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LIVED EXPERIENCES OF MOTHERS OF WITH PREMATURE BABIES IN A NEONATAL INTENSIVE CARE UNIT OF A SELECTED HOSPITAL, IN UNITED ARAB EMIRATES: A QUALITATIVE CONTENT ANALYSIS

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ABSTRACT: Background: A mother's expectation and excitement of having a healthy newborn is cut short when a baby is born premature. She is faced with the fear and anxiety of losing her baby or overwhelming thoughts of her baby suffering inconceivable distress in Neonatal Intensive Care Unit (NICU). Aim: This study explored the lived experience of mothers who had a premature baby admitted to NICU. Methods: A qualitative design with a phenomenological approach was used for the study. It was conducted from October to January 2019 among eleven women whose premature babies were admitted in the NICU at a hospital in Ras Al Khaimah, United Arab Emirates. Purposive sampling was used to choose the participants which continued until data saturation was reached. Data was collected using in-depth, semi structured face- to- face recorded interviews and analyzed using Colaizzi's method. Results: Three themes were generated from the analysis. Mother's expression of thoughts and emotions while their babies in NICU; Families experienced emotion while their premature babies were in the NICU and Mothers perception of care and support from health care professionals. Conclusion: Mothers and family members were anxious about the survival of their premature babies admitted to NICU. They exhibited emotions such as anxiety, anger and sadness. During the recovering process, mothers relied on family support, faith and hope to help get through the ordeal. Satisfaction of nurses providing competent care and provision of psychological support to the mothers helped them to cope.

KEYWORDS: Experiences, Neonatal Intensive care unit, mothers, Preterm babies

INTRODUCTION

Approximately 15 million premature babies are born worldwide every year; sixty percent of them are born in Africa and South Asia. Blencowe et al (2013). Several maternal health factors play a role in placing a woman at risk for delivering a preterm, including maternal diabetes and hypertension, increased maternal age and obstetric practices such as caesarean sections. World Health Organization (2020). Babies that are born premature are prone to complications and need medical intervention and specific nursing care in Neonatal Intensive Care Unit (NICU) due to their compromised physiological state. Hospitalization of the neonate is extremely stressful for mothers. The parents encounter traumatic experiences due to the treatments, condition and separation effecting their thoughts, state of mind, relationships, including their interactions with their premature babies.

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Some studies have addressed the experiences of mothers who have babies in NICU. When a premature baby is born physical, psychological and social preparation for a baby is interrupted and the mother of the premature baby might feel as if she is omitted out on the care Lomotey et.al. (2020). Premature babies often require substantial support because their organs are undeveloped. This can affect the attachment process between mother and child (Siegel & Hartzell 2013). All of these factors can lead to emotional stress where parents experience strong emotions (De Rouck and Leys, 2013). At this time, parents need to have hope for the survival of their premature babies. But they may at the same time recognize that their babies can die.

Other studies looked at attachment, bonding and mental health concerns. In an intensive care unit (NICU) situation parents play a lesser role in the care of their babies. Not only are other people such as neonatal nurses and neonatologists more involved in looking after their babies than themselves, but their babies' condition may change which will make it difficult for the parents to know the future of their baby. This might cause the experience of parents with premature babies in the NICU to be (Russell et al., 2014). These traumatic experiences can have a long-term effect on the mental health and functioning of the parents of premature babies to (Siegel and Hartzell, 2013) The parents' experiences of their premature babies in the ICU can have an impact on the normal attachment process, adequate bonding is the foundation for healthy parent—child relationships which is also the basis for the premature babies Steyn, Poggenpoel, & Myburgh (2017) mental health. It is therefore important for parents and their premature babies, as well as their families and the community at large, to use parents' experiences of their premature babies in an NICU to facilitate their mental health.

