

Lived experiences of hope in mothers with NICU infant (A phenomenological study)

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ABSTRACT

The aim of this study was to describe and understand mothers' experiences hope with NICU infants. The study was a qualitative (Interpretative phenomenological study) performed at Neonatal Intensive Care Units (NICUs) in Kurdistan Province, Sanandaj, Iran. The study included 12 mothers with NICU infants. A qualitative study was used to describe participants by a narrative approach. The interview texts were subjected to qualitative interpretative phenomenology. The results show mothers with NICU infants were adapted to their prematurely born infants. In this study hope has been identified as an essentially resource for mothers of premature infants and helping them in these stressful and uncertain times. Therefore, it is necessary nurses support, training, encouraging of mothers to communicate and promote their role in caring for their child. In this study emerged three themes; adaptation, hope suitability, Self-esteem, summit hopes, move forward hope eagerness and ten sub themes. In conclusion, hope that developed by mothers and caregivers in the NICU, extends its roots in the experiences of mothers' hope, which make positive relationships between mother– infant – nurse.

Keywords: Lived experience, Hope, mother, premature infant, neonatal intensive care unit (NICU)

INTRODUCTION

Having a premature infant is accompanied by certain challenges and tensions for parents including anxiety, loss of control, change in role, separation from the infant, and fear for his/her future and health (. Affleck G & Tennen H, 1991). When parents enter the NICU and see their child surrounded with lights, sounds, and various tubes and monitors, they feel stressed and hopeless. At these times, the support of the healthcare team is highly crucial (Affonso, 1992).

In such circumstances, supportive measures should be taken by the healthcare team for parents while their infant is at the NICU (3). Spirituality health provides support and hope and helps individuals find meaning and goals to guide their lives and is considered as one of the coping styles (Anderson, 2004). Weaver & Flannelly stated that faith plays an important role in helping an individual to have hope and is effective in increasing their quality of life (Bialoskurski, 1999). Other studies have also shown that hope is positively related to quality of life, health, and wellbeing in adolescents suffering from cancer as well as their parent (Blanch D'Souza, 2009; Clarke, 2011). Moreover, hope has a determining role in treating and curing cancer; therefore, nurses have an eminent role in facilitating hope in patients and their families as the main caregivers (Cockcraft, 2012). Although the word hope is used often, we do not fully contemplate on it and it cannot be defined easily; however, the effects of hopelessness can be evidently felt (Cox C L & Bialoskurski M M, 2001) and Clarke and Kissane believed that hope is the most fundamental and important part of life that gives meaning to it and makes it worthwhile (Diekelmann, 1989). Lysaker and *et al.* define hope as the state of lack of despair and hopelessness (Edey, W. & Jevne, R. Hope, 2003) and Bland & Darlington believed that hope is rooted in the present, while it extends towards the future (Feldman R, 1999). Also Edey and Jevne stated, "hope helps us live with a difficult present and an uncertain future" (Fisher MA, 1998) and make satisfaction (Cox C L & Bialoskurski M M, 2001)

Many studies have been done on the mother-child relationship in NICUs from different aspects that have led to better clinical performance in NICUs such as studies evaluating the mother's role and attachment (Hall E, 2004; Heermann, 2005), the effects of having a premature infant (Hinds, 1988), and the mothers' spirituality and having a premature infant (Hummel, 1991). When reviewing nursing literature, qualitative studies on hope in mothers with premature infants admitted to NICUs were less frequent. Although the science of nursing is rapidly developing around hope, most studies are related to the definition of hope. Considering the limitations of quantitative studies in responding to emotional, intellectual, and intuitive questions, it seems that a qualitative study design would yield for better results since participants can freely state their feelings of hope with respect to their premature infant.

Considering the lack of knowledge about the experience of hope in mothers whose premature infants are at NICUs, we aimed to perform a phenomenological study on hope among mothers of premature infants at NICUs.

METHODS

This qualitative study was conducted using an interpretative phenomenological approach. The aim was to describe and understand the lived experiences of mothers who had a premature infant hospitalized in NICU. The result of phenomenological inquiry reveals meaning embedded in experiences (Jackson, 2003). The main research question was, "What is your experiences with premature infant in NICU?" Participants were asked to describe personal experiences and perspectives based on their lived experiences.

Setting and Participants: A purposive sample of 14 mothers with premature infants was interviewed. Participants were recruited from NICU of hospitals in Kurdistan University of Medical Sciences. The inclusion criteria were tendency to participate, ability to communicate, and admission duration of 5-7 days.

