

Parental needs in infant's end-of-life and bereavement in NICU: A qualitative study

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ABSTRACT

Background and Aims: Newborn death is an unexpected outcome for parents. Parents face with several needs in infant end-of-life. The health care team is responsible for meet these needs. This qualitative study aim was to explore of parental needs in infant end-of-life and bereavement. **Materials and Methods:** For this qualitative study, 24 single semi-structure interviews were done. A qualitative content analysis method was used. Sampling conducted on purposeful with maximum variation in five Neonatal Intensive Care Unit (NICU) environments in Isfahan city. Inclusion criteria for nurses and doctors were having at least one experience of caring for an infant and their family at end-of-life. Inclusion criteria for parents and their families were having at least one infant at end-of-life or had lost their infant for 6 months before in NICU. **Results:** Data analysis uncovered two main themes. Family's support needs with two subthemes (family's support needs before infant's death and family's support needs after infant's death) and family's preparatory needs upon infant's death with two subthemes (management of the bad news of infant's death by treatment team and management of the bad news of infant's death by family). **Discussion:** Mourning mother's need for her husband's presence by her side, getting hospitalized in a separate room, and management of infant's death news by father and family were among items rarely pointed out in other studies. Exploration of these needs cab be helpful for the health care team for providing care.

Key words: Bereavement, end-of-life, family, infants, Neonatal Intensive Care Unit, qualitative research

INTRODUCTION

Newborn death is an unexpected outcome for parents.^[1] Any kind of loss is painful, but the loss of one's child, spouse or parents is very terrible. The loss of one's child is probably the

most tremendous event. Children are future heirs of parents and parents are severely damaged with their death.^[2] Infant's death has an excruciating pain on parents.^[3] Various studies have shown that child's death is the worst experience for parents;^[4] an experience that remains fresh for parents and brings about much harm to them years after the incident.^[2,5]

Most caregivers become upset upon the death of their patients, especially the death of children and infants.^[6] Loss of the child makes parent lose their social role and

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confidence. Caregivers also required exclusive skills with regard to providing bereavement care.^[7] One shouldn't be alone at times of bereavement; he or she should be supported by others then. He or she should be allowed to cry and talk about the deceased, and assured that the bereavement would decrease in time. The bereaved person should be spiritually supported by the spiritual figure of the family or a nurse who has skills in bereavement counseling.^[2] Providing information on the bereavement process can be helpful to families.^[8]

Even though Kubler-Ross identified five stages for grief reaction, Neonatal Intensive Care Unit (NICU) caregivers ought to know that these stages may not follow in their mentioned order or they may overlap one another or one stage may get completely skipped. With regard to infant loss, the concept of acceptance is criticized as parents may not get to this stage at all.^[9] At the first stages of grief, parents need preparation and support against harms imposed by shock and confusion and guidance with regard to taking care of family members.^[10] The support parents receive upon losing their infant has a significant effect on their understanding and memory of whatever has happened; it also affects their ability to cope with the loss and feeling good.^[11]

Nurses are of exclusive responsibility and ability for sympathizing with families even when there is no treatment.^[9] After infant's loss, parents mentioned that they need to make contact with their infant's caregiver. Some parents also requested a follow-up meeting with their infant's doctor. Some parents also looked for professional grief counseling and they believed such counseling must be easily accessible in hospitals.^[10] Healthcare providers can play a great role in providing support to families immersed in feelings of helplessness upon the death of their infant.^[6] In a study, parents pointed out that caring for them was as important as caring for their infant.^[12] In Williams's study, one of the most prevalent criticisms by parents was a lack of emotional support, inappropriateness of advice, frankness without sensitivity, and careless treatment of the deceased infant.^[7]

