# Becoming a mother in a neonatal intensive care unit

**KHATIJAH LIM ABDULLAH**
Faculty of Nursing, University Malaya, Kuala Lumpur
Correspondence: katlim@um.edu.my

## Abstract

With advances in medicine, more and more premature infants who require round-the-clock nursing care due to one or more complex medical conditions are able to survive after receiving intensive treatment in the neonatal intensive care unit (NICU). The increased survival rate has resulted in a higher incidence of morbidity that may impose emotional and financial burdens on families, society and the healthcare system. This paper explores the experiences of mothers with premature babies who were admitted to a NICU. A generic qualitative approach was used to gain insights into the effects of the premature baby admission to a NICU through tape recorded semi structured open-ended questions interviews with 17 mothers whose premature babies were admitted to a NICU. Inductive thematic analysis was used to identify, analyse, and report themes and patterns within the data. Qualitative analysis of the descriptive data obtained from 17 mothers identified four major themes and 13 sub themes relating to avoidance, effects of the separation, ceremonies and inadequate preparation. The findings have several implications for practice by care professionals. It can help nurses to develop interventions to prepare mothers to cope with new situations, decreasing stress and psychological problems regarding the admission of their infants to the NICU.

**Keywords:** Mother, neonatal, intensive care unit, mothering, premature baby, admission

## INTRODUCTION

Each year, approximately 150 million babies are born, of which 10% are born prematurely (Kliegman et al., 2015). In Malaysia, it has been estimated that for every 500,000 live births, 12.3% are premature (Kutty, FM, Choo, PL & Lee AE, 2014) . Premature birth is a stressful event for parents, and premature infants may be admitted to the neonatal intensive care unit (NICU) for several weeks or months. Mothers of premature infants who require intensive care treatment will have their first experience of parenthood in the strange and scary environment of the NICU. The hospitalisation of premature infants in NICU for long periods causes families, especially mothers, to feel isolated from their babies and their hope turns into stress (Ramezani, Shirazi, Sarvestani, & Moattari, 2014).

The premature birth of a baby has been well described as a crisis event for the parents and remain as one of the most important unresolved reproductive health problems (Bry & Wigert, 2019). Studies of parental response to this crisis describe parents experiencing many losses and high levels of tension and anxiety. The immaturity of the baby necessitates admission to the NICU as the premature infant is dependent on the technology and professional skills of staff working in the NICU. The NICU therefore serves as the social context in which all interactions with the baby must take place resulting in the baby frequently being regarded as an integral part of the NICU rather than the family unit. The admission of a baby to the NICU imposes considerable stress on the mothers and inevitably means separation of mother and baby. The effects of separation and emotional distress caused by the uncertainty which surrounds admission to the NICU have been reported (Roque et al., 2017).

Admission to the NICU interrupts the mother-infant bonding and establishment of breastfeeding (Crenshaw, 2014). It has been reported that an infant's NICU hospitalization is associated with anxiety and depression in mothers of preterm infants compared with mothers of healthy term infants (Friedman, Yang, Parsons, & Amin, 2011) The birth of a preterm infant is a difficult situation for any mother. When an infant is born with health problems and requires hospitalization in the NICU, parents experience intense emotional and psychological distress (Korja, Latva, & Lehtonen, 2012).

When their baby stays in NICU, parents usually feel powerless and helpless; therefore, they may be more stressed and vulnerable to emotional difficulties than parents of full-term babies (Clottey & Dillard, 2013).Thinking about their babies as sick and in danger is very stressful for parents, and it may bring them to an emotional crisis (Alkozei et al., 2014) Parents of hospitalised neonates in the NICU experience a high level of distress, symptoms of depression and anxiety, sleep disturbance and fatigue when compared with parents with full-term neonates (Busse et al., 2013).

In Malaysia, approximately 68.8% of the population are Malays, the majority of whom are greatly influenced by cultural beliefs and practices related to postpartum confinement (Fadzil, Shamsuddin, & Wan, 2016). These often cause mothers to conceal their feelings and concerns, which might in turn exacerbate maternal stress and anxiety (Chourasia et al., 2013; McMahon et al., 2011).

The parental response to the crisis of premature birth is largely dependent upon their experiences within the NICU which itself interacts with parental behaviour in such a way as to influence their ability to resolve the crisis. The overall NICU environment exerts a powerful influence on parental relationships with their baby and other social systems, which forms the background to this study (Müller-Nix & Ansermet, 2018).

**Literature Review**

The search for relevant studies covered the period from 2004–2014 using Science Direct, PubMed, CINAHL EBESCO, SpringerLink, Psychology & Behavioural Sciences Collection and Web of Science databases. Medical subject headings (MESH) was used to identify keywords. The MESH terms were explored and combined, including keywords that were a combination of parents' experience, parents' perception, parents' journey in NICU, parent's story in NICU, and infants in the NICU, babies in NICU, neonate in NICU, preterm infants in NICU, and preterm neonate in NICU.

.

The admission of a baby to the NICU imposes considerable stress on mothers and inevitably means separation of mother and baby. The effects of separation and emotional distress caused by the uncertainty which surrounds admission to the NICU have been well documented. The literature supported the claim that both mothers and fathers experience many psychological issues (Watson 2011, Heidari et al., 2013, Heinemann et al., 2013, Whittingham et al., 2014).

A qualitative study conducted by Heidari et al. in 2013 of 21 purposely selected participants (seven mothers, six fathers, three physicians and five nurses) and explored parents' experiences when hospitalising their infants in the NICU. Many factors were listed that increased stress levels related to admitting their infants to the NICU, including parents' sense of shame, guilt and social stigma, changes in family dynamics and alteration of parental roles. Whittingham et al. (2014) reported that having a hospitalised neonate in the NICU is a stressful event for the parents. The parents are exposed to many psychological problems associated with this event such as grief, isolation, distress, anxiety and depressive symptoms.

