

## Mothers experiences regarding prolonged hospitalization of their preterm babies in neonatal intensive care unit (NICU)

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### Abstract

**Background:** Hospitalization of preterm babies in Neonatal Intensive Care Unit (NICU) exposes mothers to critical care environment for as much period as it is determined by the condition of their babies. The purpose of the study is to explore the experiences of mothers about prolonged hospitalization of their babies in NICU.

**Methods:** A literature search was conducted using electronic data base such as EBSCOHOST, GOOGLE SCHOLAR; PUBMED and CINAHL for articles published between 2000 and 2015 that explore mothers' experiences regarding hospitalization of the preterm babies in NICU. Lastly, authors also made inferences from their personal experiences as players in nursing practice/education Themes were derived from the articles which included mothers' interaction with their own babies, other mothers, health care personnel and the NICU environment.

**Results:** The admission of preterm babies in NICU is stressful to the mothers. It is associated with fear, anxiety frustration which consequently interferes with bonding between the mother and the baby. This paper seeks to explore mothers' experiences regarding prolonged hospitalization of their preterm babies in NICU.

**Keywords:** hospitalization, babies, mothers, neonatal intensive care unit (NICU)

### Introduction

The birth of a preterm baby constitutes an acute adverse event accompanied by dramatic changes in life patterns of the mother (Alves, Amorin & Silva, 2014) <sup>[2]</sup>. Babies born prematurely, at a gestational age of less than 37 weeks are at increased risk of subsequent adverse outcomes in various aspects of their development which will result in their admission in Neonatal Intensive Care Unit (Kyno, Ravn, Lindemann, Smeby, Torgersen & Gunderson, 2013) <sup>[14]</sup>. Due to the state of prematurity, it is fundamental that preterm babies be hospitalized in NICU because the unit supports the infants' physiologic and neuro-behavioural growth and development (Lantz & Ottosson 2013) <sup>[15]</sup>.

Depending on the babies' gestational age at birth and the medical complications associated with prematurity which more often require critical care to minimize mortality (Linderberg, 2013) <sup>[17]</sup>, hospitalization of preterm babies can take some weeks or months (Jubenville, Newburn-Cook, Hegadoren & Lacaze-Masmonteil, 2012) <sup>[13]</sup>. During the entire period of hospitalization, mothers of preterm babies find themselves having to stay for as much period as it shall be determined by the babies' condition. Mothers of preterm babies, as the primary care givers (Feely, Waitzer, Sherrard, Boisvert & Zerkowwittz 2013) <sup>[10]</sup> will be providing a parental care in a strange and frightening NICU environment (Lasiuk, Comeau & Newburn-Cook 2013) <sup>[16]</sup>.

Previous studies exploring the experiences of mothers whose babies are admitted in NICU have indicated that mothers experience stress associated with the NICU environment (Diffin, Shields, Cruise & Johnston, 2013; Carter, Mulder, Bartram & Darlow 2013) <sup>[8,4]</sup>. In these studies, the impact of hospitalization of preterm babies on the mothers was not weighted according to the duration of hospitalization of babies. It was noted that, the longer the babies are hospitalized, the longer the exposure of the mothers to the

impacts of hospitalization. However, Jubenville *et al*, (2012) <sup>[13]</sup>, in their study about symptoms of acute stress disorders in mothers of premature infants indicated that the rates of depression and symptoms of acute stress disorders were similar in mothers at one week and at one month. Mothers experience emotional tension at one week and at a month because preterm birth occurred unexpectedly and it takes a great challenge for the mothers to adapt to the physical environment of NICU following the babies' hospitalization (Malakouti, Jabraeeli, Valizadeh & Babapour 2013) <sup>[19]</sup>. The negative impacts can be exacerbated by the fact that mothers have limited understanding of the medical implications of prematurity, therefore may not understand the benefits of prolonged hospitalization (Chhabra *et al*, 2014) <sup>[5]</sup>.