In Gold's study, parents thanked the personnel who talked to the family and stayed by their side and thus provided a great emotional support.^[6] Caregivers are responsible for facilitating the transition of the bereaved family into the society.^[7] In the study conducted by Henley and Schott families stated that they needed, healthcare personnel's proper treatment of mothers and their infant, their sympathy with parents, as well as accurate information on their infant's status before, during and after infant's death.^[11] In Williams's study on support needs of bereaved families, four themes of clear and consistent communication with compassion, Participation in decision-making, emotional and physical support at the time of death, and provision of social, mental, and medical support were identified.^[7] In Davies's review study, four themes of being by infant's side during death, being by infant's body after its death, space and privacy with infant when dying, space, and privacy with infant after death emerged.^[13] In

Gold's literature review, families pointed out the necessity of emotional support, nurses and doctors' proper treatment, financial problems, grief care, mental-spiritual, and physical support, and guilt after their infant's death.^[6] Eden pointed out that proper bereavement cares should be prepared in NICUs for families who lose their infants.^[14] As shown by the above study, families' need at end-of-life and bereavement stages of their infant's death can depend on some extent on the cultural background of their society.

As no Iranian study was found on the above subject, and as researchers of this study are of extensive experience in NICU and in caring for infants and families at end-of-life and bereavement stages, they are familiar with these families' great needs for proper support. Thus, it is necessary to identify the above needs so that appropriate support programs at hospitals or even after discharge from hospitals for reducing these families' bereavement problems can be designed. This qualitative study was conducted to explore families' needs at the end-of-life and bereavement stages so that their needs are deeply understood, and proper support is provided for reducing their grief and enabling them to cope.

MATERIALS AND METHODS

We did not find any research about family needs in infant's end-of-life and bereavement in NICU in Iran; therefore we used qualitative research for exploration of these needs. A qualitative conventional content analysis approach based on Graneheim and Lundman method was used.^[15] In the qualitative content analysis, the categories and their names were obtained from data. In this method, researcher interprets data from participant's view.^[16]

We interviewed with 24 participants (mother, father, grandmother, nurse, and doctor) who met inclusion criteria. The length of interviews was between 35 and 75 min. Purposeful Sampling was used in this study. Semi structured interview was conducted during 35 and 75 min until the new data were not obtained. Data gathering were continued until the new data were not obtained. After conducted 24 interview analyses, two additional interviews were conducted but was not found the new data. After conducted 25 interviews with 24 participants, was not found any new data, and data saturation conducted on all themes. Two additional interviews were conducted but were not found the new data. The research environment was the NICUs in the city of Isfahan in Iran in 2014. Inclusion criteria for nurses and physicians were having experienced at least one infant in end-of-life care and for families were having experienced at least one infant death in the last 6 months in the NICU. Infant medical data such as sex, diagnosis, the cause of death, and Duration of infant death from the interview were recorded.

We met some of the participants in the NICU while their infants were in the end-of-life. We called to some of the participants who lose their infant in last 6 months. All of the participants were informed about the purpose of the study.

After obtaining verbal and written informed consent, the participants were chosen time and location of the interview.

Data were collected through 25 face-to-face semi-structure in-depth interviews with 24 participants. All participants were interviewed in a quiet room at the hospital, except for two participants that were interviewed at their homes in a convenient place at their request. The first interview was a pilot.

Interview with participants began with main question about family needs duration of newborn hospitalization in NICU such as “could you please tell me about your needs, when you knew your newborn was in end-of-life and near death in NICU?” Interview with nurses also began with a general question about their experiences about newborn end-of-life care and then probing questions were asked regarding the family needs in newborn end-of-life. The researcher recorded her observation immediately after each interview.

Data analysis

Data analysis was conducted by content analysis based on Graneheim and Lundman method.^[15] In this method the first step is selecting the unit of analysis, then obtained condensed meaning unit as code, similar codes were classified into subcategories, then merging some subcategories as categories, finally classified categories and creating themes.