In a qualitative study interviewing 20 parents, Gallegos-Martinez et al. (2013) asserted that the physical environment of the NICU serves as a major source of stress for parents. This hospital unit is often inundated with unpleasant procedures and sights, loud sounds, and anxious visitors. Added to the above, parental stress levels increase with lack of knowledge about their baby's health status, recovery progress, or medical intervention and procedures.

Another qualitative study was conducted by Aliabadi et al. (2013) among a purposive sample of 12 parents with premature infants admitted to the NICU. Using semi-structured interviews, the researchers found that parents experience stress from lack of knowledge about their infants. They failed to manage their negative feelings because they felt worried, fearful, and stressed about their child's health. However, this study did not provide sufficient information about how the sample reaches saturation and how the data was analysed. The study also did not obtain approval from an ethical committee, and participants did not provide informed consent.

A cross-sectional survey in 2017 conducted in two hospitals in Jordan among 310 parents of infants in the NICU reported similar results with the mothers experiencing higher levels of stress compared to fathers, with positive correlations between stress and anxiety, depression and sleep disturbance (Almaghaireh et al., 2017) Another recent survey in a Malaysian public hospital, with 180 mothers using Perceived Stress Scale (PSS) and a State-Trait Anxiety Inventory (STAI) found that 56.5% of mothers had high levels of stress, 85.5% of mothers had a high level of state-anxiety and 67.8% of mothers had a high level of trait-anxiety (Ong et al., 2018). Feizi, Najmi,

Salesi, Chorami, and Hoveidafar (2014) suggested that parental psychological distress can led to depression, anxiety, and failure to lead a normal life at home.

A systematic review of qualitative studies exploring parental experiences in the NICU identified common themes across parents' experiences which included stress of hospitalisation, alteration in parenting roles and the impact of infant hospitalisation on psychological health (Almaghaireh et al., 2016)

However, most studies reviewed were performed in Western cultures, which may or may not be reflective of other cultures. Thus, the insight provided by this study into the reality of admission of a premature baby to NICU in an Asian country as perceived by the mother will highlight aspects of the maternal experience in this phenomenon that had not been fully appreciated by the professionals.

## METHOD

### Study Design

A qualitative research approach was conducted to explore experiences of mother with premature baby admitted to the NICU. A qualitative design was chosen for this study because of the design's inherent goals, which are to gain valuable insight; to explore in depth the richness and complexity of a phenomenon; and to examine the uniqueness of an individual's reality (Creswell, 2013; Munhall, 2012; Tashakkori & Teddlie, 2010). Specifically, the method of in-depth interviewing which seeks and values research participants' experience of social reality and to gain an understanding of their perspective in a language that is natural to them is the assumption which guided the entire data collection process (Creswell, 2013).

### Setting and Samples

A non-probability, purposive sampling was used to recruit mothers of various ethnicities in a NICU in Klang Valley in Malaysia for maximum variations of their perspectives as mothers with admitted premature baby (Munhall, 2012). In selecting the potential research sample, several factors had to be taken into consideration. Firstly, the mothers should have experience of intensive care and not just special care. The second consideration was to include only those mothers with surviving babies and who have no previous experience of having a baby admitted to neonatal unit. The final considerations were that all babies have no surgical condition which may lead to different maternal experiences.

Twenty-one (21) out of 23 mothers approached responded positively to the request to be involved in the study. Of the two mothers not interviewed, one of the infant's condition turned worse around the time the interviews were being arranged. The project was discussed with the mother and it was mutually agreed that she should withdraw. The remaining mother who did not respond to the request for interview was not followed up.

However only 17 mothers were recruited as data has achieved saturation whereby interviews were stopped when the two researchers (KLA, OMF) agreed that data categories were established and any new data fit into themes already devised. It was deemed rich and dense enough for an in-depth understanding of the topic. The qualitative sample size was determined until the data reached saturation point (Baker & Edwards, 2012; Guest, Bunce, & Johnson, 2006). Previous qualitative studies which have explored similar parental experiences reported a smaller sample size, usually between six and 12 participants (Fishering, Broeder, & Donze, 2016; Penjvini, Hejrani, & Mansouri, 2015; Granrud, Ludvigsen, & Andershed, 2014).

### Ethical Considerations

Ethics approval from the related organizations as gatekeepers was obtained before accessing the NICU. These gatekeepers included the hospital ethics committee, the neonatologist, area matron and NICU Sister. Given the sensitive nature and acknowledgement of the possibility of traumatic events such as poor neonatal outcome, deteriorating infant condition or any adverse circumstances, it was vitally important to avoid inappropriate maternal contact. Thus, the neonatologist and the NICU Sister assistance was sought in the identification and recruitment of the participants were asked to give approval for the mothers to be contacted and asked to advise if there was any reason why contact would be undesirable.

Clear information regarding study's objectives and method of data collection, how study findings would be used were conveyed to participants before written informed consent was obtained. They were informed that their choice to participate was voluntary and that they were free to withdraw from participating, at any time, if they desired. They were assured of anonymity and confidentiality of data as collected in the study.

In instances where participants became emotional as they shared their experiences, the choice of discontinuation of the interview was given to the participants concerned. Contact details of local counselling services and parent support groups were readily at hand so they could be offered to participants if necessary.

## DATA COLLECTION

Participants who consented were interviewed face to face and the interviews were audio-recorded. The method of semi-structured, in-depth, face-to-face interview is used to discuss broad areas, develop ideas, probe information, and sustain a conversation that covers a wide range of topics (Rubin & Rubin, 2011). This type of interview also identifies a clear set of information for interviewers, and provides reliable, comparable qualitative data. More importantly, this method allows participants the freedom to express their views in their own terms (Rubin & Rubin, 2011).