The researcher as the clinician has interacted with several mothers whose babies were hospitalized for prematurity in NICU in PMH. On an informal discussion with mothers, they expressed various emotional feelings such as stress, fear, emotional trauma, being overwhelmed, anxiety and homesickness. Similar feelings were reported in previous studies: (Jubenville *et al* (2012) <sup>[13]</sup>; Erdem, (2010) <sup>[9]</sup>; Bret, Stamszewska, Newburn, Jones, Taylor (2011) <sup>[3]</sup> and Wigert, Dellenmark & Bry (2013) <sup>[23]</sup>. All these studies acknowledge that admission of a preterm baby in NICU is a challenge and it is emotionally draining to the mothers, however, this was not examined in relation to the period of hospitalization. The physical environment of NICU was amongst the sources of the emotional strain to mothers of babies hospitalized in NICU. According to Hutchison, Spillet and Cronin (2012) <sup>[12]</sup> mothers feel emotionally challenged when they get into the intimidating NICU environment with a lot of unknown equipment. It is therefore evident that mothers of preterm babies hospitalized in NICU endure various emotional strains related to the physical environment of the unit. Although numerous studies have been conducted in western countries,

they did not reflect certain social, economic, cultural and environmental differences which may influence mothers' experiences in NICU. In addition, these studies were more focused on the mothers' experiences and not relating that to the duration of hospitalization of their babies. Therefore, this study intends to explore the mothers' experiences of the physical environment of NICU at Princess Marina Hospital during the prolonged period of their babies. Understanding the mothers' experiences regarding prolonged hospitalization of their preterm babies is critical to design some strategies that will cushion the uncomfortable experiences and to promote comfortable one.

### Method

A literature search was conducted using various electronic databases such as Ebscohost, Google Scholar; Pubmed and Cinahl. Terms entered to search in various combinations included, mothers, preterm, experiences and NICU. Limitation placed on the search included publication year between 2000 and 2015. Produced articles were read and were selected for inclusion based on the following themes related to mothers' experiences: Interaction of mothers of preterm babies with their preterm babies, interaction of mothers of preterm babies with NICU equipments and health care professionals, interaction of mothers of preterm babies with the NICU atmosphere, and interaction of mothers of preterm babies with other mothers. Along these themes nine (09) articles met the criteria and are included in this review (see table 1)

### Results

The results from literature are discussed according to the identified themes.

#### Interaction of mothers of preterm babies with their preterm

The emotional feelings of mothers with preterm babies were raised by the inability to interact with their babies (Al-kour, Khassawneh, Jaradat and Khader 2014) <sup>[1]</sup>. The results revealed that the need for mechanical ventilation, lower birth weight and lower gestational age were the predictors of higher anxiety level and more depression in mothers of infants admitted to NICU. Mothers felt that they did not have control over their babies' conditions because they were not participating actively in the care of the babies and they only attended to their babies for a short time and were forced leave. This resulted in unstable emotional feelings like fear, feeling of guilt, anxiety and insecurity about the babies feeding times. These feelings are attributed to their perception that their babies do not look "physically normal (Davim *et al*, (2010) <sup>[7]</sup>.

#### Interaction of mothers of preterm babies with the NICU atmosphere

The parents of preterm babies admitted in NICU experienced extreme stress of preterm birth and it was compounded by the

alien NICU environment, which was crowded with strangers and beeping and lighting machines which to them signaled crisis (Lasiuk, Comeau and Newburn-Cook 2013) <sup>[16]</sup>. Having a preterm birth catapulted parents in the unknown world of NICU, which they described as frightening, making them helpless and forcing them to rely on strangers to safeguard the survival of their babies. According to Mbwele (2013) <sup>[20]</sup>, the interaction of mothers with NICU equipment, mothers in the peripheral facilities (4.8%) were concerned about shortage of equipment and space. Many mothers at the referral hospitals (45.9%) were concerned about facility shortages. Mothers were concerned that the NICU atmosphere is very hot.

#### Interaction of mothers of preterm babies with other mothers

According to Ncube (2011) <sup>[21]</sup>, mothers of preterm babies reflected that they overcame fear because of the support they got from members of staff and other mothers in the unit. The support they got enabled them to bond with preterm babies and cope with the challenges they faced while in NICU (Ncube 2011) <sup>[21]</sup>. Mothers of preterm babies were reassured and comforted by other mothers in the unit. The support from other mothers assisted mothers of preterm babies to establish rapport with their preterm babies.

