

Information and Communication Needs of Parents in Infant End-of-Life: A Qualitative Study

Narges Sadeghi,^{1,2} Marzieh Hasanpour,^{3,4,*} and Mohamad Heidarzadeh^{5,6}

¹Students Research Center, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, IR Iran

²Department of Nursing, Islamic Azad University, Isfahan (Khorasgan) Branch, Isfahan, IR Iran

³School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, IR Iran

⁴Nursing and Midwifery Care Research Center, Isfahan University of Medical Sciences, Isfahan, IR Iran

⁵School of Medicine, Tabriz University of Medical Sciences, Tabriz, IR Iran

⁶Deputy of Neonatal Health, Ministry of Health and Medical Education, Tehran, IR Iran

*Corresponding author: Marzieh Hasanpour, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, IR Iran. Tel: +98-9122785528; +98-2161054413, E-mail: m-hasanpour@sina.tums.ac.ir

Received 2014 December 08; Revised 2015 January 01; Accepted 2015 January 07.

Abstract

Background: Hospitalization of a neonate in the neonatal intensive care unit (NICU) can be a stressful event for parents. They need specific information and communication to alleviate their stress, but these parental needs are not met by NICU staff. Exploration of these needs can help health professionals to provide better healthcare services.

Objectives: The purpose of this study was to explore the information and communication needs of families in neonatal end-of-life and bereavement in the NICU.

Materials and Methods: A qualitative content analysis method was used for this study. Data were collected through single semi-structured interviews with 24 participants. Sampling was conducted based on the purposive sampling method in five NICU environments in Iran. All interviews were taped and transcribed verbatim.

Results: Data analysis revealed two main themes: information and communication. For information, there were two subthemes (true information about the infant's health and true information about the infant's death), and communication needs also developed two subthemes (communication with healthcare professionals and communication with the infant before, during and after the infant's death).

Conclusions: According to the results, parents need accurate information about the health and the death of their neonates in the NICU. They also need to communicate with healthcare professionals and their babies. Communication is regarded as a channel for obtaining information. Therefore, the healthcare team needs to address these families' needs and attempt to fulfill their requirements in neonatal end-of-life and bereavement in the NICU.

Keywords: Intensive Care Units, Neonatal, Access to Information, Bereavement, End-of-Life Care, Infant Death

1. Background

The loss of a newborn is a fearful and disastrous event for most parents (1) and can affect them permanently (2). Parents who have an infant in the NICU need clear information about their infant's condition (3). Good care is not possible without good communication (1); the healthcare team may need to repeat information several times in clear, simple language, as parents' stress and anxiety can negatively affect their ability to learn and remember what they are told (1, 4). In this mutual relationship, parents should also be able to ask questions and identify points that need further clarification (4).

Hospitalization of a neonate in NICU can be a stressful event for parents (5). Parents experience high levels of anxiety, distress and depression compared to parents with healthy neonates (6). Parents need specific, honest and

complete information and communication about their baby's condition to alleviate their stress, even if the information contains bad news, but these needs are often not met by NICU staff (3, 5, 7). Parents liked that their feelings about the loss of a baby to be understood by the professional of health (8). Parents usually want to know the cause of their baby's death (9), and in some studies, most parents reported that they needed to see the baby's physician to receive such information and the details about their baby's death (7, 9). If the staff provides honest information, parents can understand their baby's condition and engage in truthful communication with the staff (10).

Communication is important in compassionate care (11). The results of a European comparative study (12) showed that common information could be given to parents at any time. In Spain and Italy, information was given to families on a daily basis and according to a plan. In

Sweden, Great Britain and the Netherlands, parents were informed immediately upon the deterioration of their baby's health. In France, Germany, Italy and Spain, parents were not informed until the staff members had a clear understanding of the baby's condition. In the first stages of infant hospitalization, communication is one-way, as parents are passive receivers of information, but in the later stages, communication is two-way (12).

Parents need to communicate with staff before, during and after a baby's death in the NICU. Explanations about the neonate's condition, the NICU environment and equipment and warnings about changes in the neonate's health are very important for parents and prepare them for bonding with their neonate (13). Providing too much information can cause anxiety, but providing too little information can cause fear for parents (5). Bereaved parents do not forget the respect, understanding and warmth they receive from healthcare team members; these are important memories from their pregnancy and from their neonate's short life (1). Families and nurses need to have mutual interaction in the NICU, with the depth of this communication depending on the duration of the neonate's hospitalization (14).