Prior to each interview the infant's medical case notes were reviewed and brief details of the baby's medical history and, where possible, subsequent progress was noted to ensure that no mothers were caused any distress by inappropriate contact. An interview protocol was constructed based on the protocol suggested by Creswell (2014) for asking questions and recording answers during interview. The interviews were guided by four open-ended questions which were reviewed by a panel of five experts which consists of a neonatologist, two neonatal sisters, a lecturer and a staff working in the NICU:

a. How did you feel when your baby was admitted to the NICU?
b. What do you need when your baby was admitted to the NICU?
c. Why are these needs important to you in the NICU?
d. Please give me an example of one of your visits to the NICU.

The researcher is made the primary instrument to ensure effective data collection. No more than one interview was arranged for any one day with a maximum of four interviews in any week to ensure adequate time for data analysis before the next interview. The interviewing process spanned ten weeks in total.

Participants were interviewed in a closed room beside the NICU to ensure privacy and prevent interruptions during the interview. First, the researcher explained the aims and process of the interview, and assured parents that all data would be confidential. The parents were informed that they could withdraw at any time from the interview. Next, informed consent was obtained prior to the interview. During the interview, the researcher asked parents open-ended questions, encouraging parents to explain their ideas, answers, and feelings. Parents were requested to explain their responses, and the researcher did not proceed until the parents did not have any more information to share for a particular question. After asking all three questions, the researcher ended the interview and thanked the participants.

All interviews, each lasting from about one to one-and-a half hours, were conducted in the languages as chosen by the participants as the researcher was able to understand English, Mandarin, and Bahasa Malaysia (Malaysian national language). Majority of the participants in this study consented to be re-interviewed within one week after the initial interviews for verification of the data and to clarify any matters arising from the previous interviews. This form part of the process to ensure trustworthiness and credibility of the data analysis.

## DATA ANALYSIS

Translated verbatim transcripts for Bahasa Malaysia and Mandarin were verified by a bi-lingual language expert. Textual data from interview transcripts were managed by the computer-assisted qualitative data analysis software NVivo 7.0. Verbatim transcription was done for all the audio taped records and the transcription started right after each interview session. The recordings were listened to repeatedly during transcription and during data analysis.

Thematic analysis guided by Creswell's six generic steps of data analysis was conducted (Creswell, 2013) This involved preparing and organizing of textual data for analysis, reading through textual data, coding to generate themes, representation of themes and interpretation of participants' experiences. During the coding process, all the unit of information (data segments) that had been coded from within a single document (interview transcripts) were inspected and compared with the others within the data sources which also had been coded at. There was a repeated moving back and forth between different parts of the data source in order to explore the context of certain coding references and the various textual data of the transcripts. A particular document in the

data source would be returned to for more coding, un-coding, or annotating of that source if necessary. Supervision of the coding process and review of the identified themes and subthemes by the co-author who is a university lecturer with expertise in qualitative data analysis enhanced the interpretive rigor. The researchers reflected and debated on any potential biases until agreement was reached, in order to improve the credibility of the data analysis (Creswell, 2013).

# RESULTS

Seventeen mothers with hospitalized infants in one NICUs were interviewed by the researcher. A brief description of the background characteristics is provided to facilitate reader's understanding. The subsequent section presents the various findings from the thematic analysis of the interview transcripts and field notes. Findings were organized into main themes and their sub themes. The major themes underlying their experiences which were elicited from the analysis are avoidance, separation, ceremonies and inadequate preparation. Various sub themes were identified under each major theme. Selected quotes from the parents' interviews are presented together as illustrations for the themes and sub themes.

**Characteristics**

The mean age for the mother was 28.5 years (range between 18 to 40 years). Seven mothers were primigravida (pregnant for the first time) with a mean age of 26.4 years (range 24 to 32 years) and ten were multigravida (pregnant more than once) with a mean age of 28.4 years (18 - 40 years). Of the multigravida (ranging from 2 - 6 pregnancies) three had previous miscarriages or abortions. Most of the mothers were of Malay ethnicity with only three of Chinese ethnicity and two of Indian ethnicity.

.

The gestational age at delivery ranged between 28 – 32 weeks (mean of 31 weeks gestation). Birth weights ranged between 0.960 -1.440kg (mean weight being 1.25 kg) with a gender distribution of seven males and ten female babies. Eight mothers had deliveries by caesarean section and the remaining nine had vaginal deliveries including two with assisted forceps delivery. Fifteen mothers were married and two were single.

**Theme 1:** Avoidance

The focus of avoidance behaviour and the wish to disengage from the reality of the situation had strong and negative elements. These negative responses were closely associated with fear, anxiety and loss of control within situations which were unfamiliar, different from expectations and where there was uncertainty about the outcome.

Most of the mothers made avoidance statements or described avoidance behaviours. Initial avoidance behaviour could be attributed to the sense of shock which surrounds the crisis of preterm birth as illustrate by the quotes from the mothers:

*'I was not expecting it … it takes such a long time for it to sink in, all of it. I was so shocked that nothing really registered for a while, quite a long while, Nothing was real… it just wasn't real …' (mother with a 29-week gestation baby)*

**Sub theme:** Self - Protective

There was a strong self-protective component to avoidance statements and behaviour exhibited by mothers.

*'I tried to detach myself because all this time we didn't know if the baby was going to survive or not… I didn't want to face it.. I couldn't think of him as my baby, I just couldn't.' (mother with a 28-week gestation baby)*

*'I tend to bottle things up and pretend everything is going to be all right …. I was terrified really. It was terrible really.….' (mother with a 29-week gestation baby)*

*'I don't want to admit something is wrong.... I didn't want to admit that I couldn't cope, so I suppose I just shut things out ..'(mother with a 32-week gestation baby)*

**Sub theme:** Guilt

Negative comparisons with the normal processes of childbirth at term, fostered maternal feelings of blame, guilt and low self-esteem which were supported and compounded by the avoidance behaviour.