A study by a group of authors who focused on anxiety observed that majority of mothers had state anxiety whereas above half had trait anxiety (Margaret et al. (2014). The findings of these authors aligns with the result of the study to reduce the level of anxiety being experienced by the mothers of neonates in the NICU whose anxiety and fears was imminent in their response. It is a fact that psychological state dominates physical stability and needs in human being especially when they are under stress. So it imposes a great challenge for the health care professionals to provide appropriate care and support for the mother to meet this emotional challenge, hence creating the need for health care professionals to provide counselling sessions to mothers who delivers preterm babies against their expectation of a full term babies. To bridge the gap of neglect or being seen as just a normal occurrence. The present qualitative study was conducted to explore the lived experience of mothers of premature neonates admitted in NICU.

METHODOLOGY

Research purpose

To lived experiences of mothers of with premature babies in a Neonatal Intensive Care Unit of a selected hospital, in United Arab Emirates.

Research design

A Qualitative design with phenomenological approach was used in the study. The qualitative study was conducted between October and January 2019 to explore mothers lived experiences of

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having a neonate admitted in NICU. Phenomenology can help us learn from the experiences of others and not just describing human experience. The goal of this approach is to enter into another person's world and discover the understanding found there Neubauer, Witkop, & Varpio (2019)

Participants

Participants were selected as per inclusion criteria from the selected hospital under Ministry of Health and Prevention (MOHAP). Purposive sampling technique was used in to recruit information rich candidate with diverse characteristics that was relevant to the phenomenon till saturation of data was achieved (Gentles et al., 2015). Time for interview was finalized after explanation of the purpose of the study to the mother. The demographic characteristics of the participants included age of mother, education, parity, mode of delivery, place of delivery, gestational, age and neonatal birth weight.

Inclusion and Exclusion criteria: Mothers with babies born before 37 weeks of gestation, who were mentally stable and can speak English or Arabic or both were eligible to take part in the study. Mothers whose preterm babies were critically ill and had congenital anomalies were excluded from participation due to the exceptional demands of those conditions. Eleven mothers were purposively sampled until data saturation was reached. The researchers contacted mothers at the preterm unit and the nature and purpose of the study were explained to them. Appointments were made for individual in-depth interviews with the mothers who accepted to participate in the research. All mothers who could speak and understand English or Arabic and who gave consent to participate and also have their voice audio recorded during the interview were included in the study.

Data collection

The in-depth individual face- to- face interviews took place in a quiet room adjacent to the NICU after written consent had been obtained from participants. The interviews were conducted in English or Arabic and recorded using an easy voice recorder. Verbal consent was obtain initially on tape that the mother agreed to be audio taped. The interview started with general demographic questions followed by a semi-structured interview guide was used to allow participants to describe their experiences from the birth of the preterm baby beginning from admission to the preterm unit. During the interview, mothers were asked to narrate what it felt like to have their babies born before term and be admitted to a highly intensely critical environment as the NICU. Prompts were used to elicit more information. The questions guide is shown table one. A total number of 11 interviews were conducted by the research team members lasting 20-25 minutes.

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1	Did you had any premature baby before?		
2	How did you feel when you learned your baby is admitted in Neonatal Intensive Care Unit		
3	What was your experience when you first visited your baby in the Neonatal Intensive Care		
	Unit?		
4	What was the feeling of your family and spouse on baby's admission in Neonatal Intensive Care Unit?		
5	What was your expectations of the health care team in caring for your neonate especially nurses?		
6	What was your feelings on the condition of your neonate in the Neonatal Intensive Care Unit?		
7	How do feel on the care being given to your baby by health care team?		

Table 1- Question guide for the interview

Data analysis

Data was analyzed using Colaizzi's method (Morrow, Rodriguez, & King (2015). Members from the research team individually and collectively read the verbatim transcripts of the mothers. Significant statements relating to the phenomenon were extracted from each mother's transcript and by hand. Team members met to review significant statements. Meanings were formulated from the statements and themes arranged to create a rich and exhaustive description of the mothers' lived experience.

