stevens2(anglia.ac.uk))

Second supervisor: Dr. Trudy Stevens

Email: [Trudy.Stevens\(anglia.ac.uk\)](mailto:Trudy.Stevens(anglia.ac.uk))

Why have I been invited?

You have been invited to take part in this study because you are a potential health care provider of breastfeeding support for preterm infants or you are a mother of a preterm infant. Your knowledge and/or experience of breastfeeding preterm infants mean that you would be able to make an important contribution to this work.

Do I have to take part?

Your participation is voluntary. I will describe the study and go through this information sheet with you. I will then ask you to sign a consent form to show that you have agreed to take part. If you choose not to take part, any care or treatment that you are currently receiving will not be affected. You are free to withdraw at any time, without giving a reason. Withdrawing at any time will in no way affect your future health care.

What will happen if you agree to take part (brief description of procedures/tests)

If you wish to participate in this study, you will be observed during your stay in the NICU. Informal interviews will be part of this study. At some points of the study, formal interview might be necessary. Interviews will be placed in a suitable private room at the hospital to maintain confidentiality. Your hospital records will be reviewed and care will be taken for anonymity.

Risks to participants

The researcher does not anticipate any major disadvantages to taking part in this project. However, if you feel uncomfortable or fatigued during the interview, it will be your choice to take a break, postpone the interview or withdraw from the study.

What will happen to any information/data that are collected from you?

All information that is collected about you during the course of the research will be kept strictly confidential. Your name or any contact details will not be recorded on the interview transcripts. In addition, any details which potentially could identify you will also be removed or changed. My academic supervisors will have access to the anonymised transcripts of your interview, but I will be the only person to have access to the original recordings of the interview, your consent form and any of your contact details.

The information gained from this study will NOT be used for any other purpose than the study and participants will not be named.

What are the possible benefits of taking part?

Whilst there may be no personal benefits to your participation in this study, the information you provide can contribute to the future development of programmes to support breastfeeding preterm infants in Jordan.

Will my participation in the study be confidential?

Yes, all information provided by you will be kept confidential and only used by the researcher. Your confidentiality will be maintained by not identifying you by name and by concealing any identifying characteristics.

I must however inform you that in the event of poor practice, or if you disclose information that may result in you or anyone else being put at risk of harm, I may have to inform the appropriate authorities. If this situation arises we will discuss all possible options before deciding whether or not to take any action.

THANK YOU FOR READING THIS INFORMATION SHEET

YOU WILL BE GIVEN A COPY OF THIS TO KEEP, TOGETHER WITH A COPY
OF YOUR CONSENT FORM

APPENDIX F: Participant information sheet/ Arabic

ورقة معلومات البحث للمشاركين

عنوان المشروع: أنماط الرضاعة الطبيعية للأطفال الخدج في اثنتين من المستشفيات الاردنية في منطقة إربد

مقدمة

عزيزي المشارك ، أنت مدعو للمشاركة في هذه الدراسة البحثية. من المهم قبل أن تقرر الاشتراك أن تفهم لماذا يجري البحث وما سينطوي عليه. لذا يرجى أخذ الوقت الكافي لقراءة المعلومات التالية بعناية ومناقشته مع الآخرين إذا رغبت في ذلك . إذا كان هناك أي شيء غير واضح أو كنت ترغب في مزيد من المعلومات ، يرجى الاتصال بي أو أحد المشرفين على بحثي من خلال التفاصيل الواردة أدناه. تستطيع أخذ بعض الوقت لتقرر ما إذا كانت ترغب أو لا ترغب في المشاركة .

ما هو الغرض من الدراسة؟

أنا طالبة دكتوراه فيجامعة أنجليا روسكين في مدينة كامبردج/ المملكة المتحدة مبعوثة من جامعة العلوم والتكنولوجيا الاردنية، يشرف على دراستي الدكتور أندري ستيفنز ، والدكتورة ترودي ستيفنز.