Data Collection: McMillan & Schumacher, stated Qualitative research is multi-method in focus, involving an interpretative, naturalistic approach to the subject matter. This kind of research studies participants in their natural setting, attempting to make sense of or interpreting phenomena in terms of the meanings that they generate for themselves. In this study, the researchers used depth explanations of the phenomenon of interest. Dieklmann, Allen & Tanner devised a step-by-step process of analyzing text narrative based on Heideggerian philosophy. Their basic format for hermeneutic analysis was adapted for this study (Johnson, 2008).

Analysis is typically performed by an interpretive team and involves seven steps -1 reading the interviews to obtain an overall understanding, -2 writing interpretive summaries and relatively systematic process of selecting, categorizing, comparing, synthesizing, and interpreting coding for emerging themes, - 3 analyzing selected transcripts as a group to identify themes, - 4 returning to the text relatively systematic process of selecting, categorizing, comparing, synthesizing, and interpreting coding for emerging themes, -5 comparing and contrasting texts to identify and describe shared practices and common meanings, - 6 identifying patterns that link the themes, and- 7 eliciting responses and suggestions on a final draft from the interpretive team and from other who are familiar with the content or the methods of study study (Johnson, 2008). In this study, the hermeneutic analysis began when the first researcher listened to the tape recordings repeatedly to extract the true meaning of the data (Karl, 2006). Interviews were transcribed, and the entire set of first and second participant interviews were read and examined together to obtain an overall understanding of the texts. This required reviewing texts before each subsequent interview, summarizing the texts, and identifying potential themes. The team continued data analysis according to the seven phases developed by Dieklmann *et al.* (Johnson, 2008), classified as described in this article. The themes eventually became interrelated and evolved into a constitutive pattern. All transcripts were read repeatedly and compared with records to confirm the accuracy of the data. Credibility of results and interpretations were assured through prolonged engagement with the data during all phases of the research.

RESULTS

In this study, we included mothers aged 18-34 years with education levels ranging from illiterate to associate degrees whose infants were admitted to NICUs of hospitals affiliated to Kurdistan University of Medical Sciences. By categorizing the interviews, we found that the three main themes of adaptation, hope suitability fitness hopes, self-esteem hope suitability, and moving forward summit hopes were more important.

Adaptation, hope suitability: One of the points that were repeatedly mentioned by the mothers was the necessity to take care of their infants. Care plays an important role in the acceptance and adaptation with the infant.

Participant 1 stated: *"I think I adapted with this environment and I go along with it". "I feel my child is being taken care of here and I expect to take him home in good health and care for him at home and breastfeed him...To feel he's my own child ... I do not want lose of my child"*.

The mothers felt their child's presence and therefore, they wanted to take care of, feed, and understand their child. One of the mothers stated (4): *"You have to feel you're becoming a mother. I felt it. You have to feel it. I felt it. I didn't know it before, but I'm looking forward to becoming a mother"*.

Participant 7 said: *"Since my child was not well before, I felt guilty. I was worried and blamed myself for not taking care of myself and my baby...but now that my baby's well I'm happy and feel much better. I have a good feeling and feel that my baby will get better. I feel like the whole world is mine"*.

Spirituality and faith have a central role in health behavior and the mothers' attitudes towards their sick and premature children. These key concepts indirectly affect the healthy birth of a child and have protective effects on the mothers.

In this regard, participant 1 said: *"Hope means a new beginning and a new birth...in life, faith is first and foremost, and the rest comes next"*.

Mother 7 claims: *"We as mothers sing lullabies to our children that are close to our religious faith. This way we have a better feeling. Pray for us. I read one of the suras of the Quran to my child when I was pregnant and now she feels soothed when I read this sura. Other mothers have also done this with other suras...These all mean hope."*

The participants in our study helped each other and completed each other's knowledge. One mother (3) stated: *"I have a good relationship with other mothers. We became friends and learned from each other. We wrote down each other's address and want this friendship to last...Because we have a similar problem. We also help new moms with premature children like ours"*.

Self-esteem, summit hopes

Family-based care and skin-to-skin contact between the mother and premature child is effective in increasing the mother's self-esteem and reducing her anxiety regarding her hospitalized infant.

One of the mothers said (9): *“you have to feel your baby and know that you’re a mother now. He moved inside me. It was my baby. One must feel motherhood. I have a good feeling about my child even if he is little. I hold my baby and we both enjoy it... It is very enjoyable for both of us”*.

Another mother said (5): *“I have a good feeling. I think my baby will get well here... God had felt I deserve to be a mother to have given me this baby. I have a better and closer feeling to my child. I love him now more than ever”*.

Mother 1 stated: *‘I am hopeful because after many years of expectation, I gave birth to this baby... This was god’s will... With faith in God, I managed to become a mother and I am happy about it and I feel proud in front of my husband and family’*.

Another participant said: *“I try to give hope to myself...With all these recent advancements in medicine, I feel more self-esteem. I hope my baby gets better and I’m sure she will. It’s been 10 days and she’s getting better and better”*.