For instance, “initial notification to father and family of infant’s condition,” “treatment team’s preference to talk to infant’s father on its death,” “father preparing mother for the news of infant’s death,” “initial notification to infant’s father of infant’s death,” “delivery of the news of infant’s death by infant’s father to its mother” were the codes that constituted the subcategories of “family and father’s role in delivery of the bad news of infant’s death to its mother.” “Family and mother’s unawareness of infant’s condition,” “nurses making decisions for infant’s mother,” “not informing infant’s mother about infant’s condition and death,” “treatment team not asking infant’s family about their preference for being with the infant when dying,” “notifying infant’s family after infant’s death” were the codes constituting “family’s need to get informed about the bad news of their infant’s death” category. Then the subcategories of “family and father’s role in delivering the bad news of infant’s death to its mother” and “family’s need to get informed about the bad news of their infant’s death” emerged under the category of “management of the bad news of infant’s death by family;” this category with the category of “management of the bad news of infant’s death by treatment team,” emerged under the main category of “preparatory needs for infant’s death.”

To achieve rigor of research, participants were chose with various experiences. Furthermore, member check, peer review, and prolonged engagement in this study were done. For member check, two parents, and four nurses who were participants, reviewed codes, categories, and themes and confirmed that their views had been properly interpreted. Moreover, as a peer check, codes, categories, and themes

were reviewed by one pediatric physician, two PhD nurses, and four nurses PhD students who were not participate in this study. For transferability, categories, and themes were discussed and approved by two nurses and one mother who had experienced a similar with those of the participants. To achieve confirm of data, an external audit was conducted in collection and analysis of data.

This study was approved in relevant ethics committee of Isfahan University of Medical Sciences (IUMS) by number 393, 003. We obtained a written and verbal consent form from all of the participants before every interview. The participants were assured that their information keeping confidential and they could withdraw from this study without any reason in each phase. We considered supports of participants who might experience negative effects due to study, but none of the participants did not apply for these supports.

Findings

The research population was mothers (9), fathers (2), grandparents (3), nurses (9), and neonatologist (1). The nurses had approximately 14 years working experience in NICU. Of the 12 the death newborn, 7 were boys and 5 girls, 2 were twin and girl, and 1 were triple. The most important reason of newborn death in NICU was prematurity. Two themes regard to parental needs in infant end-of-life and bereavement in NICU that emerged was: Family’s support needs and family’s preparatory needs upon infant’s death.

Theme one: Family’s support needs upon infant’s death

Family’s support needs upon infant’s death included two categories are family’s support needs before infant’s death and family’s support needs after infant’s death. Family’s support needs before infant’s death were of three subcategories: “A need for the presence of spouse by mother’s side,” “a need for the bereaved mother’s bed not being by the side of a mother having an infant,” and “a need for the healthcare personnel’s proper behavior of infant’s mother.”

Family’s support needs after infant’s death was of three subcategories: “A need for maintained contact between treatment team and the bereaved family,” “family’s need for receiving information on how to treat a bereaved mother,” and “a need for counseling and training.”

Family’s support needs before infant’s death

This category was of three subcategories. The first subcategory was “a need for the presence of a spouse by mother’s side” such that one of the most important needs pointed out by families was the hospitalized mothers’ needs in the related ward. Most of the families mentioned that it is necessary that spouse be present by the hospitalized mother’s side in women’s ward or spouse be at least allowed to visit the mother so she can be supported by him.

One of the mothers mentioned

“My husband was not by my side from the moment of delivery. He was not by my side for the first 1½ days. I was feeling

terrible, and I needed him. One sometimes needs someone to talk to, for support and sympathy, for encouragement. However, he was not there.”

Another mother said

“... When they were taking me to the delivery room, I was so stressed-out. I would have felt less stressed if my husband were by my side. It would have been so different if they had let him come up to the delivery room door. It would be very nice if they make it possible to have husband’s support from the very first moment.”

The second subcategory was “a need for the bereaved mother’s bed not being by the side of a mother having an infant.” All mothers whose infant were hospitalized in NICU or had lost their infants liked to be hospitalized in a separate room and not by the side of other mothers whose infant was by their side. They mentioned that seeing other mothers holding their infants or breastfeeding their infants or even hearing infants’ cry was annoying to them.