الغرض من هذا البحث هو استكشاف أنماط الرضاعة الطبيعية والخبرات والدعم المقدم لأمهات الاطفال الخدج في اثنتين من وحدات العناية المركزة للاطفال حديثي الولادة في مستشفيات ضمن منطقة إربد في الأردن. من خلال مشاهدة ما يجري، والتحدث مع الأفراد المشاركين ، والمشاركة في أنشطة الرضاعة الطبيعية في الوحدة نأمل أن نفهم ثقافة الرضاعة الطبيعية من قبل هذه المجموعة وآرائهم حول الأسباب الكامنة وراء عدم البدء المبكر بالرضاعة الطبيعية للطفل الخديج أو أن الرضاعة الطبيعية له تكون لفترة محدودة فقط. إن دراسة هذه القضايا تساعد العاملين في مجال الصحة لتحديد الكيفية التي تمكنهم من دعم الرضاعة الطبيعية للاطفال الخدج على نحو أفضل وفهم القيود والمعوقات التي تواجه الامهات اللواتي يبنون إرضاع أطفالهن من لحظة دخول طفلها وحدة العناية المركزة لحديثي الولادة ، وبالتالي محاولة إيجاد حلول لها.

ماذا سيحدث لنتائج الدراسة؟

سوف تستخدم نتائج الدراسة في رسالتي للدكتوراه .وستعرض المواد في المؤتمرات الأكاديمية والمهنية والمجلات الأكاديمية .كما أن النتائج تكون متاحة للعاملين في وحدات العناية المركزة لحديثي الولادة وللمعنيين بأمورهم في المستشفيات المعنية.

مصدر التمويل للبحث

يجري تمويل هذا البحث من قبل جامعة العلوم والتكنولوجيا الأردنية/ إربد

للاتصال من أجل الحصول على مزيد من المعلومات:

الباحثة: خلود شطناوي. رقم الجوال : 0779318368

البريد الإلكتروني: khulood.shattnawi@student.anglia.ac.uk

المشرف الأول: الدكتور أندري ستيفنز

البريد الإلكتروني: Andy.Stevens2@anglia.ac.uk

المشرف الثاني: الدكتورة ترودي ستيفنز

البريد الإلكتروني: Trudy.Stevens@anglia.ac.uk

المشرف من الاردن: الدكتورة منتهى غرايه. البريد الإلكتروني: muntaha@just.edu.jo

لماذا تلقيت هذه الدعوة؟

أنت مدعو للمشاركة في هذه الدراسة إما لأنك فرد من أفراد وحدة العناية المركزة للأطفال حديثي الولادة أو أنك أم لطفل خديج موجود في الوحدة. وباعتقادي أن معرفتك أو/و تجربة الرضاعة الطبيعية لطفلك الخديج إن وجدت، تعني أنك سوف تكون قادر على تقديم مساهمة مهمة في هذا العمل .

هل لا بد لي من المشاركة؟

مشاركتم طوعية .سأقوم بشرح هذه الدراسة وقراءة هذه المعلومات عن الدراسة معك. وسأطلب منك بعد ذلك التوقيع على استمارة موافقة لظهور موافقتك على المشاركة. بالطبع أنت حر في الانسحاب في أي وقت ، ودون إبداء أي سبب .

ماذا سيحدث إذا وافقت على المشاركة؟

إذا وافقت على المشاركة في هذه الدراسة ، سوف اكون موجودة في الوحدة واقوم بمراقبة ما يجري من أمور خاصة بالرضاعة الطبيعية وسوف يكون هناك مقابلات غير رسمية كجزء من هذه الدراسة. أحيانا قد يتطلب الأمر تحديد موعد يناسبك للقيام بمقابلة رسمية . سوف يتم تسجيل المقابلة على مسجل صوتي الكتروني من اجل نقله لاحقا الى نص كتابي.

هل يوجد مخاطر قد يتعرض لها المشاركون ؟

الباحثة لا تتوقع أي مخاطر تترتب على المشاركة في هذا المشروع. في حال شعورك بعدم ارتياح لإتمام المقابلة يمكنك إيقافها أو تأجيلها الى إشعار آخر.