One mother (6) said: *“I feel satisfied, happy, warm, self-worth and cheerful. I have hope and without hope I would not be happy. God will also help me and my baby. He will give my baby the strength to get better and stronger”*.

Move forward, hope, eagerness: Some mothers were worried about the future of their infants (possible complications and how to care for their child). Their worry mostly resulted from the low birth weight of the neonate, not being able to breastfeed or care for the neonate, and possible complications.

In this regard, participant 8 said: *“I want to be a good mother for my baby. I want him to grow, become bigger and keep our generation running. I feel really happy when I think about him growing...for example, I wish to buy him shoes and socks and clothes. I have these images in my mind and they give me hope...I see a bright future for my son”*.

One of the mothers (5) said: *“I never cry when I am with my baby. I have a good feeling, but the doctors don’t have such a feeling. I have hope in the days and years to come. When my baby grows up, I would say all these things to him. Yeah, I would tell him he had another brother but that he was the one who made it and stayed and made me his mother”*.

Another participant (3) also exclaimed: *“I believe my baby would get better and think we would go home in about two weeks’ time. Hope, give me hope towards life. If I take my baby home without hope, he would die or suffer more complications. Hope forced me to care for my baby and overcome problems whole heartedly. I want to be hopeful...this is also one solution”*.

Participant 4 stated *“I wish I could learn how to take care of my baby and be able to breastfeed him and then go home. I’m hopeful he would get better and that I could get out of here without any worry...But I want to leave when my baby gets better, going home otherwise means returning to this place again...and this is hard for me. Only God knows what will happen”*.

DISCUSSION

The results of this study show that most of the participants had gained a comprehensive and adequate understanding of hope. They had stated that hope had been created in this environment and the mother-child-nurse communication process had been established. However, signs of anxiety still existed and could be seen and some mothers felt guilty because of having feelings of inefficiency, being separated from their child, and not knowing how to care for their child. Nagorski *et al.* and Hummel *et al.*, found that if sufficient training is provided for the mother on how to care for their child at home and at the hospital, mothers can perform their supportive caring role better and the mother-child relationship would increase. As a result, mother-child attachment would be facilitated and mothers would be committed to their children and ultimately have higher self-esteem during their child’s hospital stay (Krause, 1998; Lysaker, 2005) and after discharge. Since, the process of becoming a parent comprises taking care of, loving, and nurturing a child, parents should participate in caring for their sick children. Such participation increases their knowledge and awareness and reduces their stress (Magaletta, 1999).

It should be noted that we encouraged the participants to use the Kangaroo Mother Care method for caring for and feeding their infants. Anderson G C, Moore E, Hepworth & Bergman N (2004) also found this method effective in enhancing the mother-child relationship (McMillan & Schumacher, 2001). Moreover, by performing the Kangaroo Mother Care and family-centered care methods, parents of premature infants have a more positive feeling about the recovery and health of their children (Miles, 1993). On the other hand, the mothers mentioned that they could not control how to care for their infants and faced a challenge in this regard. Infants who are ill and are admitted to NICUs are at risk of separation from their parents and their attachment process is terminated (Mok E and Lung S, 2006).

We found that the mothers felt closer to God by reading Quran, lullabies, and prayers, and felt higher spirituality and as a result had less stress, and more strength to sustain problems and adapt to their situation. Human beings use adaptation strategies related to their psychosocial development, such as hopefulness to cope with their tensions (Moore, 2005). Some researchers believe that the concept of hope is related to conformity, faith, and empowerment and by making existing difficulties tolerable, it can be considered as an effective response to different stressors (Nargoski, 2007).

In this study, adaptation was the first resulting theme from the mothers’ experiences in which one of the sub themes was pleasant moments. In this regard, the mothers stated that they felt pleased and happy by being beside their infants. For instance, one mother mentioned the physician and nurses’ support during difficult situations and that they had allowed her to care for her child. By establishing the mother-nurse relationship, mothers will show their positive feelings and feel more responsible (Neu, 1999). The mothers had understood other positive experiences regarding the mentioned these such as an expression of affection, love, and friendship towards their child, breastfeeding, taking care of their child, helping experienced mothers, and having a

closer and a more friendly relationship with mothers to help them accept the new environment. It is important to establish and develop a relationship based on trust for family-centered care in NICUs and facilitate the mothers' accessibility to information [31]. When mothers feel closer to the nursing staff and can establish positive relationships with them, a unique care could be (Panthmatharith, 2007) provided (Pendleton, 2002). Another study showed that when mothers are trained according to their needs, their stress is reduced (Polit, 2006). Moreover, nurses who are sensitive in meeting the mothers' needs at the NICUs and support such mothers can guide and help them strengthen their motherly responses and reactions towards their children (Rowe, 2005).