One of the mothers mentioned

“The first problem I had was that when I was hospitalized after delivery, all mothers who were hospitalized there had their infant by their side, but mine was not with me. It was horrible. I was hospitalized in a ward where all other mothers had their infant with them, breastfed them, and I was exactly in the same room. In my opinion, it would be better to have such mothers hospitalized in another room. It was so annoying to me and affected me negatively.”

The third subcategory was “a need for the health care personnel treating infant’s mother properly.” Mothers needed nurses and doctors to understand the condition of the mother whose infant was in NICU or deceased and thus treat them differently and more properly and do not ask questions unwittingly on infants as it would lead to mother’s annoyance.

One of the mothers said

“I expected them to *treat* me properly and answer my questions properly and do not mislead me.”

Another mother in this regard said

“Nurses’ attitude toward mothers who do not have their infant by their side should be different than that toward mothers who have their infant by their side. They must mind their words. They should talk differently. They should mind what they should say and should not say. It has happened to me several times when I did not know about my infant’s condition, and they asked where my infant was. I used to reply that I did not know about my infant as it is in the incubator.”

Family’s support needs after infant’s death

This category was of three subcategories. The first subcategory was “a need for maintained contact between the treatment team and the bereaved family.”

Most nurses mentioned that they did not keep in touch with bereaved families after their discharge from hospital; while

families stated that they start wandering at the hospital, and they go through events that required treatment team’s support.

One of the nurses said

“I am not in touch with them anymore. It is so busy here, and it would be really good if someone follows up bereaved parents for mental and spiritual support.”

One of the mothers said

“... Many get depressed, after all, these issues. They face many problems. I came to terms with myself, but I am not sure I can avoid depression after my infant’s death. I try to adapt and cope, but it is very difficult. It takes a lot of time to get prepared and resume my normal life.”

The second subcategory was family’s need for receiving information on how to treat a bereaved mother. Most families needed guidance and information on how to treat their bereaved mother, and they did not know how to reduce her grief when she got back home.

One of the grandmothers said

“... Please tell me now what I should do. What should I do with her mood? What her husband should do? I am at my wits’ end. I need your help. Please tell what I should do.”

The third subcategory was family’s “need for counseling and training” after infant’s death. Most families required counseling and training on the physical and mental problems after delivery, follow-up for future pregnancies and counseling with a clergyman or a religious person.

One of the mothers said

“... Counseling on doctors I can refer to for avoiding reoccurrence of this issue. I wish hospitals could introduce some doctors who are experts at this ...”

Theme two: Family’s preparatory needs upon infant’s death

Family’s preparatory needs upon infant’s death included two categories: “Management of the bad news of infant’s death by treatment team” and “management of the bad news of infant’s death by family.”

“Management of the bad news of infant’s death by treatment team” this category was of three subcategories: “A need for preparing the family for delivering the bad news of infant’s death,” “the difficulty of delivering the news of infant’s death,” and “avoiding mother’s sudden knowledge of infant’s death.” “Management of the bad news of infant’s death by family” category was of two subcategories: “Family and father’s role in delivering the bad news of infant’s death to its mother” and “family’s need to get informed about the bad news of their infant’s death.”

Management of the bad news of infant’s death by treatment team

The first subcategory under this theme was “the need for preparing the family for delivering the bad news of infant’s

death.” Most of the treatment team members believed that infant’s family should be prepared for the news of infant’s death from the moment the infant is hospitalized for not its condition.

One of the nurses said

“I was taking care of an infant who was delivered after 10–12 years of infertility. It weighed around 600–700 g and we really tried for this infant. The infant was placed on mother’s breast by continuous positive airway pressure for Kangaroo Mother Care. However, the infant died. The parents were extremely attached to the infant. It was a shock to me as we had not prepared the family for the news as it was progressing well, and the infant was feeling well those days.”

The second subcategory was “the difficulty of delivering the news of infant’s death.” Most nurses mentioned a need for an experienced person for delivering the bad news of infant’s death to families. They said delivery of such news is of the most difficult tasks. There is a dispute over who is the best person to deliver the news to mothers; some believe it should be an experienced nurse, some believe the doctor, and some believe a member of mother’s family should deliver the bad news to mothers.