ماذا سيحدث لأية معلومات وبيانات يتم جمعها عنك؟

ستبقى جميع المعلومات التي يتم جمعها عنك أثناء البحث سرية .لن يتم اظهار اسمك أو أي تفاصيل عنك يتم تسجيلها على نصوص المقابلات. بالإضافة إلى ذلك ، فإن أي تفاصيل يحتل أن تحدد شخصيتك سيتم إزالتها أو تغييرها. المشرفين الأكاديميين على دراستي سوف تعرض عليهم النصوص للمقابلات برموز وليس بالاسم الحقيقي لك. لذا، سأكون أنا الشخص الوحيد المتمكن من الحصول على التسجيلات الأصلية من المقابلة، ونموذج الموافقة على الدراسة الخاص بك أو أي تفاصيل عنك. لن يتم استخدام المعلومات عن المشاركين لأي غرض آخر غير البحث.

ما هي الفوائد من المشاركة في هذه الدراسة؟

في حين قد لا يكون هناك منافع شخصية لمشاركتم في هذه الدراسة ، إلا ان المعلومات التي تقدمها يمكن أن تسهم في التنمية المستقبلية لبرامج دعم الرضاعة الطبيعية للأطفال الخدج في الأردن .

هل ستكون مشاركتي في هذه الدراسة سرية؟

نعم ، جميع المعلومات التي تقدمها ستكون سرية وتستخدم فقط من قبل الباحث .وسيتم الحفاظ على السرية الخاصة بك من خلال عدم تحديد اسم لك، وإخفاء أي تحديد يمكن ان يدل عليك. ولكن علي التنويه إلى أنه في حال حدوث سوء ممارسة في العمل أو قمت بكشف معلومات قد تؤدي إلى تعرضك أو تعرض الآخرين للخطر فلا بد من إبلاغ المعنيين. في حال حدوث هذا الأمر، سوف نناقش كل الخيارات الممكنة قبل أن نقرر ما إذا كان علينا اتخاذ أي إجراء.

وأخيراً، شكراً لك على قراءة هذه المعلومات عن الدراسة، مع اميناتي من أن تتمكن من المشاركة في هذه الدراسة .

سوف تحصل على نسختك من هذه الاستمارة مع نسخة من استمارة الموافقة على اجراء البحث الخاصة بك

APPENDIX G: Participant consent form/ English

Title of the project: **Patterns of Breastfeeding of Preterm Infants in Two Jordanian Hospitals**

Main investigator contact details:

Khulood Kayed Shattnawi, Contact Number: 00962 xx

Email: khulood.shattnawi@student(anglia.ac.uk) - shattnawi@yahoo.com

Members of the research team: **Dr. Andy Stevens and Dr. Trudy Stevens**

1. I agree to take part in the above research. I have read the Participant Information Sheet which is attached to this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.
2. I understand that I am free to withdraw from the research at any time, for any reason and without prejudice.
3. I understand that the interviews will be tape-recorded and some of my words may be quoted.
4. I understand that the researcher can be given access to my hospital records.
5. I have been informed that the confidentiality of the information I provide will be safeguarded.
6. I am free to ask any questions at any time before and during the study.
7. I have been provided with a copy of this form and the Participant Information Sheet.

Data Protection: I agree to the University² processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me*

Name of participant:.....Signed.....Date.....

Name of witness:.....Signed.....Date.....

If you would like to be sent a summary of the results of this study, please enter your name and contact address below:

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of project: Pattern of Breastfeeding of Preterm Infants in Two Jordanian Hospitals

I WISH TO WITHDRAW FROM THIS STUDY. Signed:

_____ Date: _____

² "The University" includes Anglia Ruskin University and its partner colleges

APPENDIX H: Participant consent form/ Arabic

عنوان الدراسة : أنماط الرضاعة الطبيعية للأطفال الخدج في اثنتين من المستشفيات الاردنية
في منطقة إربد

الباحث الرئيسي وتفاصيل الاتصال بها:

خلود كايد شطناوي، جوال 0779 xxxx

khulood.shattnawi@student anglia.ac.uk

البريد الالكتروني:

Shattnawi@yahoo.com

أعضاء فريق البحث : دكتور آندي ستيفنز و دكتورة ترودي ستيفنز من بريطانيا، والدكتورة
منتهى غرايه من جامعة العلوم والتكنولوجيا في الاردن

1. أوافق على المشاركة في البحث أعلاه. لقد قرأت ورقة المعلومات عن الدراسة للمشاركة المرفقة
مع هذا النموذج. وأنا أفهم ما هو الدور الخاص بي في هذا البحث ، ولقد تمت الإجابة على جميع
أسئلتني المتعلقة بالدراسة المنوي القيام بها.