#### Interaction of mothers of preterm babies with NICU equipments and health care professionals

The results of the studies indicated that mothers of babies hospitalized in NICU underwent several emotional feelings such as depression, anger, anxiety and loss of self-esteem (Al-kour, *et al* 2014) <sup>[1]</sup>. The mean (+- SD) score of State-Trait Anxiety Inventory Y-1(51.7 +-10.1) for mothers of infants admitted to NICU was significantly higher than the mean score of State-Trait Anxiety Inventory Y-1(41.4 +-10.1) for mothers of infants born at term and not admitted in NICU (P=0.0005). The level of anxiety was high in mothers of preterm babies hospitalized in NICU and it was brought about by the sophisticated equipment attached to the babies to support their lives. The physical environment was scary and caused feelings of sadness in mothers because the mothers did not know the medical devices like monitors which were attached to their babies. To them, the connection of the devices to the babies indicated worsening of the babies' conditions (Malakouti *et al* 2013) <sup>[19]</sup>

According to Mbwele (2013) <sup>[20]</sup> some mothers were not satisfied about the amount of time spent with doctors consulting the babies, the results indicated that 72 mothers (90.6) were not satisfied with the time spent by the doctors to see their babies. Thirty eight of 80 mothers (47.5%) from the periphery centre reflected that there was too little or no opportunity to ask health care workers questions about their babies. Higher satisfaction was recorded on mothers at the referral hospital, with 28 of them (87.5%) reporting that there was enough opportunity to ask questions.

**Table 1:** Summary of studies reviewed

Authors & year	Study design	Participants Description	Findings
Lasiuk, Comeau & Newburn-Cook 2013 <sup>[16]</sup>	Interpretive descriptive study	14 parents in face to face interview 7 parents in focus group discussion. 5 health care workers who work with preterm	The NICU environment was frightening, making them helpless and forcing them to rely on strangers (health care professional) to safe guard the survival of their babies.
Davim, Enders & Rosendo da Silva	Exploratory descriptive study with a quantitative approach	33 women who had given birth to preterm babies and rooming in	Mothers described the birth of a preterm baby as the beginning of sorrow, guilt, disappointment and frustrations. There is fear related to the strange environment of NICU and harming of the babies.
Al-kour, Khassawneh, Jaradat & Khader 2014 <sup>[1]</sup>	Qualitative design using State-Trait Anxiety Scale, the Edinburgh Postnatal Depression Scale and Socio demographic questionnaire	75 mothers preterm infants admitted in NICU and 75 mothers of full time babies not admitted in NICU.	Mothers underwent several emotional feeling such as depression, anger, anxiety and loss of self-esteem. The high level of anxiety in mothers of preterm babies was brought about by the sophisticated live support equipments attached to their babies
Malakouti, Jebraeili, Valizadeh & Babapou 2013 <sup>[19]</sup>	Qualitative phenomenological design, using a semi structured interview as instrument for data collection	20 mothers who had experienced a baby hospitalization in NICU	Mothers felt that they do not have control over their babies' condition because they were not participating actively in the care of the babies. This resulted in unstable emotional feelings like fear, feeling of guilt, anxiety and anxiety about the babies feeding times.
Heidari, Hasanpour and Fooladi 2013 <sup>[11]</sup>	Qualitative Inductive content analysis	21 participants consisting of 13 parents, 5 nurses an 3 physician from NICU	Unexpected delivery of a preterm baby on its own was stressful which was provoked by the subsequent admission of the baby in NICU. Mothers experienced anxiety, fear, nervousness and overwhelming sense of restlessness when the baby was admitted in NICU.
Darcy, Hancock and Ware 2008 <sup>[6]</sup>	Exploratory descriptive study using mixed methods	Level of noise in NICU.	Noise levels in NICU were higher than the recommended 45 decibels and often exceed the recommended 50% decibels in more than 10% of the times
Preyde, & Ardal, 2003 <sup>[22]</sup>	A cohort study design with a control group for comparison	Mothers with singleton or twin preterm babies delivered before 30 weeks or whose birth weight was less than 1500grams. Babies should be less than 10 days old and not having any complication	21 (87.5) of mothers in the intervention group indicated that their buddies were very helpful or helpful. Two mothers reflected no difference and one (1) mother reflected the buddy to be unhelpful. Mothers who participated in the parent buddy program reported less stress, anxiety and depression than mothers in the control group. Mothers indicated that interaction with their buddies helped to reduce their feeling of isolation, provided validation of their emotional experiences and help to normalize the situation.
Mbwele, Ide, Reddy, Ward, Melnick, Masokoto, & Manong. (2013) <sup>[20]</sup>	Cross sectional study using qualitative and quantitative approaches. Semi-structure interviews conducted	Hundred and twelve (112) from both peripheral and referral hospitals	Quantitative indicated that the support and friendliness of health care professional differ according to two (2) clusters. 45% of mothers at periphery centre and 16% at referral hospital referred to the services as very much supportive
Ncube 2011 <sup>[21]</sup>	Phenomenological design, qualitative, exploratory contextual study	Mothers whose preterm babies were hospitalized in NICU	Mothers were shocked by the unexpected birth of preterm babies. They were scared by the small sizes of the babies in NICU. Mothers had fear and anxiety which was exacerbated by the unfamiliar and intimidating environment of NICU. The kind of environment interfered with bonding between mothers and their preterm babies.