Rigor

Accuracy of findings was achieved through prolonged engagement and adequate time for analysis of the data. Data was analyzed by using steps described by Colaizzi's method; familiarization, identifying significant statements, formulating meanings, clustering themes, developing an exhaustive description. Following these steps organizes data and provides structure which elicits meaning from the data. The purpose of data analysis is to organize, provide structure to, and elicit meaning from data.

Ethical consideration

Ethical approval was taken from Institutional and regional ethical committee (RAK Medical and Health Sciences University (RAKMHSU-REC- 141-2018-F-N) and United Arab Emirates Ministry of Health and Prevention Research Ethics Committee)

Informed consent was taken from all participants who were willing to participate in the study. Confidentiality of the information was maintained by using coding method and keeping it with principal investigator only

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RESULTS

Table 2- Socio Demographic characteristics of the mothers (N=11)

Mothers demographic data	Frequency	Percent (%)
Age		
below 2 2	1	10%
23 – 40	10	90%
Education level		
Secondary	9	81%
Bachelor	1	9%
Post Graduate	1	9%
Parity		
1	4	36%
2-5	5	45%
More than 5	2	18%
Mode of delivery		
Normal Vaginal Delivery	8	72%
C-Caesarian	3	27%
Gestational Age:		
28 and less	9	81%
More than 28		18%
Neonate Birth weight		1070
Less than 2.5 Kg	7	70%
= 2.5 Kg	3	27%
More than 2.5 Kg	1	9%
Total alayan mathana nantiainatad in tha	. 1 3.5	

Total eleven mothers participated in the study. Majority of mothers (90%) were young adults. More than 50% were multipara and 72% gave birth to premature babies via normal delivery .With respect to age of neonates majority were between 28 -36 weeks of gestation and 70% babies had birth weight of less than 2.5 kg.

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Themes	Subthemes	
1)Mother's expression of thoughts and emotions while their babies in NICU	Mother's experienced feelings of being scared, angry and sorry while their premature babies were in the NICU.	
	Mother's experienced feelings of happiness and trust on supreme power while their premature babies were in the NICU	
	Parents expressed hope about their babies health in the ICU .	
	Parents' spirituality was challenged by their experience to have a premature baby in the NICU	
2) Families experienced emotion while their premature babies were in the NICU	Families experienced feeling of psychological shock while their premature babies were in the NICU	
	Families shows expression of unhappiness and fear of babies death	
	Families shows support	
3) Mothers perception of care and support from health care professionals	Families expressed feelings of satisfaction with the care provided for the baby	
	Families expressed good interpersonal relationship with nurses as an educator	

Table 3: Experiences of mothers with Preterm neonates

Themes generated through analysis were mother's expression of emotions with their premature baby in NICU, Families experienced emotions, hope and support on their baby's admission to the neonatal intensive care unit and mother's feeling of satisfaction related to care provided by the nurses and progress observed in health of their babies in NICU.

Mother's expression of thoughts and emotions while their babies in NICU

1a. Feeling scared, angry and sorry: These were the negative emotions expressed by the mother when they realized that their baby is in need of special care and will be separated from them. It was expressed as "I was scared" (P1), "Felt angry" (P9) and "Felt sorry" (P6). Feeling angry is a secondary emotion which is basically can arise from the experience of loss, disappointment, anxiety, worry etc. In the present study it was due to unexpected birth of a baby who needs separation and hospitalization. Feeling scared is an indication that individual has perceived some

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danger. Participants of the present study were scared may be due to the perception of threat to their baby's life.

Feeling of scared was also prominent among the participants when they saw their baby first time in NICU where baby was surrounded with machines, tubes in mouth, nose and other gadgets. Mother M1said: "Honestly, I was scared .They were too small and were connected to machine" Other participants stated that: "I cried" "My heart was broken but Alhamdulillah" but I had to stay with him every day and every two hours." (P6) Another response, "I was really scared to see all the wires and tubes in his mouth and so many tapes and cotton stuck on his body" (M 1)