*'You just want to hide.. You feel embarrassed about it .. You feel a failure.. it's as if you haven't done the right thing and it is all my fault the baby's down there (in NICU) …' (mother with a 31-week gestation baby)*

*'You see (other mothers) walking up and down….they talk to each other….you try to avoid them…I think I am frightened they are going to ask me 'how much did yours weigh'.. scared to say one kilogram and two hundred and fifty grams. …' (mother with a 29-week gestation baby)*

**Sub theme:** Staff reactions

More than half of the mothers described avoidance behaviour exhibited by the hospital staff. They perceived their status when compared with the number of mothers with term healthy babies created a disadvantaged environment for care in which they received low priority ranking as illustrated by the quotes:

*'I felt as if I was a burden to them because all the other mums had their babies with them…. I felt as if they didn't care about us…' (mother with a 32week gestation baby)*

*'I find that the nurses on the postnatal ward tended to sort of avoid you…I don't think they knew how to deal with you because you hadn't got your baby there.' (mother with a 29-week gestation baby)*

*'I think they tend to avoid you because they were busy with other babies' (mother with a 30-week gestation baby)*

*'I was very frightened…I know the (postnatal) ward is very busy but I just wanted them to let me know he was alright….but no one ever did. No one came to me, I had to go to them'(mother with a 31-week gestation baby)*

**Sub theme:** Being in the way

Regarding the NICU, expression of 'being in the way' were commonly expressed. Mothers felt inhibited by the machinery and lack of space in the NICU.

*'Really I felt that it would be better for them if I was out of the way and they could get on.'(mother with a 29-week gestation baby)*

*'I didn't feel able to sit by Rose (baby's name).... the unit was so busy and so many people…I felt in the way'*

*(mother with a 31-week gestation baby)*

*'Your felt constantly in the way…there was nowhere you felt was your space to sit…'(mother with a 28-week gestation baby)*

**Theme:** Separation

The separation of mother and baby soon after birth has been shown to be an inhibiting factor on the development of maternal-infant attachments. A gestation age of between 28 to 32 weeks necessitate immediate admission to the NICU for all babies in this study, resulting in all 17 mothers being separated from their babies shortly after birth.

The separation following preterm birth is compounded by that imposed by caesarean delivery. Nearly half the mothers (eight out of 17) had caesarean sections and in addition to any negative feelings which the mother had about not being 'involved' in the baby's delivery, the feelings of being separated from the mother was intensified by the physical constraints following abdominal surgery

*'When you've had as operation, you can't just walk…you can't go down and visit….you got to ask someone to get the wheel chair and everyone is so busy .. they haven't always got time to wheel you down' (mother with a 29-week gestation baby)*

*'Sometimes you had to wait a while but they would try to get someone to take you down….Then you had to ask someone to come and pick you up and take you back to the ward.. obviously they're (midwives in postnatal ward) busy so you have to wait again.'(mother with a 29-week gestation baby) .*

**Sub theme:** Emotional responses

Preterm birth has already been shown to be a highly emotional event surrounded by uncertainty about the outcome. When the drama of the delivery was over, and the baby taken away to the NICU, many mothers described being left in an emotional void

*'When she was actually born….I felt really happy and glad, and then they just took her away.. and then I went back to feeling loss' (mother with a 30-week gestation baby)*

*'I didn't feel anything for him…. I just didn't at first. Just total confusion' (mother with a 28-week gestation baby)*

**Sub theme**: Effects of the separation

Seven out of the eight caesarean sections were performed under general anaesthetic. Not only is the mother unaware of the delivery but she has no immediate confirmation of the baby. It was usual for several hours to lapse between delivery and the mother's first visit to the NICU to see her baby. Within a room full of tiny babies these mothers had little proof (other than the name labels) that the baby they were shown was actually theirs. Given the negative events and circumstances experienced by these mothers in addition to being separated from their baby it is hardly surprising that the described feelings of delayed bonding due to the separation

*'You wake up and they tell you you've got a baby boy…and when you are fit enough, they take you down (to NICU) and show you that is your baby…. It could have been anybody's…the bonding isn't there , not at first ( mother with a 29 -gestation baby)*

The mothers' enforced separation from their babies was highlighted for them on the postnatal wards. All the mothers commented on the upsetting experience of seeing and hearing especially at night other babies on the ward whilst their baby was in NU.

*'My room was opposite the nursery…I had to listen to other women's babies crying all night while mine was in NICU.. it wasn't fair' (mother with a 31-week gestation baby)*

*‘.. all the other women with their babies. And babies crying when you are trying to sleep..I miss him a lot then (mother with a 30 week gestation baby)*

The reality of separation was further intensified when mothers were discharged home while their babies are still in NICU. It is the normal convention after childbirth for mother and baby to proudly go home together. This happy occasion was denied for mother of preterm babies who must endure the ordeal of going home empty handed.

*‘The day the doctor discharged me…I felt really empty.. I really felt low and let down as I couldn’t carry my baby home…’ (mother with a 29-week gestation baby)*

*‘It is so hard to walk away from the hospital leaving without Rose. It felt strange that we had to go to the hospital to visit her ... it was horrible’ (mother with a 30-week gestation baby)*

*‘I was very torn…I had one son at home and one son in NICU .. I just didn’t know what to think…I was very torn’ (mother with a 32-week gestation baby)*

**Sub theme**: Support

Many mothers felt the need for physical and moral support to enable them to visit their baby.