2. أفهم أنني املك كامل الحرية في الانسحاب من البحث في أي وقت ، لأي سبب من الأسباب ،
ودون أي مسائلة.

3. قد تم إبلاغي أنه سيتم الحفاظ على سرية المعلومات التي تقدم.

4. لي كامل الحرية في طرح أي سؤال في أي وقت قبل وأثناء الدراسة.

5. قدمت لي نسخة من هذا النموذج ونسخة من ورقة معلومات الدراسة للمشاركة.

أوافق على الاشتراك في هذه الدراسة

اسم المشترك..... التوقيع التاريخ.....

اسم الشاهد..... التوقيع..... التاريخ.....

سوف تحصل على نسخة من هذا النموذج للحفاظ عليها

إذا كنت ترغب في الانسحاب من البحث ، يرجى ملء النموذج التالي وإعادته إلى الباحث
الرئيسي المذكورة أعلاه.

أنا أرغب في الانسحاب من هذه الدراسة

التوقيع : _____ التاريخ _____ :

APPENDIX I: Interview guide: mothers and staff

1. Interview guide: Mothers

- Identify demographic details: age, delivery type, parity, level of education, work, class, and infant gestational age and birth weight.

Opening statement:

- Tell me about your pregnancy

Following questions:

- experience of the pregnancy and the birth of their preterm infant
- Experiences and emotions during the time in the NICU
- Why she thinks she had a preterm birth
- Feelings toward the baby, first sight, first touch, first breastfeed
- Previous experiences and beliefs of breastfeeding
- Reasons for choosing breastfeeding or bottle feeding
- Actual practices of breastfeeding in the unit
- sources of information and support
- Barriers/facilities to breastfeed
- Strategies used when problems arose or when she felt uncomfortable in a situation

2. Interview guide: Staff

- Identify demographic details: age, gender, job, level of education, marital status, breastfeeding experience, and work experience.

Opening statement:

- Tell me about the situation of breastfeeding or using the breast milk in your unit for preterm infants

Following questions:

- Your beliefs of the importance of breastfeeding and/or breast milk for preterm infants how important do you think BF is viewed in this unit?
- Is there a particular strategy for feeding preterm infant in your unit? If so what is it?
- Is there any written policy for breastfeeding of preterm infants in your unit? If so, how useful would you think this is?
- Do you think there are any barriers/facilities to breastfeeding? If so, what might these be?

- What it might take to implement a breastfeeding policy in this unit?
- Do you have breastfeeding educational classes for mothers in your unit?
- What are your observations in comparing infants on bottle feed with infants on breastfeed?
- How do you react to the presence of mothers in the unit?

2011/2/27

توأمين، 33 اسبوع. دخول كحالة خداج، قصور تنفسي . ولادة قيصرية. تخدير عام. الأم 35 سنة 5 اولاد
3 ذكور 2 اناث ولاده قبل 10 ايام (2/18) توفي الطفل الاول في اليوم التالي 2/19 والثاني توفي بعد
يومين من اجراء المقابلة 3/1. الأم خروج من المستشفى بعد 5 ايام من العملية (2/22)

س: احكي لي عن حملك

ج: كانت الدكتوراه تبعت العياده تقول لي عندك سكر حمل وضغط لا تاكلي هيك ضللت تقول لي تامني خلصت. انا
كنت 70 ك وصرت 60 ك مع الحمل حرمت حالي من كل الاكل عشان الحمل من كل نوعيات الاكل