The communication needed between nurses and families does not depend on the progress of the disease. When nurses are there to share a common sense of humanity with the parents, the parents will not feel abandoned or alone (11). But conflict between care providers could decrease the parents' trust in the physicians (10). The first step in providing comprehensive end-of-life care is to provide the opportunity to families to express their values and beliefs in a truthful and nonjudgmental environment (11). It is important that the healthcare team actively listen to the families and empathize with them (15). Parents need to trust the healthcare team to provide the best possible care to their neonate. Parents will trust physicians who are honest and who have the capability of providing the best care (10). Parents want the physicians to explain about their neonate's condition with a caring and compassionate tone (16).

Parents also need to communicate with their hospitalized neonate. Interaction with the baby plays an important role in parents' perception of themselves as parents. Parents' most important need is to have skin-to-skin contact with their baby in the NICU (13). There is much love and compassion in the relationship between parents and their baby in end-of-life (17). In one study, parents who had not had any contact with their neonate before its death or who had not spoken with their spouses about its death showed greater degrees of grief and mourning (11). Some parents have a special relationship with their baby and believe that this relationship can continue after the baby's death (17).

Cultural diversity and spiritual/religious beliefs should be taken into consideration in communication in the NICU. The staff must be able to have an effective relationship with parents and listen to them (11).

2. Objectives

The purpose of this study was to explore the information and communication needs of families in neonatal end-of-life and bereavement in the NICU.

3. Materials and Methods

A qualitative content analysis method was adopted to explore families' information and communication needs in neonatal end-of-life and bereavement in the NICU. In a qualitative approach, researchers interpret data from participants' point of view (17). Content analysis is a suitable method to use with subjective data for the purpose of generating classifications, coding and themes (18). In this study, sampling was conducted as per the purposive sampling method, considering maximal variation in five NICU environments in Isfahan city. Inclusion criteria for nurses and doctors included having at least one experience in caring for infants and their family in end-of-life. Inclusion criteria for parents and their families involved having had at least one infant at end-of-life or having lost their infant within the previous six months in an NICU. Participants were first contacted at the hospital. Data were collected through a single interview by the researcher in a quiet room in the hospital. Semi-structured 35- to 75-minute interviews were conducted up to data saturation point, where no new data were obtained. Two additional interviews were conducted after the analysis of the 24 previously conducted interviews, but no new data was obtained.

All interviews were taped and transcribed verbatim after being listened to several times. Families were asked to describe their information and communication needs during their infant's hospitalization in the NICU.

The first author conducted the interview with the general question, "Would you like to talk to me about information and communication needs during neonatal end-of-life?" Further questions were asked in the later stages of the interviews, based on the responses made.

Conventional content analysis was utilized in this study. In this method, categories and their names are obtained from the collected data. The present study employed a qualitative content analysis based on Graneheim and Lundman's approach. This method of analysis includes the following steps: selecting the unit of analysis,

identifying the important sentences and phrases as meaning units, condensing sentences as condensed meaning units, labeling condensed meaning units as codes, grouping similar codes as subcategories and merging subcategories as categories, and finally, creating themes (18).

Two investigators analyzed the collected data and checked the transcriptions independently. The meaning units were read several times. Then similar codes were classified for subcategories and categories. The themes were specified and labeled separately by the authors, and then any existing minimal disagreement was resolved.

To ensure data credibility, participants with various experiences were selected; member checks, peer checks and prolonged engagements with participants were also taken into consideration. For member checking, two parents and four staff among the participants reviewed the codes and categories to determine whether their opinions were appropriately interpreted. Furthermore, peer checking was performed by a pediatric physician, a nurse who had a PhD in nursing and four PhD nursing students who were not the members of the research group. To facilitate transferability, themes and categories were discussed with and approved by two nurses and one mother who were similar to the participants. To facilitate conformability, an audit trail was also done. All research processes and procedures were recorded very carefully.

This study was approved in the respective ethical committees at the Isfahan University of Medical Science, under the code 393003. A code number was given to all participants. Participants' informed written and verbal consent was obtained before the commencement of interviews. Participants were ensured of the fact their information would be kept confidential and that they could withdraw from the study whenever they desired. The time and venue of interviews were chosen by participants. Support for participants who might be affected negatively was prepared, but none of them requested any support.

4. Results

Of 24 participants, 14 (60%) were parents and family members, 9 (36%) were nurses and 1 (4%) was a neonatologist. All of the nurses were women who had worked for approximately 14 years in the NICU. The most common cause of infant death was prematurity. Eight of the infants who died were male, and six of them were female (Table 1). Analysis of the data revealed two themes: information needs and communication needs (Box 1).