The second theme of our study was related to the mothers' self-esteem. One of its sub themes was search for information. The participants wanted to gain more information about their infants and care taking measures. Mothers whose infants are admitted to NICUs face various challenges such as lack of information regarding their child's condition as well as necessary treatment measures. According to Blanch D'Souza, Five fundamental coping approaches that these mothers can use in challenging situations are hopefulness, asking for help, having faith that their child would receive the best care, responsibility in relation to child and search for information.

Self-confidence was another sub theme. In this regard, Brett *et al.* believed that reducing the parents' stress and their confrontation with fear, anxiety, and guilt, increases their self-esteem and ability to take care of their children (Polit, 2006) as well as assist them in caring for their child at home and reduce their hospital stay and recurrent admissions (Rowe, 2005). Another sub theme the mothers mentioned was the experience of becoming a mother. Researchers have found that when a mother becomes a parent, she transforms from an inactive independent mother to an active and involved parent that cares for her child in a parental development process. In such conditions, mothers need family-centered care (Sloan, 2008). Moreover, if parents take care of their premature children at NICUs or interact and bond with them, they gain more self-esteem and can relate to their child more efficiently. This mental health helps the parent and the whole family and brings about a brighter perspective of the infants future (Streubert & Carpenter, 2003).

The third theme in our study was moving on. The mother considered hope as a dynamic goal-oriented experience which meant that they were hopeful that their child would get better. Also, they considered hope along with the support of the healthcare staff, the infant's growth, and looking towards the future. One of the most important sub themes of this theme was returning home, which some mothers considered as a wish, aim, or hope for their child's well being. However, another study showed that parents might not be prepared for accepting a premature or sick child. They sometimes experienced feelings of self-esteem at discharge and stated that they had adapted to their child's condition during hospitalization (Tarling, 2002).

Other researchers have stated that taking the infant home or staying in the NICU is a dilemma (Tutton, 2009). The other subtheme was the mothers' satisfaction with the health care team. This finding was consistent with other studies in which the nursing staff had trained mothers on how to care for their child and made a positive initial impression when meeting the mothers (Van Riper, 2001). The nurses were actually sources of strength and knowledge who reduced the mothers' anxiety and provided the foundations for a closer mother-child relationship (Weaver & Flannelly, 2004).

CONCLUSIONS

This present study extends our understanding of Kurdish mothers' experiences hope of premature infants. The findings of this study was multifaceted, involving hope for becoming mother, care, trust, sense of responsibility, adaptation, spirituality and faith and peer, nurse, support. Mothers in this study seeking for cues from their infant which indicated s/he was gaining in health enough to go home. Hope for mothers meant be their infants and they would be ok in the future. Nurses had a significant role in the hope experiences of mothers in this study.

Author contributions

SP and SV were responsible for the study conception and design. SP performed the data collection. SV, SP& AN performed the data analysis. SP &MM was responsible for the drafting of the manuscript.

Ethical Considerations

The research protocol was approved by the ethics committee at the Tabriz University of Medical Sciences, Tabriz, Iran. Participants volunteered to take part in this research and were assured of anonymity.

Conflict of interest

There are no conflicts of interest.

Table.1. Maternal hope. Examples of data analysis

Main category	Subcategories	Citation from the original data
Adaptation, hope suitability	Care trust	"Hope to me means good caring of my child" "I adapted with this environment and this situation" "I want to care of my child" "I expect to take him home in good health and care for him at home"
	Believe to becoming mother	"You have to feel you're becoming a mother. I felt it" "I feel like being a mom" "I got sense of responsibility" "I'm looking forward to becoming a mother"
	Spirituality and faith, rising optimism of hope	"Hope means a new beginning and a new birth...in life, faith is first and foremost, and the rest comes next" "We mothers sing lullabies to our children that are close to our religious faith"
Self-esteem, summit hopes	Family Centered Care: Axis of hope inspiration	"I have a good feeling. I think my baby will get well here... God had felt I deserve to be a mother to have given me this baby " I love him now more than ever" "I try to give hope to myself...With all these recent advancements in medicine, I feel more self-esteem. I hope my baby gets better and I'm sure she will."
	Kangaroo Mother Care: delightful sense of hope	"I do kangaroo mother care, I hold my baby and we both enjoy it... It is very enjoyable for both of us" "I feel satisfied, happy, warm, self-worth and cheerful"
Move forward, hope eagerness	Joy and peace means hope	"I never cry when I am with my baby. I have a good feeling, but the doctors don't have such a feeling " "I'm hopeful he would get better and that I could get out of here without any worry...But I want to leave when my baby gets better, going home otherwise means returning to this place again...and this is hard for me. Only God knows what will happen"

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