كان جوزي بده اولاد بعد 10 سنين من اخر ولد

كانت الدكتوراه تقول لي السكر عندك عالي ومرات تقول اذا بنزلش بدي اعطيك انسولين بس من خوفي حرمت
حالي فكان ينزل بس برضه الدكتوراه تقول بدنا اياه ينزل كمان. بطلت اكل بالمره، عالخير والبندوره اتعشى
خسه وافطر تفاحه. يحرم علي بناتي يقاتل علي وجوزي يقاتل علي يقول لي يا بنت الحلال انتي بتردي علي
الدكاتره في كل اشئ؟ كنت اقله يا ابن الحلال انت بدك تموتني يقول خلص اللي بدك اياه . والله مرات لما
احط الاكل يطرنني يقول قومي من قدامي انا يعني اكل وانت تنفجي علي

س: ايوه وشو صار بعدين؟

ج: كان يجيني وجع، الصراحه انا وقعت. رحت اجيب طبخه وكنت بالسابع.....بس قمت حسيت الدنيا
كلها لفت في ووقعت علي ركي. روحت عالددار والمغرب حسيت بالوجع يجي من ظهري علي قاع بطني
وينزل لتحت واشكي لبناتي اقول شافيه يمه انا بثبتش للتاسع.....

ظليت استنى علي حالي واصبر بحالي . مش اروح عالمستشفى . والله الدكتور بهدلني قال لو انك اجيتي
بنيمك يومين ثلاث بعطيك ابره اي اشئ تاتحملي

ظليت في البيت لثاني يوم الجمعه صحيت الفجر بدي اصلي ما قمت من الفرشه ولا شو... نزلت مية الراس

لقو عندي 4 سم فاتح. لما شافنتي الدكتوراه هون ما ظل براسها عقل كانوا الاولاد تعبانين مليح اللي تلاحقوا
بيهم كانوا تعبانين الله بده بستر علي ويشفق علي الاطفال. واحد الله يرحمه والثاني الله يشفق عليه

كنت بنص الثامن وزنه 2 كغم واللي توفي كمان 2 ك الا شوي

اول مرة بحمل بتوم

س: شو كان شعورك لما دخلتي قسم الخداج

ج: انا لما طلعتوني من العمليات قعدت نص ساعه تاصحيت. بس صحيت سالت شو جيت لانه الدكتوراه قالتلي
فيكي بنات قلت المهم الخلقه التامه مش فارقه. انا قتلت حالي حتى ما يندقوش ابره اسولف لبناتي اقولهم يمه
بكره يجوا معللين اركض عالدكاتره انا بتحملش ولد يندق ابره، اذا كنت انا ما بتحملش الابره

الدكتور اللي هون قال لي يا اختي انتي ما فيكيش سكري ولا ضغط

*خرجت عن الموضوع فكان علي تذكريها اين وصلت: ايوه وبعد ما صحيتي من العملية شو صار؟

ج: آه. قالن الممرضات حطيناهم في الخداج عشان ترتاحي. ما قالن انهم تعبانين او اشئ!

قلت ياالله مليح ما بقدرش اقوم ما انا عامله عمليه وخليهن يعتنن فيهم. بس بالليل حسيت نار ودارت روحي
طلعت قلت بدي اروح اشوفهم. عمليه عمليه مش راح اموت اللي الله بده ينجي

ساعدتني اختي....رحت، جيت....(صمتت برهه)

لو انك شفتي.....

كانوا حاطينهم في نفس الحاضنه بس هذاك كان تعبان تعبان. كانوا حاطينله الجهاز ولا بتحرك ولا اشي. بس فتت الخداج، فتح عيونه...والله اني بس فتت فتح بس فتت فتح (تبكي) فتح واطلع علي

اجيت عليهم ثاني يوم الساعه 2 بالليل والساعه 3 كل شوي آجي . تقولي الممرضه يا اختي الواحد بيجي مره واحده مش كل شوي...اقولها يا اختي انداري! انداري! قالت يا اختي الساعه 8 بتيجي بس ننظف