4.1. Information Needs

Information needs is one of the two themes revealed through the data analysis. This theme is further divided

into two subthemes (true information about the infant's health and true information about the infant's death).

4.1.1. True Information About the Infant's Health

Most participants wanted to have access to nurses and doctors to speak with them and get clear information about their infant's condition and any changes to it. They regarded true information as an explicit understanding of the infant's status and were confused due to a lack of knowledge about their infant's condition. They were questioned frequently about the infant's survival or any health problems or its probable disability in the future.

"The first important thing at hospital is talking with the doctors and nurses. They must tell us everything about our infant. We need to know all the details about our baby".

"I asked the staff to explain to me about my neonate's condition and tell me whether my baby was better or there was no change. They explained, but it was not enough for me."

4.1.2. True Information About the Infant's Death

Nearly all parents who had lost their babies were seeking the cause of death. They reported that they had some questions about the reason for the infant's death and that they wanted answers to their questions. They expected doctors and nurses to be honest with them and explain the real cause of the infant's death. All of the parents wished to be informed when their baby was in end-of-life.

"I wished the doctor had come up and had clearly explained to me about the real cause of my infant's death. I had a lot of questions about the reason of death but I didn't receive any answers."

"I desired to see my baby before her death. I didn't see her; it was a great harm to me. The staff didn't let me. I can't accept my baby's death. Why didn't they tell me? I needed to know about her death. Why didn't they let me see her? I really needed to see my baby before her death."

4.2. Communication Needs

Communication needs is the second theme yielded by the results of this research. This theme includes two subthemes (communication with the healthcare team and communication with the infant).

4.2.1. Communication With the Healthcare Team

Parents regard communication with the healthcare team as a channel for receiving information. They needed truthful communication and a mutual truthful interaction with the healthcare team. They needed understanding and respect from nurses and doctors in their communication.

Table 1. Family Characteristics of Infants

Number of Participants	Infant Sex	Cause of Infant Death	Single or Twin	Time Before Interview When Infant Died
P1	Girl	Prematurity	Single	1 day before
P2	Boy	Prematurity	Single	4 months before
P3	Boy	Prematurity	Single	4 months before
P4	Boy	CHD	Single	In End of Life
P5	Boy	Prematurity	Single	1 day before
P6	Girl	Prematurity	Single	28 days before
P7	Girl	Prematurity	Single	1 day before
P8	Girl and boy	Prematurity	Twin	1 day before
P9	Boy	CHD	Single	7 days before
P10	Boy	Prematurity	Single	In End of Life
P11	Boy	Prematurity	Single	6 days before
P12	Girl and girl	Prematurity	Twin	14 days before
P13	Girl	Prematurity	Single	1 day before
P14	Girl	Prematurity	Single	8 days before

Box 1. Themes and Subthemes

Theme/Sub-theme ^a
Information needs
True information about infant health: 21 (87.5)
True information about infant death: 19 (79.2)
Communication needs
Communication with healthcare providers: 22 (91.7)
Communication with infant: 20(83.3)

^aData are presented as No. (%).

"I wish I could ask nurses to be always cheerful. We want a genial nurse to answer our questions, even in the worst conditions."

"I think the best thing for parents is doctors who spend more time speaking with parents; and they must treat parents kindly."

4.2.2. Communication With the Infant

Parents needed to stay with their baby in the NICU, be involved in their care and even hold and touch their baby, if allowed. Some parents were upset because they were not informed when their baby had died. They wanted to be with their baby. Some parents regarded the burial and funeral arrangements as a peace factor; they wanted to keep alive the baby's memory.

"When baby's funeral was finished, I held and talked

with him. If I didn't do so, I wouldn't have solace and comfort now. I said to him that I would see him in another world."

"I wish I were with my baby when he was in the incubator. I wanted a motherly communication with him. I longed to touch and kiss him, but they didn't let me do so. I wanted to be with my baby at the time of death, but they didn't inform me. I'm very sad."

"Sometimes, I pray for my death in the hope of seeing and holding my baby in another world in a different life again."

"I go to the cemetery every week and speak with him. This sustains me emotionally."

5. Discussion

The results of this study provide a new insight into parents' information and communication needs in neonatal end-of-life situations in the NICU and during bereavement. Exploration of these needs can help the healthcare team provide better family-centered care services. The two important needs revealed in this study were information and communication needs.