One of the nurses explained

“I suggest that there should be one person to talk to the families on infants’ condition and death. Not all nurses do have the information and experience. For instance, only the head nurse can talk to them. I mean they do not accept anyone else’s words. It would be better if the words come from an experienced person.”

The third subcategory was “avoiding mother’s sudden knowledge of infant’s death.” All nurses agreed on the idea that mother’s sudden encounter with her infant’s death should be avoided.

Another nurses explained

“They had told her that she could breastfeed her infant from the day after. However, the infant had gone through some bleeding the night before and, therefore, had passed away. It was really difficult. The mother did not believe it at all. She just fell on the ground.”

The same nurses said

“... I saw a mother with two bags of milk in her hands. She was looking for her infant. She went to NICU and could not find her infant there. All of us were embarrassed. They told her that her infant was in NICU. She could not find her infant there as well. The head nurse called her then and told her that her infant had passed away.”

In this regard the researcher observed

“An infant got ill. All team members joined to resuscitate her. Despite all efforts, the infant passed away. The mother was walking in the corridor and was thinking that her infant was simply ill like before. After the infant had passed away, the

nurse wrapped its body. The mother, while unaware of her infant’s death, entered the ward and went toward her infant, but suddenly faced the corpse of her infant. She then just fainted and fell on the ground.”

Management of the bad news of infant’s death by family

This category was of two subcategories: “Family and father’s role in delivering the bad news of infant’s death to its mother” and “family’s need to get informed about the bad news of their infant’s death.”

The first subcategory was “family and father’s role in delivering the bad news of infant’s death to its mother.” Most nurses preferred first to let the father of a family of infant’s death so he could gradually deliver the news to the mother. However, fathers usually find it very difficult to deliver such news and ask for treatment team’s assistance in this regard. Only in one case, mother’s acceptance of infant’s death was better than that of father’s. She even consoled her husband. Most families required accurate information on the condition and reason of infant’s death.

Some nurses said

“As we never deliver the news of infant’s death directly to the mother, I never do that; we try to deliver the bad news to infant’s father. Or we do not deliver it to the mother during the night. The mother may know that the infant is not well, but we never tell her that the baby may die that night. If the infant dies, we never let the mother know, unless the father is so sympathetic.”

“... We usually deliver the bad news to the father and set the scene through the father so that the father supports the mother and deliver the news gradually as mothers are less patient.”

“As mothers are more sensitive, and as mothers are more attached than fathers to their infant, then we prefer to deliver the bad news to fathers.”

The second subcategory was “family’s need to get informed about the bad news of their infant’s death.” Families requested to get informed about infant’s death so they can make proper decisions on the way to deliver the news to the mother. All families requested treatment team’s support for delivering the news to the mother.

One mothers said

“... I just prefer doctors to tell mothers all the things, to tell the truth to mothers.”

The same mother said

“At the hospital, the first request is that doctors talk to the mother, nurses talk to the mother and tell the mother everything. They should not make decisions on behalf of mothers. If there is any problem with infant or mother herself, it should be told to them clearly and without any ambiguities so the mothers have everything in her mind.”

DISCUSSION

Further to an assessment of the needs of the families who have hospitalized infants at end-of-life stage in NICU or bereavement stage, two themes of families support needs upon infant's death and families' preparatory needs upon infant's death emerged. Families needed to receive some support from the treatment team and others before infant's death. Mothers requested to have their family members, especially their husband, by their side when hospitalized in women's ward. Laing pointed out that parents need grief counseling and emotional support after their infant's death.^[17] In Williams' study, parents' needs during their grief and bereavement period required some clear and compassionate communicative skills, as well as joint and proper decision-makings, social mental and medical follow-ups, and emotional and physical supports for mourning parents; most of the families also requested their families' presence by their side during end-of-life caring stage.^[7] The above results confirm those obtained by similar studies, but due to some religious considerations, husbands are not allowed into women's wards at Iranian hospitals except of informed time, and this might explain why this aspect is more highlighted in this study than similar studies.