وهاي هي...هذاك الله يرحمه وان شاء الله زي ما بيقلوا الناس يكون شفاعه الي

س: بتحبي تحكي اكثر عن وفاته؟

ج: آه والله يا اختي صرت اخاف من التلفون. والله الليل بسكر التلفون بفتحوش. كنت اتلف لما واحد يحكي معي تلفون احب الناس تحكي معي...طقت الباب....سلفي عشنو جابلي الخبر والله ما بحب يجي علي قسما بايات الله بس يقولوا فتحي عالباب ، هيك بظللي انتفظ . شو بدني اسوي كله من رب العالمين . لا خلقت فيه ايد ولا اجر ولا بقدر احطله روح الله اللي بيشفي بني ادم

س: كيف خبرتك مع الرضاعه

ج: الحمد لله اولادي كلهم من صدري. كنت ارضع الولد بحدود سنتين واحمل بعد السنتين

س: الان شو بالنسبه لحليبك؟

ج: والله كان صدري هيك (واشارت انه مليء بالحليب) وشفطته واكبه سلفاتي جابن شفاطه وساعدني وحطتن فيه سخنه وبنزل الحليب ويا حرام اكبه

س: هل تقومين بشفط الحليب لابنك؟

ج: يا ريت لو انه اجيبه الحليب ويرضعوه اياه يا ريت. لو ببصير اجيبه كان تحسنت نفسيتي بس ما حد حكالي انه ببصير

س: احكي لي عن زيارتك لأبنك

ج: والله لو يهملي انام عنده ما بوفر والله والله لو يقولولي نامي هون وعالكوسي واطل طول الليل قباليه ما بوفر. لانه والله بس يجي الليل عزرائيل بتقوللي مسك روعي ما بنامش لا الليل ولا النهار بالليل كلهم بناموا وانا بظل صاحيه انا وربي بدعيه

يا من درى والله بشفط لو آخر يوم لو اخر نقطه بدمي بشفط

نفسى احملة بين ايدي واطلع من المستشفى واغيرله وارضعه.....

APPENDIX K: Selected parts of an interview/English

27/2/2011

Two preterm infants; 33 weeks admitted to the NICU as a case of RDS for respiratory support. General anesthesia, C/S. They were born in the 18 / 2. The first infant died in 19 / 2. The mother discharged from the hospital 5 days after the C/S (22/2). The second baby died two days after this interview, in 1/3. NS2-M6 is 35 year-old mother. She has 5 children; 3 males 2 females. She gave birth to her twin infants 10 days ago.

Level of education: High school (Tawjeehi)

Q: Tell me about your last pregnancy.

A: my physician, at the health centre, told me that I have a high level of glucose and high blood pressure, and she asked me not to eat a lot of things. I did what she told me to do, but it seems that I exaggerated it. My general health dropped back and I lost a lot of weight; my weight was 70 kg and became 60 kg, even with the pregnancy. I deprived myself of many kinds of food for this pregnancy. It was my husband who wants a child again after our youngest became ten year-old.

My doctor said to me on each visit: your sugar [blood glucose level] is very high. And sometimes says: If you do not manage to drop it back, I will have to give you insulin injections. This scared me so much, so I kept depriving myself of a lot of food. The sugar level was getting down sometimes, but this was not considered enough for the doctor, and she would say: keep going, we need lower blood sugar level. I followed her instruction to the point I was living on cucumbers and tomatoes, having Lettuce for dinner and an apple for breakfast. My daughters and my husband begged me to eat some food. My husband used to say: oh dear, why have you need to follow all the physician's instructions? I would answer: oh darling, do you want me to die by not following her instructions? So he replied: Well, do whatever you like to do. Sometimes when I offer him the food, he used to ask me not to sit down with him, and says: I cannot eat while you are looking at me and not eating. Silence.....

Q: What happened after that?

A: I had severe pain. In fact I fell to the ground. That was when I went to do some shopping; I was in the seventh month of pregnancy. I was sitting waiting for processing my request. At the moment I stood up, I felt dizzy and fell on my knees. I got back home and immediately started to feel pain starting from my back and moving down to my tummy and my legs. I knew that I will not complete my pregnancy up to the end. I told my daughters that I usually do not carry on my pregnancies to the end.