1 b. Expression of positive emotion and trust on supreme power Though majority of participants were feeling bad, sorry and scared one participant said "It's totally different from the mother who gives birth in due time, yet I am happy that I can see them (twins)" (P4)In fact, faith in God brought comfort and cheer, even in the midst of stress and crushing difficulties which was observed in most of the participants. One participant said: "I was little nervous and worried about what can happen, what can go wrong with the baby? But at the same time Al Humdulliah if Allah gave me this baby, he will take care of my baby." (P4)

1.c. Feeling/expression of hope: Hope is considered as positive emotion in which individual envisions the brighter future for self or for loved ones. It was evident from the feelings stated by participants when they were asked to express their feelings about the condition of their neonate. Most of the mothers were happy as their babies were improving. One said: "Better and good baby improving but he is always asleep".(P11) Another mother said, "I feel that he is improving he differs than before. "(P2) "They are much better than before Now they are crying and opening their eyes as well I can breast feed them." (P4) I hope they get better as soon as possible and can go home" (P8) But in case of one mother said that her feelings depend on the condition of her child, to be precise in her words she said, "My feeling ah on condition it goes up and down. Sometimes when I get to know his news that he not gaining weight or there is something wrong with his blood or that again he is not breathing it goes down, But again Alhamdulillah there is something happening good with the care of the nurses and the doctors. The medication that they provide and all the care there is something good at the same time." (P4) Yet another participant said "Now I feel he is better and I hope and wish that they discharge him today or tomorrow." (P6)

Families experienced emotion while their premature babies were in the NICU: Hospitalization of a newborn to NICU not only leads to overwhelming of emotional reactions from the mother but the whole family which was evident from their responses narrated by participants. 2. a. Feeling of psychological shock: Feeling shock is a psychological reaction which can be triggered due to occurrence of unexpected event in human being. It was observed in the present study when Participants shared reaction of their family members towards birth of premature baby and need of hospitalization in NICU. One participant said,

"They were shocked. Because when I delivered my baby they came he was perfect, he didn't seem he is sick or he had illness or something wrong. So when they saw they thought I gave birth and I

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was going out tomorrow so nobody came to visit until they knew." (P6). For the family of on baby, the mother said, "Though they were aware of premature delivery but not expecting that the condition of the baby will be so critical." (P1) One participant said "the feeling is of fear because you never expect that your child will come to the nursery, you want your child to stay by your side, but love is inexplicable [...] (P7)."

Expression of unhappiness and fear of death: It is a natural expectation that baby will go home along with mother after the delivery. But when it did not happen for the mother (M11) especially when she gave birth to the baby after 15 years since last baby, family members were disappointed upon knowing that the baby will be kept in NICU for special care. Similar response was also expressed by the family member of mother "They are happy that I have baby but unhappy that baby is not with me." (P7) Admission to a critical care unit is usually associated with feeling of uncertainty especially with outcome of the life. It was obvious from the response from the family member of two mothers. Participant said "they felt unhappy and afraid too that baby may die and not go home with me". (P9) Another participant said "They were feeling very sad as they were not sure whether baby will survive or not". (P8)

2. c. Family support: Family support plays an important role in the outcome of baby and reliving stress of mother. Overall, all family members were very supportive. One participant said "They all supported me from all sides, they also made Duwa (prayer) for me. Though this was not expected to happen they wish that it should not happen to the next baby. They gave me all support and they were all happy that at least we got the baby safe" (P4)

Mothers' perception of care and support from health care professionals

Families expressed feelings of satisfaction with the care provided for the baby Admission of a premature baby in NICU brings an overwhelming emotions like fear, anger, guilt, powerlessness etc. among parents as they are not prepared for this untimely birth. Moreover when parents observe that their baby is attached to various machines and tubes it adds up to tension related to care of the baby. During this period it is observed that parents become very sensitive and critical about the care of the baby. It imposes a great challenge for the health care professionals to maintain the balance and harmony with them which is necessary for ensuring quality care for the baby and psychological health of family members. In the present study when participants were asked to speak about their experience related to the care provided by nurses working in NICU feeling of great satisfaction was expressed by all participants. It was expressed with the statements like

[&]quot;The health care team, especially the nurses are taking good care of my baby. The care is excellent and good". (P1)

[&]quot;Um the expectation were really it was average I thought it would be all taken care by the machine and I was very happy that it was 24 hours taken care by the nurses and the doctors. They were always available so I was really happy with that. And the machines are really advanced so there is always an alarm if something goes wrong and the nurses were very caring "(P4)

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This finding indicates that parents were satisfied with the care provided by the nursing personnel and availability of competent staff round the clock for the baby has contributed in developing trusted relationship with the parents.