*‘I wouldn’t go on my own….. I was just so scared’ (mother with a 29-week gestation baby)*

Another mother commented:

*‘I made my husband come with me…I just couldn’t walk in the room (NICU) on my own’ (mother with a 31-week gestation baby)*

Most who felt the need for this support avoided visiting when the support was not available and rationalised this in a variety of ways.

*‘I wasn’t too concerned quite honestly. He was dependent on the staff and on machinery, not on me. I felt it didn’t matter whether I was anywhere nearby or not’ (mother with a 28-week gestation baby)*

This type of avoidance behaviour clearly has implications for the frequency of visiting and opportunities for the involvement of care and bonding.

**Sub theme:** Acceptance

Once at home the reality of actually having a preterm baby and being separated from the baby reinforced the abnormity of a situation that was hard to accept. Visiting their baby in hospital had a very unreal, almost detached feeling about it for many mothers. ‘*It was like going to see a car in a show room*’ is how one mother explained the experience.

Another described feeling ‘*like you borrow them for the time that you are there’ (mother with a 28-week gestation baby).*

*'Even though they tell you it is your baby in there (NICU), it is not your baby really, is it? Because you are not looking after the baby… until the baby comes out of there and you look after her, you don't feel that it's yours somehow… it is like a little stranger to you '(mother with a 29-week gestation baby)*

*'You could visit her in the morning and then go home again….but you don't know because you are not there with her that she be alright until the next morning.. it is awful and unacceptable. You could just be doing ordinary things whilst your baby is going through a really bad crisis' (mother with a 31-week gestation baby)*

**Theme:** Ceremonies

Childbirth is surrounded by ritual moments and social customs of significance to mothers. Antenatal women developed expectations or fantasise about how the baby will look like. These ritual moments or ceremonies make an important contribution to the emotional adaptation of women to the processes of childbirth and early motherhood. When these ritual and customs do not occur, women experience a sense of loss.

**Sub theme:** Sense of loss

Preterm birth is associated with many losses and not least amongst these are the loss of many important events or ceremonies. Unexpected preterm birth for example interrupts 'nest building' preparations and baby showers parties with friends and colleagues which form an important part of psychological preparation for changing roles and motherhood. Mothers of term healthy babies proudly show off their baby to their visitors. This ceremony is denied to others of preterm babies on two counts. Firstly, the avoidance behaviour of some relatives and friends who decide not to visit and secondly, visiting restrictions imposed by NICU allowing only parents.

The following quotes illustrate the mothers' emotions.

*'I was so looking forward to painting the nursery and having a baby shower....now we dare not even think or talk about it' (mother with a 29-week gestation baby)*

*'We were planning to have a naming ceremony when he is born but now we put it to hold…we are not sure when he is well enough to be discharged' (mother with a 28-week gestation baby)*

**Sub theme**: Sense of regret

The loss of ceremonies appeared to be compensated for by alternative ceremonies which was reported by the mothers as significant and important. The transfer of babies from the intensive care to special care was regarded as a major significant event by all mothers. This was perceived as a sign that the baby is progressing well and that the baby was 'out of danger' thus an achievement of a major goal.

However, none of the mothers recalled being involved in this important and highly significant move and expressed regrets at not being involved.

*'These things are just automatically done for you. They don't ask you if you like to be there, it is just done'(mother with a 29-week gestation baby)*

*'I would have liked to do these things…we were told about things she got better on but it would have been nice to be there .. I would have felt really proud taking him out of that (intensive care) room' (mother with a 32-week gestation baby)*

The baby's first fed and bath were similar significant events for mothers in which they express a desire to participate.

*'I wish I was there when they gave him his first bath '(mother with a 32-week gestation baby)*

*'I was so happy when they told me that he finished his first feeds with no breathing problems ... I wish I was the one who did it '(mother with a 32-week gestation baby)*

**Theme:** Inadequate preparation

Preterm delivery interrupts the mother's anticipated time for preparation for childbirth and motherhood. The sudden and unexpected nature of events becomes even more frightening due to lack of information and knowledge on which to base expectations and understanding of the process involved in both delivery and child care. The acquisition of information and knowledge frequently seemed to be subject to an element of chance for those mothers who were not following the usual pattern of antenatal and postnatal care.

**Sub theme:** lack of knowledge

Most antenatal classes start from around 28 weeks gestation onwards. This fact alone excludes women who delivered very preterm babies from attending and benefiting from such sessions,

There were also difficulties experienced in recognising the onset of labour. In all cases primigravidae were disadvantaged by their lack of knowledge. The unexpected timing of the labour made it difficult for women to initially recognize its significance, even those who had experience labour before.

*'Having not experienced it and not knowing anything about it and being so early you just don't expect to have gone into labour, you feel stupid really. Everyone assumes you know when you go into labour, but you don't when it all happens so early' (mother with a 29-week gestation baby)*

The lack of antenatal preparation caused most of the mothers to be unprepared on how to look after the baby and highlighted the lack of knowledge in parenting as illustrated by the quotes below.

*'I just look at him (the baby)... I am not sure whether I can touch him (the baby).. he (the baby) looks so tiny ..like a doll' ( mother with a 31-week gestation baby)*

*' the nurse asked me whether I want to breast feed the baby or not .. and I am like what.. I have not even think about it yet. I have not even attended the antenatal class yet' (mother with a 28-week gestation baby)*

**Sub theme**: Lack of information

In the NICU they attributed lack of information to high workload and insufficient number of staff. Nevertheless, they described omissions in information as disappointing frustrating or distressing depending on the circumstances.