My fault was that I did not go to hospital immediately, but waited at home hoping that the pain will go away. When I came to the hospital, the doctor was very upset from being late, and said if you came since your pain began, I would admitted you to the hospital two or three days to get a bed rest or gave you some medication so you would feel better. But by not coming immediately, you put yourself and your babies in danger. I felt so bad about that. She was right, I have waited at home until the second day, that was Friday, and when I woke up for Fajr prayer [first prayer for Muslims before the sun rise] and stood up, I felt a gush of water coming down. It was the babies' fluids. I went to the hospital and found to have 4 cm dilatation. The doctor was very worried about my children's situation. They were in critical condition, and the doctor was able to rescue them in time. But one of them died and I pray to Allah to heal the other. I was in the middle of the eighth month. Their birth weights were 2 kg each. This was the first time that I carry twins.

Q: tell me how was it like when you first came to the NICU?

A: It took me half an hour until I woke up after I left the operating room. When I woke up I asked what I gave birth to. They told me you gave birth to two boys. I thought that I am pregnant with two girls, that was what my doctor told me. It does not matter their gender, their health is more important to me than their gender.

I was exhausted in this pregnancy. I have suffered so as my children will not need hospitalisation, and will not suffer any pain. I told my daughters: I am depriving myself from everything so as not to give birth prematurely, and not to give birth of sick children and spend all of my time between doctors. I can't stand seeing them in the hospital or being punctured by all kind of needles. I myself can't stand having injections.

The doctor in this hospital told me that: Who told you that you suffer from diabetes or high blood pressure? You do not have anything like that!!!

* *****she occasionally forgot what she was talking about, so I had to remind her of what she was saying.so, after you woke up from surgery, what happened?

A: Oh yah. The nurses told me that my children are alright, and that they admitted them to the neonatal unit so as I can get some rest after the operation. She didn't tell me that they were in critical conditions.

I said to myself: This is the best, I am really very tired now and I can't look after them for the time being, so it is better for them to stay in this unit so someone will take care of them. But not later than the evening that day, feelings of sorrow and anxiety came to me, and a strong desire to see them. So I said to myself: I want to go to see even so I had an operation whatever happened to me, I will not die unless Allah wanted me to die.

My sister helped me in getting out of bed and in coming to this unit.....[long period of silence]

Oh God, if you just saw them..... [another period of silence]

Both of them were in the same baby warmer. One of them was too tired. He was on a respiratory support apparatus, with no any obvious body movements. But as I entered and approached him, he opened his eyes. I swear that he had opened his eyes.....when I approached him, he opened his eyes and looked at me.....[mother started crying]

I returned back the second day at 2 am, and then at 3 am, the nurse said to me: you come to the unit so often, why you are doing that, you suppose to come once a day. I do not have an answer. I just replied: I do not know, I do not know. The nurse said: go to your room [as she was still in-patient] and come in the morning only, eight o'clock will be good, just after cleaning up the unit.

This is what happened, my first baby died, mercy upon him from Allah, I pray to Allah that he will accompany me on the Day of Judgment, as they are saying.

Q: Would you like to talk about his death?

A: Oh, I received a phone call telling me about death while I was at home. I have become afraid of hearing the phone rings. When the evening approaches, my fears intensify, and I become very conscious to any phone ring. I am scared of hearing bad news about my second infant. I am afraid that he might die as well.

Before this event, I used to be delighted to phone calls; I really love talking to people. I also become anxious of hearing the door bell, since I received the news of my son's death. Even I can't stand to hear the name of my brother-in-law because he is the person who delivers that bad news to me. When they tell me that Fatihi, [her brother-in-law] is on the door, my whole body shivers. I feel that I do not want to see him anymore, as if he was responsible for the death of my child. I know that there is nothing I can do about that, I have no power or control over this death. All are from Allah, the Lord of the World. He created him. I created neither his hands nor his legs and thus can't put back his soul. And only Allah has the cure for the other.