Families expressed good interpersonal relationship with nurses as an educator::Nurses working in NICU play an important role in preparing the baby for discharge from day one. For this it is necessary to involve the mother in providing care for the baby. In the present study nurses working in NICU implemented this by involving mother (M1) in simple procedure like Diaper changing.

DISCUSSION

The present study aimed to explore the lived experiences of mothers who have given birth to a baby prematurely and the baby was hospitalized in NICU. Three main themes were generated from the interviews to explore. The first identified was mothers' expression of emotions with their premature baby in NICU. Secondly identified were families experienced emotions, hope and support on their baby's admission to the neonatal intensive care unit. Lastly, mother's feeling of satisfaction related to care provided by the nurses and progress observed in health of their babies in NICU. Various similar studies have been done describing mothers lived experience during the hospitalization of their preterm in NICU which demonstrated similar feelings of emotional instabilities, isolation, family relationship challenges Abuidhail, Al-Motlaq, Mrayan & Salameh (2017). Various needs were identified and examined in the studies of parental experiences and needs encountered in NICU which coincided and were similar with the results of this study (Magliyah & Razzak, 2015).

A qualitative study was done related to NICU admission and maternal stress level and it was observed that out of 122 participants, Seventy percent of mothers perceived higher level of stress in two domains namely parental role alteration and looks and behavior of the baby. Looks and behavior consisted of attachment to machine, equipment, tubes, color, and small size of their baby (Beck & Woynar2017).

Feelings of fear were extracted in a similar study about perception of mothers when visiting their child in the neonatal unit for the first time they found that all mothers verbalized a desperate and sense of anxiety and fear Ued et al., 2019. In another study mothers immediately after birth, mothers of premature newborns experienced feelings such as anger, anxiety, and depression. (Sansavini & Faldella, 2013). This goes in line with the results of this study. In particular our results pointed out that mothers and families of preterm children feel more anxious and more depressed with lots of emotions, but got enough support from their families. Another study showed that the maternal thoughts and feelings stem from separation and fear of not having a chance to reunite or interact with the infant. These perceptions are the main reasons for emotional disturbances and later maternal—infant emotional attachment Abuidhail , Al-Motlaq , Mrayan & Salameh (2017).

Another study suggested that preterm birth usually causes negative thoughts in mothers and fathers: generally, they are not ready to deal with this event, and they may feel weaker and tired

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(Beck & Woynar 2017), This study concluded that mothers were weak physically. In our sample mothers were weak due to their physical conditions. There was no data collected in this study to support that fathers high levels of weakness and weariness as fathers were not questioned. In fact, there highlighted that parents are tired after the birth of their baby, and some mothers needed care after a complicated and exhausting delivery hence parents needed to leave the NICU to recover themselves which is similar the report of our study where mothers are allowed time to rest before visiting their babies in NICU Abuidhail, Al-Motlaq, Mrayan & Salameh (2017). indicated that parents with premature infants admitted to NICU require various forms of emotional support from the staff caring for their child, professional psychological comfort and companionship with other patients' parents. Parents also needed to be able to maintain a solid sense of trust in the NICU and its staff. Furthermore, the atmosphere of the family was one of sadness, depression, and uncertainty over what would happen to the baby and hope. In Arab culture, fathers traditionally take responsibility for meeting the financial needs of the family, and mothers are responsible to rear and take care of children even if they are working mothers(Saifan et al., 2014). Husbands of the participants in our study were at work during the daytime, it was found fathers of premature infants admitted to NICU were able to arrange their work schedules and times of visitation to meet the schedule imposed by their infants' stay in the NICU. The mothers in our study were torn between their hospital responsibilities and their families as stated by few mothers who are already discharged and always come from their homes to visit and take care of their babies in NICU (Saifan et al., 2014). This situation was clearly expressed in their stated feelings of fear. Results of the present study suggest that immediately after preterm birth parents of premature children experience the preterm birth as a stressful event that could increase stress and negative feelings such as anger, anxiety, and depression which is in line with the result of a previous study(Sansavini and Faldella, 2013).. In particular our results pointed out that mothers and families of preterm children feel more anxious and more depressed with lots of emotions, but got enough support from their families.