Our research showed that parents need to receive correct information from healthcare professionals about their neonate's condition, and they also need to be able to communicate with the healthcare team to ask for information. They wanted clear information about treatment, prognosis and any changes in the neonate's condition. Parents need to trust the staff members who take care

of their baby. Good communication is an important factor in building this trust (1). In Meert et al.'s study, parents described trust in communication as a need to receive accurate and correct information about the infant's condition (10). Henley and Schott, and Brosig et al. mentioned that parents should participate in discussion meetings in a proper environment where they can discuss their infant's health and ask their questions (1, 3). In Brosig et al's and Gold's studies, parents appreciated the staff who had provided straightforward information about their baby's condition (3, 9). The results of the present research were in line with the abovementioned studies.

The results also showed that parents need to receive clear information from healthcare professionals about their neonate's death. Controversy exists as to whether parents should be with the baby at the time of its death. However, some parents regretted that they had not been with their baby at this time. The data collected in this study lends additional support to studies that have reported that most parents needed to be warned about their baby's death and sought for the reason for the death. In most of the studies, parents reported that they needed to be there during CPR and at the end-of-life moment (3, 9, 10, 19). If they were not allowed to witness the event, they at least needed to receive detailed information from the staff about their baby (10, 17).

In Kauffman and Hauck's study, parents did not want to be with their babies at the end-of-life moment because they believed that the baby would receive respect and dignity from the staff and would not die alone (20). In Henley's study, all parents who had lost their baby needed to ask questions and talk with staff about their worries and concerns before they could go home (1). The results of the present study are also in line with those of the abovementioned studies.

Another important parental need included communication needs, including two subthemes (need for communication with healthcare team and need for communication with infant). Most families reported that they needed to have good communication with the healthcare team. Gold's study mentioned that there was an inappropriate interaction between healthcare professionals and parents; such negative communication can persist in parents' minds for months and even years after their infant's death (9). But in Branchett and Stretton (2012) and Meert et al. (2005), parents appreciated nurses and doctors who provided truthful communication and who showed respect and dignity both to the parents and to their baby (8, 10). According to Robinson et al., healthcare professionals' compassionate care shows their humanity (17), while Guillaume et al.'s view is that a good relationship with the parents and their baby is an important factor in creating a hu-

man bond (13). Williams et al.' study also showed that one of the bereaved families' needs was clear and consistent communication with compassion (4). The present study is in line with the viewpoint of studies mentioning that clear and good communication with parents is an important need in neonatal end-of-life and bereavement in the NICU.

The study results indicated that parents need to communicate with their infant before, during and after their baby's death. Before the baby's death, parents needed to communicate with their baby through their physical presence and through caring for and touching their baby in the NICU. At the moment of death, most parents needed to be at their baby's bedside to touch and hold their baby and know what was going on. And after the death, they needed to communicate with their baby through memories and mementos. In Guillaume et al.'s study, parents mentioned that interaction with the child played an important role in their perception of their own parenthood (13). In Williams et al.' study, physical contact with the infant, supporting parents in saying goodbye and preserving baby's memory, and supporting them through the arrangements for the burial and funeral were important factors for parents in neonatal end-of-life (4). In Meert et al.'s study, most parents needed to touch and hold their infant in the PICU (10). In Davies' study, parents needed some time to be with infant's body after death, while the deceased infants were taken away to the morgue immediately (19).

As indicated by Davies' and Robinson's studies, in this present research, most families were not informed about their infant's death or were informed when their baby's body was in the mortuary (17, 19). The present study is in line with the viewpoint that parents believe that the transcendental quality of parent-child communication can continue after the baby's death. Memories of their infant's life and death were very important for parents; they needed to spend their lives with their baby's memories (8, 19). According to Meert et al., the healthcare team can help parents to better cope with their infant's loss by providing good memories from the last days of the infant's hospitalization (10).

The results of the present study are consistent with those of the abovementioned studies with regard to the sense of motherhood being a general sense for all mothers. Unfortunately, the parents who participated in the current study either were not aware of their infant's death and could not say goodbye to their infant or they did not have any memento from their infant. Based on the study results, healthcare teams need to address these family needs and attempt to fulfill their requirements in neonatal end-of-life and bereavement conditions in the NICU.

5.1. Limitations

A weak point of this study is that due to the small population size, the results cannot be generalized and applied to a similar population. The maximum variation sampling method was used to resolve this problem and, as a strong point of the study, samples were selected from parents with a maximum variance in age, parity, number of children, days after infant death, duration of infant hospitalization and type of hospital (educational, non-educational, private and public).

A limitation of this study was a lack of access to both parents of an infant for interviews. The researcher interviewed either mothers or fathers of infants in end-of-life or bereavement, but not both.