Most of the mothers who had their infant hospitalized in NICU or deceased requested to be hospitalized in a separate room from those where mothers with infants were. The bereaved mothers were also bothered by unwitting questions asked by the treatment team with regard to their infant. As mentioned by Henley and Schott, it is necessary for all the personnel who work in the ward and deal with bereaved mothers should know about their loss so that they do not ask unwitting questions and not to add to mothers' distress.^[11] In Gold's study, parents were annoyed by nurses' questions on the condition of their infant, which was due to their unawareness of their infant's hospitalization and death.^[6] In the current study, due to a shortage of hospital beds, most of the mothers whose infant were hospitalized in NICU or had died were hospitalized in women's ward where all other mothers with their infant were; thus, they encountered many unwittingly asked questions on their infant's condition. This led to their annoyance consequently. Therefore, this issue should be taken into serious consideration.

Families also need to receive support after their infant's death. A Maintained contact with families, counseling, and training were among families' greatest needs. Meert *et al.* stated that holding conferences after infant's death may help parents learn about their infant's condition and death. It also provides an opportunity for them to discuss their feelings and emotions.^[10] Williams *et al.* maintained in his study that meeting a religious and cultural figure for receiving support might be beneficial.^[7] In a study conducted by Brosig *et al.*, participants maintained that contact with the doctor and other clinical personnel after infant's death and visiting them at their home is very important.^[12] In Branchett's study, it is pointed out that one should be quite attentive to families' needs after their infant's death as they cannot think clearly

and make appropriate decisions.^[18] In the present study, proper support was not provided to families after their infant's death and families felt abandoned after their infant's death and required much counseling, training, and follow-up after discharge from hospital.

Preparatory needs upon infant's death were among other needs felt by families. Some participants believed that treatment team should manage the tragic news of infant's death. The bad news of infant's death is divided into two groups of sudden death and gradual death.^[17] Anyhow, delivering bad news is always difficult and coupled with some stress; however, proper delivery of bad news also does not decrease the pain that is felt by parents. One of the difficult aspects of bad news for personnel is that they do not know how to react to bad news and answer families' questions.^[11] In Branchett's study, parents required to get prepared with regard to prescience and whatever is happening.^[18] Henley and Schott stated that inappropriate delivery of news can add to families' short-term and long-term distress.^[11] Meert *et al.* pointed out that doctors should prepare families for the bad news and consider some time for families' emotional reaction and answering their questions and concluding the information and whatever is going to happen in the future.^[19] In Zuzelo's study, nurses expressed their annoyance with doctors who often avoided delivering the news of infant's death to families.^[20] Gold stated that hospital personnel can play an important role in providing bereavement care services.^[6] In the current study, management of the bad news of infant's death is mainly with nurses, and doctors usually do not get involved in this issue. Although most families needed to get in touch with their infant's doctor and hear the facts from doctors themselves, unhappily doctors did not have enough time for being in touch with the families and preparing them for their infant's death.

In the current study, some nurses preferred to have the bad news managed by the families themselves. They mainly resorted to fathers as they were believed to be more logical when hearing the news and thus can better prepare their wife for the news. Of course, family-centered decision-making was another request of families at the end-of-life stage. Most parents wished to be involved in decision-making with regard to providing care services at end-of-life stage for the infant, although they did not like to be responsible for the final decision. In Brosig's study, parents requested to be involved in decision-makings on caring for their infants and emphasized the importance of parents' follow-up after their infant's death.^[12] In Meert's study, most parents stated that they needed to meet the doctor of NICU after their infant's death to obtain some information.^[19] In Brosig's study, reliance on families for coping with infant's death was considered as the most important solution.^[12] However, father of the family was the reliance point in this study for delivering the bad news and helping mother for better coping with her loss. Nevertheless, the father may not be able to cope with this great responsibility and may not accomplish it successfully, but as no follow-ups occur after

discharge from hospitals in Iran, the resulting outcomes cannot be surmised.