*'I didn't really know what facilities there were. All I knew was how to get from my room to the unit' (mother with a 32-week gestation baby)*

*'We didn't know about the coffee room for a while actually. It wasn't until nearer the time (to go) that we knew about it' (mother with a 29-week gestation baby)*

*"....the doctors use too many medical terms and give too many different answers to the same questions... it makes you think they don't really know what they're talking about. ....it feels like a death sentence for your child when they come in and explain test results, and then rush out again before the information has sunk in." (mother with a 28-week gestation baby)*

## DISCUSSION

The findings of this study reported four main themes and 13 subthemes. The first theme is avoidance. The focus of avoidance behaviours or statements and the wish to disengage from the reality of the situation had negative elements. These negative responses were closely associated with fear, anxiety and loss of control within situations which were unfamiliar, and different from expectations.

Mothers acknowledged that the premature birth and care of the premature baby were largely out of their control either by relinquishing or struggling to maintain some element of control. Mothers may feel when their child is admitted to the NICU that the staff has become the primary caregiver, thereby giving the mothers the feeling that they have lost their role and identity. More insecure feelings may follow, which may cause stress, anxiety, depression, and sleep disturbance. Their attempts to minimize losses involved the use of avoidance behaviour (Abuidhail, Al-Motlaq., Mrayan, & Salameh, 2016.). Avoidance behaviour was not only detectable in the mothers in this study but also through the avoidance behaviour of others such as relatives, friends and hospital staff. The mother enforces separation from their babies who required admission to another unit i.e. NICU, was highlighted in the second theme: Separation. All 17 mothers commented on the upsetting experience of seeing and hearing especially at night, other babies on the ward whilst their baby was in the NICU. Many mothers described needing physical and moral support to enable them to visit their baby. This support was received from a variety of sources, primarily from partners but also from relatives and friends. This result is congruent with Patil (2014) who found that social support such as family support, friend support, other parents' (peer) support and nurses' support is one of the coping strategies among parents with hospitalized infants in the NICU.

Childbirth is surrounded by ritual moments and social customs of significance to mothers. These ritual moments or ceremonies make an important contribution to the emotional adaptation of women to the process of early motherhood (Russell et al., 2014). The customs and social rituals surrounding childbirth provide reassurance of normality and acceptance, these ceremonies have a developmental role in the formation of expectations preparation for motherhood and for changes in role, identity and social status. Premature birth shattered all expectations of anticipated ceremonies and formed a source of loss. These sudden and unexpected losses of maternal unpreparedness physically and emotionally are made worse by the loss of control faced by the mothers (Latifnejad, Zakerihamidi & Merghati, 2011)

Mothers with premature infants are less prepared to accept their new role, as the later months of pregnancy are the period in which preparations for labour and infant birth take place; mothers with premature deliveries therefore miss this opportunity, shattering all their expectations of delivering a healthy baby (Varghese, 2015) The findings in this study showing that mothers were concerned about being separated from their infants were in line with those of Woodward et al. (2014). The authors reported that the item 'being separated from their infant' from the parental roles' alteration subscale scored highest due to the abrupt interruption of the expected nine months' normal pregnancy process. Under normal circumstances, mothers would have developed a feeling of readiness for their child's birth, and when the process is suddenly shortened, they are left with strong feelings of loss and anxiety (Woodward et al., 2014).

The amount, content and appropriateness of information given to mothers was extremely variable and appeared to leave the mothers in this study with more questions than answers. The volume and content of information required to maintain a perceived sense of control varied from mother to mother. The acquisition of information surrounding preterm delivery has been shown to be subject to an element of chance, many of the mothers commented on the relative lack of information available which compounded their already strong feelings of being abnormal in comparison with mothers of term healthy babies. Our finding of the importance to parents of communication is consistent with previous studies which found parental satisfaction to be highly dependent on the amount and quality of communication and information giving session between the care providers and the parents (Cescutti-Butler & Galvin 2003, Russell et al., 2014).

Antenatal preparation for labour and delivery was virtually non-existent for this group of women. This naturally led to difficulties in recognizing the onset of labour, even for those with previous experience. The fear and anxiety associated with preterm delivery was exacerbated by this lack of knowledge. Moreover, when the infant needed admission to the NICU, the preparations for parenthood and the normal parenting process were interrupted

(Arnold et al., 2013). Similarly, Watson (2011) found that the parent–infant attachment was interrupted during the hospitalisation period. The childbirth preparation was a recurring and significant factor in the maternal acquisition of information and knowledge. Much of the fear, anxiety and stress induced by ignorance could be overcome by adjusting the amount and content of information.

It would appear that for the mothers in this study, not only practices avoidance behaviour, but also perceived avoidance behaviours in relatives, friends and hospital staff, which can result in a lowering of confidence and guilt. Separation was intensely felt indicating mothers in this study quite likely lacked sufficient support.

Ceremonies or social customs surrounding full term pregnancy and childbirth are additional losses experienced by mothers in this study. Important milestones in the baby's progress for example having the first baby bath was identified as significant events they would like to be involved in. It was also noted that mothers of preterm babies do not follow the normal expected patterns of antenatal and postnatal care and are therefore subject to gaps in information leading to lack of knowledge in the preparation of childcare.

**Limitations and strength of the study**

One possible limitation of this study is that the mothers might be reluctant to express critical comments about the care, a so-called 'gratitude bias' towards the staff who cared for their preterm baby (Van Teijlingen ER, Hundley V, Rennie AM, Graham W, Fitzmaurice, 2003) This should have been minimised by the fact that the researcher carrying out the interviews was not involved in clinical care. However, the involvement of clinicians in identifying potential participants may have influenced who responded to the invitation to participate and may have led to a socially desirable response (Sawyer et al., 2013). Future studies should consider methods to remove this potential bias, such as letters being sent from someone not involved in the mother's or baby's care.