Q: How did you experience breastfeeding

A: Thanks God, I breastfed all of my children. I usually breastfeed each child up to two years and then get pregnant again. After I gave birth to those two infants, my breasts became full of milk. So I started hand pumping the milk and throwing it away. I felt bad about throwing the milk away. I asked my sister-in-law if it possible to breastfeed her daughter. She accepted that and I did breastfeed her. But I needed to pump the milk again as my breasts were full and tender. My sisters-in-law brought me a breast pump. It makes it easier for me. They also advised me to use warm water on my breasts to make the milk flow even easier. I am pumping now hoping to breastfeed my second child when he gets better Insha-Allah [God willing].

Q: Did you pump milk for your son?

Surprisingly she replied: Oh, can I? I hope so, I wish this would happen. I wish if I can bring him my milk. This will make me feel much better. But no one told me about that.

Q: tell me about your visits to your baby

A: Oh God, if it is in my hand or is my choice, I would prefer to stay here to his side, day and night sitting in this uncomfortable chair, just observing and watching him. I swear to God, every night I begin having feeling of pressure over my chest, as if I am dying. I do not sleep at all, not at night nor during the day. Everyone sleep at night except me. I keep praying for his recovery. Oh dear! I swear to God that I will pump milk for him to the last day of my life and to the last drop of my blood. I am dreaming that I will be able to carry him between my hands and leave this unit to my home. I am dreaming that I will be able to change his diapers and his clothes and put him on my breasts and feed him.

APPENDIX L: Examples of some nursing professional standards

Standard	Example of some indicators
1. Professional responsibility and accountability: nurses and midwives are responsible for performing practice in line with the nursing professional ethics.	<ul style="list-style-type: none"> • The nurse should identify obstacles to the provision of proper nursing care
2. Practice based on nursing knowledge: nurses and midwives base their practice on knowledge derived from nursing and other human sciences	<ul style="list-style-type: none"> • Nurses and midwives should seek to attain information based on scientific research to expand and utilize nursing knowledge for enhancing professional practice • Nurses and midwives should practice effectively in research efforts related to their profession and its enhancement.
3. Nursing performance efficiency: nurses and midwives utilize knowledge and skills in practice.	<ul style="list-style-type: none"> • Nurses and midwives should updated their knowledge, skills, and judgments for providing safe care. • Nurses and midwives should seek continuous professional development that is needed for safe professional practice standards and ethics.
4. Communication and cooperation: nurses and midwives communicate and cooperate with the clients and health care team for providing nursing care	<ul style="list-style-type: none"> • Nurses and midwives should practice effectively in solving issues related to professional practice.
5. Complains with professional ethics: nurses and midwives provide nursing care in line with the nursing professional ethics guide approved by the council	<ul style="list-style-type: none"> • Nurses and midwives should report any improper practice, professional inefficiency, professional mismanagement, misconduct, or inability to meet professional requirements through the right channels to proper authority.
6. Safe environment	<ul style="list-style-type: none"> • Nurses and midwives should create safe environment for both clients and employees within the framework of public safety.
7. Total quality management: nurses and midwives adopt a total quality management and continuous quality improvement philosophy as a general framework for upgrading nursing care	<ul style="list-style-type: none"> • Nurses and midwives use concepts of total quality management for providing nursing care through: <ul style="list-style-type: none"> • Identify fields of nursing care which are in need of verification and follow up • Upgrade policies and procedures for improving the quality of care • Implement activities for improving the quality of nursing care • Evaluate nursing care within the framework of total quality management • The nurse/midwife shall consolidate and expand continuous educational programmes related to quality management
8. Scientific research: nurses and midwives rely on scientific research and evidence based for improving care	<ul style="list-style-type: none"> • Nurses and midwives should use scientific research results and evidence based for enhancing the practice according to policy approved • Nurses and midwives should identify clinical problems which require carrying out further research
9. Development and education: nurses and midwives participate and lend support to the development and educational activities maintaining information and nursing efficiency.	<ul style="list-style-type: none"> • Nurses and midwives should identify educational needs • Nurses and midwives should contribute to the implementation of educational program • Nurses and midwives should participate effectively in attending educational programs • Nurses and midwives should acquire knowledge and skills for upgrading nursing care • Nurses and midwives should seek to create a proper environment for success in development and implementation of educational activities.

Adopted from Jordanian Nursing Council (Jordanian Nursing Council, 2012)