Acknowledgments

This study is a part of a nursing doctoral dissertation and a research proposal which was approved by the Isfahan University of Medical Sciences and the neonatal health office, ministry of health. The authors would like to thank all the university, Neonatal health office and ministry of health authorities and all the parents and staff who participated in this study.

Footnotes

Authors' Contribution: Study concept and design, analysis and interpretation of data and drafting of the manuscript: Narges Sadeghi, Marzieh Hasanpur and Mohammad Heydarzadeh; acquisition of data: Narges Sadeghi; analysis: Narges Sadeghi and Marzieh Hasanpur; study supervision: Marzieh Hasanpur and Mohammad Heydarzadeh.

Funding/Support: This study was funded and supported by the department of research and technology, Isfahan University of Medical Sciences, and by the neonatal health office, ministry of health.

References

- 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**(5):325-8. doi: [10.1016/j.siny.2008.03.003](#). [PubMed: [18450529](#)].
- Laing IA, Freer Y. Reorientation of care in the NICU. *Semin Fetal Neonatal Med.* 2008;**13**(5):305-9. doi: [10.1016/j.siny.2008.03.009](#). [PubMed: [18486575](#)].
- Brosig CL, Pierucci RL, Kupst MJ, Leuthner SR. Infant end-of-life care: the parents' perspective. *J Perinatol.* 2007;**27**(8):510-6. doi: [10.1038/sj.jp.7211755](#). [PubMed: [17443196](#)].
- 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**(5):335-40. doi: [10.1016/j.siny.2008.03.005](#). [PubMed: [18472317](#)].
- 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**(2):159-73. doi: [10.1016/j.pec.2009.01.014](#). [PubMed: [19321288](#)].
- Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. *J Perinat Educ.* 2009;**18**(3):23-9. doi: [10.1624/105812409X461199](#). [PubMed: [20514124](#)].
- 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**(1):2-7. doi: [10.1097/01.PCC.00000298644.13882.88](#). [PubMed: [18477906](#)].
- Branchett K, Stretton J. Neonatal palliative and end of life care: What parents want from professionals. *J Neonat Nurs.* 2012;**18**(2):40-4. doi: [10.1016/j.jnn.2012.01.009](#).
- Gold KJ. Navigating care after a baby dies: a systematic review of parent experiences with health providers. *J Perinatol.* 2007;**27**(4):230-7. doi: [10.1038/sj.jp.7211676](#). [PubMed: [17377604](#)].
- Meert KL, Thurston CS, Briller 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**(4):420-7. doi: [10.1097/01.PCC.00000163679.87749.CA](#). [PubMed: [15982428](#)].
- Rosenbaum JL, Smith JR, Zollfrank R. Neonatal end-of-life spiritual support care. *J Perinat Neonatal Nurs.* 2011;**25**(1):61-9. doi: [10.1097/JPN.0b013e318209e1d2](#). [PubMed: [21311271](#)].
- Cuttini M, Rebagliato M, Bortoli P, Hansen G, de Leeuw R, Lenoir S, et al. Parental visiting, communication, and participation in ethical decisions: a comparison of neonatal end policies in Europe. *Arch Dis Child Fetal Neonatal Ed.* 1999;**81**(2):F84-91. [PubMed: [10448174](#)].
- Guillaume S, Michelin N, Amrani E, Benier B, Durrmeyer X, Lescure S, et al. Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. *BMC Pediatr.* 2013;**13**:18. doi: [10.1186/1471-2431-13-18](#). [PubMed: [23375027](#)].
- Kain VJ. An exploration of the grief experiences of neonatal nurses: A focus group study. *J Neonat Nurs.* 2013;**19**(2):80-8. doi: [10.1016/j.jnn.2012.04.001](#).
- Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliat Med.* 2010;**24**(8):753-70. doi: [10.1177/0269216310375860](#). [PubMed: [20659977](#)].
- Zuzelo PR. Exploring the moral distress of registered nurses. *Nurs Ethics.* 2007;**14**(3):344-59. doi: [10.1177/0969733007075870](#). [PubMed: [17459818](#)].
- Robinson MR, Thiel MM, Backus MM, Meyer EC. Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics.* 2006;**118**(3):e719-29. doi: [10.1542/peds.2005-2298](#). [PubMed: [16950963](#)].
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today.* 2004;**24**(2):105-12. doi: [10.1016/j.nedt.2003.10.001](#). [PubMed: [14769454](#)].
- 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**(4):288-300. doi: [10.1177/1367493505056482](#). [PubMed: [16275666](#)].
- Kauffman SG, Hauck C. Palliative Care in the NICU: A Case Study. *J Obstet Gynecol Neonat Nurs.* 2010;**39**(s1):S96.