The exclusion of fathers from this study may have disenfranchised important information within the mother–father dyad. Taking the view that in Asian societies, men are less involved in taking care of infants, resulting in the mothers having extra responsibilities, and given that fathers are not traditionally viewed as having a primary caretaker role in traditional Asian cultures (Ahn & Kim, 2007), to group them together would not provide a sufficiently comprehensive and thorough evaluation of the differences between parent gender groups In addition although admittedly gender inequalities have decreased in recent decades, the house-hold division of labour remains gendered with women doing majority of unpaid work in the home (Gershuny, 2011).

## CONCLUSION

The key issue linking the four identified themes of maternal needs was identified as the loss of control which was associated with uncertainty and unpredictability which surrounds premature birth. The effects of avoidance behaviour or statements are negative. This negativity appears to interfere with effective communications and maternal infant bonding, and is detrimental to maternal emotional health.

The expressed need for more information throughout their experience is a recurring feature. The inadequate preparation associated with access to and receipt of information is generally avoidable as in continuous and comprehensively planned care might facilitate the progressive acquisition of appropriate information. Positive ceremonies created around identified significance moments help to create positive memories within an overall negative event. Celebrating the baby achievement each day may help to create positive moments for these mothers.

**Acknowledgements**

The authors are grateful to all the mothers who share their experiences during their babies' admission to the NICU. We also thank the Neonatologist, Nursing Management and Staff at the NICU for the precious cooperation in this research.

## REFERENCES

Abuidhail, J., Al-Motlaq, M., Mrayan, L., & Salameh, T. (2016). The Lived Experience of Jordanian Parents in a Neonatal Intensive Care Unit: A Phenomenological Study. Journal of Nursing Research.

Ahn, Y. M., & Kim, N. H. (2007). Parental perception of neonates, parental stress and education for NICU parents. Asian Nursing Research, 1(3), 199–210.

Aliabadi, F., Kamali, M., Borimnejad, L., Rassafiani, M., Rasti, M., Shafaroodi, N., & Rafii, F. (2013). Parent's Learning Strategies: A qualitative study on parents of preterm infants. Iranian Rehabilitation Journal, 11, 15-20.
Alkozei A., McMahon E., Lahav A. (2014). Stress levels and depressive symptoms in NICU mothers in the early postpartum period. The Journal of Maternal-Fetal & Neonatal Medicine, 27, 1738–1743. doi:. 10.3109/14767058.2014.942626
Almaghaireh D, LA Khatijah, Choing CM, Chua YP & Mariam S.(2016) Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit. Journal of Clinical Nursing 25;19-20.doi:10.1111/jocn.13259
Almaghaireh D, LA Khatijah, Chong CM Chua YP & Mariam S. (2017) Stress, Anxiety, Depression and sleep Disturbance among Jordanian mothers and fathers of Infants admitted to Neonatal Intensive Care Unit: A Preliminary Study. Journal of Paediatric Nursing 36,132-140. doi: http://dx.doi.org/10.1016/j.pedn.2017.06.007
Arnold L, Sawyer A, Rabe H, Abbott J, Gyte G, Duley L & Ayers S (2013) Parents' first moments with their very preterm babies: a qualitative study. British Medical Journal Open 3, e002487
Baker, T., Elsie, S. & Edwards, R. (eds.) (2012) *How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research* (National Centre for Research Methods Reviews) Southampton, GB. National Centre for Research Methods 43pp.
Blencowe, H., Cousens, S., Chou, D., Oestergaard, M., Say, L., Moller, A.-B., & Lawn, J. (2013). Born too soon: The global epidemiology of 15 million preterm births. Reproductive Health, 10(1), S2. https://doi. org/10.1186/1742-4755-10-S1-S2
Bry, A., Wigert, H. Psychosocial support for parents of extremely preterm infants in neonatal intensive care: a qualitative interview study. BMC Psychol **7,** 76 (2019). https://doi.org/10.1186/s40359-019-0354-4
Busse M, Stromgren K, Thorngate L & Thomas KA (2013) Parents' responses to stress in the neonatal intensive care unit. Critical Care Nurse 33, 52-59
Carter JD, Mulder RT, Bartram AF, Darlow BA (2005) Infants in a neonatal intensive care unit: parental response. Arch Dis Child Faetal Neonatal Ed 2005;90:F109–F113. doi: 10.1136/adc.2003.031641
Caplan, G, Mason, EA, Kaplan, DM (1965) Four studies of crisis in parents of prematures. Community Mental Health Journal, Vol1(2) 149-161
Cescutti-Butler L, Galvin K: Parents' perceptions of staff competency in a neonatal intensive care unit. J Clin Nurs. 2003, 12: 752-761. 10.1046/j.1365-2702.2003.00783.x.
Chourasia, N., Surianarayanan, P., Adhisivam, B., & Bhat, B. V. (2013). NICU admissions and maternal stress levels. The Indian Journal of Paediatrics, 80(5), 380–384
Crenshaw JT (2014). Healthy Birth Practice #6: Keep Mother and Baby Together-It's Best for Mother, Baby, and Breastfeeding. J Perinat Edu Fall;23(4):211–7.
Creswell, J. W. (2013). Research design: Qualitative, quantitative, and mixed methods approaches. Sage publication
Clottey M., Dillard D. M. (2013). Post-traumatic stress disorder and neonatal intensive care. The International Journal of Childbirth Education, 28, 23–29
Fadzil, F., Shamsuddin, K., & Wan Puteh, S. E. (2016). Traditional postpartum practices among Malaysian mothers: A review. The Journal of Alternative and Complementary Medicine, 22(7), 503– 508.
Feizi A, Badroddin,N, Salesi A, Chorami M , Hoveidafary, R (2014) Parenting Stress Among Mothers of Children With Different Physical, Mental, and Psychological Problems. J Res Med Sci Feb;19(2):145-52.
Fishering, R., Broeder, J. L., & Donze, A. (2016). A Qualitative Study: NICU Nurses as NICU Parents. Advances in Neonatal Care. 16(1):74-86. doi: 10.1097/ANC.0000000000000221.
Friedman,SH., Yang, SNN, Parson, S & Amin.J. (2011) Susan Maternal mental health in the neonatal intensive care unit. NeoReviews Februar 12 (2) e85-e93; DOI: https://doi.org/10.1542/neo.12-2-e85
Gallegos-Martinez, J., Reyes-Hernández, J., & Scochi, C. G. S. (2013). The hospitalized preterm newborn: the significance of parents' participation in the Neonatal Unit. Revista latino-americana deenfermagem, 21(6), 1360-1366.
Gershuny, J. (2011).Time-use surveys and the measurement of national well-being.Report funded by the UK Office of National Statistics. Centre for Time-useResearch, Department of Sociology, University of Oxford.
Granrud, M. D., Ludvigsen, E., & Andershed, B. (2014). Parents' Experiences of Their Premature Infants' Transportation From a University Hospital NICU to the NICU at Two Local Hospitals. Journal of pediatric nursing, 29(4), e11-e18.
Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods, 18*(1), 59-82.
Heidari, H., Hasanpour, M., & Fooladi, M. (2013). The experiences of parents with infants in Neonatal