CONCLUSION

The results of this study offered a new outlook with regard to the needs of the families whose infant is hospitalized at NICU or are at grief and bereavement stage. Mourning mother's need for her husband's presence by her side, getting hospitalized in a separate room, and management of infant's death news by father and family were among items rarely pointed out in other studies. This must be due to the fact these issues are resolved in other countries for their cultural condition. In our society and in some hospitals, husbands are not allowed into the wards where their wife is hospitalized while this has been stated as a need by almost all mothers. Proper facilities should be provided for mothers whose infant is going through end-of-life stage or has passed away so that they can be hospitalized in separate rooms and not with other mothers whose infants are with them; this helps to avoid many emotional issues in mothers. On the other hand, most nurses preferred to deliver the news of infant's death to infant's father at first while this has rarely been pointed out in other studies. It thus seems necessary to have appropriate programs in Iran so that mothers' needs are taken into consideration as religious and cultural aspects are also respected.

Research limitations

We did not access to infant's fathers and mothers together thus we interviewed with infant's fathers or mothers separately or another family's who involvement in the care of an infant.

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Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Fortney CA. Evaluating Quality of Death at the End of Life in Neonates in the NICU. The Ohio State University; 2012.
2. O'Brien ME. Spirituality in Nursing.: Jones & Bartlett Publishers; Boston Toronto London Singapore 2008.
3. Kain, V.J., An exploration of the grief experiences of neonatal nurses: A focus group study. *Journal of Neonatal Nursing*, 2013; 19:80-88.
4. Youngblut JM, Brooten D. Perinatal and pediatric issues in palliative and end-of-life care from the 2011 Summit on the Science of Compassion. *Nursing Outlook* 2012;60:343-50.
5. Bremner, I., Reactions to loss. *Medicine*. 2008; 36:114-117.
6. Gold KJ. Navigating care after a baby dies: A systematic review of parent experiences with health providers. *J Perinatol* 2007;27:230-7.
7. Williams C, Munson D, Zupancic J, Kirpalani H. Supporting bereaved parents: Practical steps in providing compassionate perinatal and neonatal end-of-life care. A North American perspective. *Semin Fetal Neonatal Med* 2008;13:335-40.
8. De Rouck S, Leys M. Information needs of parents of children admitted to a neonatal intensive care unit: A review of the literature (1990-2008). *Patient Educ Couns* 2009;76:159-73.
9. Rosenbaum JL, Smith JR, Zollfrank R. Neonatal end-of-life spiritual support care. *J Perinat Neonatal Nurs* 2011;25:61-9.
10. Meert KL, Thurston CS, Brillier SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: A qualitative study. *Pediatr Crit Care Med* 2005;6:420-7.
11. Henley A, Schott J. The death of a baby before, during or shortly after birth: Good practice from the parents' perspective. *Semin Fetal Neonatal Med* 2008;13:325-8.
12. Brosig CL, Pierucci RL, Kupst MJ, Leuthner SR. Infant end-of-life care: The parents' perspective. *J Perinatol* 2007;27:510-6.
13. Davies R. Mothers' stories of loss: Their need to be with their dying child and their child's body after death. *J Child Health Care* 2005;9:288-300.
14. Eden LM, Callister LC. Parent involvement in end-of-life care and decision making in the Newborn Intensive Care Unit: An integrative review. *J Perinat Educ* 2010;19:29-39.
15. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24:105-12.
16. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277-88.
17. Laing IA, Freer Y. Reorientation of care in the NICU. *Semin Fetal Neonatal Med* 2008;13:305-9.
18. Branchett K, Stretton J. Neonatal palliative and end of life care: What parents want from professionals. *Journal of Neonatal Nursing*. 2012;18:40-4.
19. Meert KL, Eggly S, Pollack M, Anand KJ, Zimmerman J, Carcillo J, *et al.* Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med* 2008;9:2-7.
20. Zuzelo PR. Exploring the moral distress of registered nurses. *Nurs Ethics* 2007;14:344-59.