### Summary

The literature review by Mbwele (2013) <sup>[20]</sup>, Al-kour, *et al* (2014) <sup>[1]</sup>, Preyde and Ardal (2003) <sup>[22]</sup>, Ncube (2011) <sup>[21]</sup> and (Malakouti *et al* 2013 <sup>[19]</sup>) revealed that mothers of preterm babies tend to interact with the NICU environment during the period of their babies hospitalization. The interaction occurs between mothers of preterm babies and other mothers in the unit, members of staff, equipments and preterm babies. The kind of interaction that occurs between mothers of preterm babies and the physical environment of NICU influences their experiences. According to these authors the interaction of mothers with NICU environment yields various emotional experiences such as fear, anxiety, depression and

intimidation. Most of the studies cited were conducted in developed countries and the one conducted in Botswana was exploring mothers' experiences regarding care of their babies. None of these studies reflected the experiences of mothers of preterm babies when they are in exposed for a prolonged period in the NICU environment. There is a need to explore how prolonged exposure to the NICU environment influences the experiences of mothers.

### Recommendations

The literature reflected that admission of preterm babies is NICU is stressful to the mothers. Based on these findings, the following recommendations were made;

### To health care providers

Health care providers should conduct a comprehensive orientation to mothers who babies are admitted in NICU. The orientation should embrace a comprehensive education about the machines and all the appliances used in the management of the babies because according to Malakouti *et al* (2013) <sup>[19]</sup>, they are the major source of stress. Lack of Knowledge about these equipment, makes mothers to associate them with the worsening of the babies' condition, further worsening the stress level. Furthermore health care providers should schedule routine counselling to mothers of preterm babies. This will assist in diagnosing mothers coping levels during the period of the babies' hospitalization and timeous intervention will be instituted.

### To Health Training Institution

The curriculum of health training institution should incorporate comprehensive counselling skills. This will assist in dealing with mothers who are undergoing stressful situation related to their babies' hospitalization. More importantly a health care provider with counseling skills will be able to diagnose stressful mothers and intervene accordingly.

### To mothers of preterm babies

Mothers of preterm babies should establish some supporting groups among themselves. The support groups will facilitate information sharing among mothers of preterm babies. Some mothers will use their personal experience to alley teach other mothers and alley anxiety brought about by the NICU environment. Mothers can use technological devices and open some social media groups like WhatsApp to enhance information sharing. Mothers of preterm babies who are able to read should search for information about their babies' conditions and read so that they understand clearly about their babies conditions. It is also recommended that mothers should ask health care providers about anything that is not known or not clear to them.

### Research

More researches can be conducted to evaluate the long term consequences of stress that mothers of preterm babies go through during the period of their babies' hospitalization. Since most of the studies reviewed were not specific about prolonged hospitalization, a study that is specific about prolonged hospitalization should be conducted. Furthermore research can be done to explore how best mothers of preterm babies can be assisted to minimize the level of stress that they go through during their babies hospitalization.

### Conclusion

Delivering preterm baby on its own is stressful to the mother. The state of prematurity of the baby results in hospitalization for as much period as it is determined by the baby's condition. Hospitalization is mandated on preterm babies to prevent and manage complications of prematurity. Mothers of preterm babies, as the primary care givers will experience the environmental conditions in the NICU, which comprises of members of staff, other mothers, the live support machinery and the babies themselves. In addition to stress of having preterm babies mothers are stressed by this environmental condition. It is unfamiliar and intimidating to the mothers, and causes fear, anxiety and frustration. Furthermore, the NICU environment is said to be interfering with bonding

between the mothers and babies.

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