Intensive Care Unit. *Iranian journal of nursing and midwifery research, 18*(3), 208.
Heinemann, A. B., Hellström-Westas, L., & Hedberg Nyqvist, K. (2013). Factors affecting parents' p esence with their extremely preterm infants in a neonatal intensive care room. *Acta Paediatrica, 102*(7), 695-702.
Korja R, Latva R, & Lehtonen, L(2012). the effects of preterm birth on mother-infant interaction and attachment during the infant's first two years Acta Obstet Gynecol Scand/ Feb;91(2):164-73. doi: 10.1111/j.1600-0412.2011.01304.x
Kutty FM, Choo LPL& Lee AE (2014) Report of the Malaysian Neonatal ; A Study of Critically Ill Babies in Neonatal Intensive Care Units. Ministry of Health http://www.crc.gov.my/wp-content/uploads/documents/report/nnr_Report2014.pdf
Latifnejad Roudsari R, Zakerihamidi M, Merghati Khoei E. Socio-Cultural Beliefs, Values and Traditions Regarding Women's Preferred Mode of Birth in the North of Iran. IJCBNM. 2015;3(3):165-176.
McMahon, C. A., Boivin, J., Gibson, F. L., Hammarberg, K., Wynter, K., Saunders, D., & Fisher, J. (2011). Age at first birth, mode of conception and psychological wellbeing in pregnancy: Findings from the parental age and transition to parenthood Australia (PATPA) study. Human Reproduction, 26(6), 1389–1398
Müller-Nix, C., & Ansermet, F. (2018). Prematurity, risk and protective factors. In C. H. Zeanah, Jr. (Ed.), *Handbook of infant mental health* (4th ed.). New York, NY, USA: The Guilford Press.
Munhall, P. L. (2012). *Nursing research*: Jones & Bartlett Learning.
Ong, SL, Khatijah LA, Danaee M, Soh KL, Soh KG & Japar S(2018) Stress and anxiety among mothers of premature infants in a Malaysian neonatal intensive care unit, Journal of Reproductive and Infant Psychology, DOI: 10.1080/02646838.2018.1540861
Patel, C. (2013). *The complete guide to stress management*: Springer.USA
Penjvini, S.,Hejrani, M. S., & Mansouri, M. (2015). Lived experiences of hope in mothers with NICU infant (A phenomenological study). Journal of Chemical and Pharmaceutical Sciences, 8(8).
Ramezani, T., Shirazi, Z. H., Sarvestani, R. S., & Moattari, M. (2014). Family-centred care in neonatal intensive care unit: A concept analysis. International Journal of Community Based Nursing and Midwifery, 2(4), 268
Roque,ATF, Lasiuk,G,Radunz V & Hegadoren K (2017) Scoping Review of the Mental Health of Parents of Infants in the NICU.Journal of Obstetric Gynecologic & Neonatal Nursing 46(4)DOI: 10.1016/j.jogn.2017.02.005
Rubin, H. J., & Rubin, I. S. (2011). Qualitative interviewing: The art of hearing data: Sage.
Russell, G., Sawyer, A., Rabe, H. (2014) Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study. *BMC Paediatr* **14,** 230-238.. https://doi.org/10.1186/1471-2431-14-230
Sawyer A, Rabe H, Abbott J, Gyte G, Duley L, Ayers S (2013): Parents' experiences and satisfaction with care during the birth of their very preterm baby: a qualitative study. BJOG. 120: 637-643. 10.1111/1471-0528.12104
Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*: Sage Publications Inc.
Van Teijlingen ER, Hundley V, Rennie AM, Graham W, Fitzmaurice A (2003) : Maternity satisfaction studies and their limitations: "What is, must still be best". Birth. 2003, 30: 75-82. DOI:10.1046/j.1523-536X.2003.00224.x.)
Varghese, M. (2015). A Study on Parental Stress in the Neonatal ICU Using Parental Stressor. Pediatrics, 135(Supplement 1), S9-S9.
Watson, G. (2011). Parental liminality: a way of understanding the early experiences of parents who have very preterm infant. *Journal of clinical nursing, 20*(9-10), 1462-1471.
Woodward, L. J., Bora, S., Clark, C. A. C., Montgomery-Hönger, A., Pritchard, V. E., Spencer, C., & Austin, N. C. (2014). Very preterm birth: Maternal experiences of the neonatal intensive care environment. Journal of Perinatology, 34(7), 555–561
Whittingham, K., Boyd, R. N., Sanders, M. R., & Colditz, P. (2014). Parenting and prematurity: Understanding parent experience and preferences for support. *Journal of Child and Family Studies, 23*(6), 1050-1061.