Assessment of Parent's satisfaction is a fundamental need for ensuring quality care. According to the results of a study, when mothers became involved with care of their babies in the NICU, they developed a sense of trust, confidence in the nursing staff as well as themselves and it was a positive experience(Russell et al., 2014).. Information sharing was also considered to be of importance in this study and others. The cross sectional study done at King Fahd Hospital in Saudi Arabia NICU unit showed that perception of nursing support decreased parental stress (Alsaiari, Magarey and Rasmussen, 2019). A quantitative study involving family in decision making and care of infant decreased stress leading to parental satisfaction. From this study, 83.3 of parents wanted gentle safe care of their infants and also wanted current and accurate information about their newborn. There was a strong relationship between obtaining information about baby and satisfaction exhibiting a p value of <0.001. The result of the study stressed the need for parents to have information about the care of their babies, emotional support, and preparation for discharge planning and teaching which is supported by other studies which recommend incorporating familycentered care into the NICU to support the parenting roles of family Hall and Hynan, 2015). Results of the study also observed that parents and family members were angry initially but later expressed hope when they saw that their babies getting well due to the quality care provided by the health care team. Furthermore our results pointed out that in our sample, mothers, fathers and family of

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preterm babies were angrier initially but later expressed hope in their babies getting well with the adequate care provided by the health care team which is supported by what another study confirmed where there were high levels of hostility initially which then lessoned after parents became comfortable and less stressed after seeing the quality of care given to their infant (Sansavini and Faldella, 2013).

The participants described many positive experiences of receiving psychosocial support from the health care staff. It also revealed areas of satisfaction where parents expressed support from their families and health care professionals giving care to their babies in NICU. One study examined how parents have various experiences and challenges involving how they feel, what they think and their relationships; some of them are traumatic and some of them are encouraging. However, in one study, it was noted that post-traumatic growth is more likely when parents are able to take responsibility for what they feel. The findings of this study also highlight the effect of the admission of an infant to the NICU on the daily lifestyle of a family and on the parents and siblings Abuidhail , Al-Motlaq , Mrayan & Salameh (2017). Admission to the NICU altered the family unit, lifestyle, and the relationships among family members. It was observed in another study done in Jordon to that mechanical ventilation, lower birth weight and lower gestation age were predictors of higher anxiety level and depression among mothers of infants admitted to NICU and anxiety decreased after the mothers were more content once they knew that their babies were getting the best care (Al-Akour et. al., 2015).

The strength of this study is that the nurse's role is significant in providing appropriate care for the preterm infant. They also assisted the mothers through this stressful, challenging experience in NICU by providing therapeutic and trusting relationship, providing emotional support with accurate information and involving the parents in the care pf the neonates. The limitation of the present study was limited number of participants available in the three month period of the study. It was not easy to get adequate time and cooperation from mothers as some mothers worked or had responsibilities at home. Some interviews were rescheduled as mother was not able to come at original scheduled time.

CONCLUSION

Findings of this study clearly suggests that admission of a premature baby to NICU is a stressful situation for mother and family members. But it was appreciating to note the strong support from family members and health care professionals working in NICU received by mothers is vital for the wellbeing of mother and baby. The nurses supporting the parents and involving them in the care of the newborn contribute to reducing the stressful emotions experienced by the family.

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