

**Original Article**

# Spiritual Needs of Families With Bereavement and Loss of an Infant in the Neonatal Intensive Care Unit: A Qualitative Study



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**Abstract**

**Context.** The hospital is a place full of distress and questions about the meaning of life. The death of a child can cause a spiritual struggle and crisis. Therefore, it is necessary for health care providers in the neonatal intensive care unit (NICU) to assess the spiritual needs of families that have lost a child.

**Objectives.** The purpose of this study was to explore the spiritual needs of families in Iran at the end of their baby's life and through bereavement in the NICU.

**Methods.** This study was an exploratory qualitative study performed using purposeful sampling and semi-structured interviews with 24 participants. Inclusion criteria for families, nurses, and physicians included having experienced at least one newborn death in the last six months in the NICU. The research environment was the NICU in Isfahan, one of the largest cities in Iran.

**Results.** Data analysis revealed three main themes: spiritual belief in a supernatural power, the need for comfort of the soul, and human dignity for the newborn.

**Conclusion.** The results of this study created a new vision in addressing spiritual needs of Iranian families who experience the death of a newborn. *J Pain Symptom Manage* 2016;52:35–42. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

**Key Words**

*Spiritual needs, family, end of life, infant, Neonatal Intensive Care Unit, Iran*

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**Introduction**

The main goal of palliative care is providing the best support for increasing quality of life for patients and their families. In a palliative care approach, psychosocial and spiritual care are offered based on patient/family needs, beliefs, value systems, and culture.<sup>1</sup> Spirituality is defined in different ways at different points in our lives and has a unique meaning for each

individual.<sup>2</sup> Spirituality is a characteristic and a domain that allows a human being to find his or her purpose and meaning in life.<sup>3</sup>

Parents usually find a spiritual meaning for their own lives that is focused on their children's lives.<sup>4</sup> Therefore, admission of neonates in the neonatal intensive care unit (NICU) can be a traumatic experience for parents.<sup>5</sup>

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The hospital is often a place full of distress and that raises questions about the meaning of life. The NICU in particular is a critical environment because it is a place where lives may end or change in important ways.<sup>6</sup> The number of cesarean sections, overall neonatal morbidity, and the percentage of premature deliveries also has increased in last 20 years.<sup>7</sup> Each year approximately four million neonates die of 130 million live births around the world;<sup>8</sup> three-quarters of neonatal deaths occur in the first seven days,<sup>9</sup> and the majority occurs in the NICU.<sup>10</sup> Most childhood deaths occur in the newborn period.<sup>11</sup> A child dying before a parent is an unusual and stressful process, contrary to the normal order of things.<sup>12</sup>

Parents who have lost an infant experience a tragic event.<sup>5</sup> The death of a child can cause a spiritual struggle and crisis while searching for meaning and purpose of life.<sup>13</sup> This can lead to even deeper spiritual distress if these needs are ignored for a long time;<sup>2</sup> therefore, it is necessary for health care providers in the NICU to assess the spiritual needs of families that have lost their child.<sup>4</sup> Spiritual distress can be identified as a questioning about lack of meaning in life in loss or grief.<sup>14</sup>

In the context of infant death, most parents rely on their faith and spirituality for finding answers and comfort.<sup>4,11</sup> Health care providers are ideally situated to detect spiritual distress and perhaps even to begin to address such needs and, therefore, should comprehend the concept of spirituality and religion from the perspective of families. Studies have shown that spiritual needs of parents caring for children at the end of life have unaddressed spiritual needs.<sup>13,15</sup> Spiritual care is an important factor in the support of families in the NICU.<sup>4</sup> Awareness about spiritual needs falls within the framework of spiritual care;<sup>2</sup> to organize spiritual care interventions in the NICU, it is necessary to first evaluate spiritual needs of families.

Different spiritual needs have been identified in several studies, needs that are dependent on cultural, historical and social backgrounds and specific religious beliefs.<sup>2</sup> In the cultural context of Iran, Islam is practiced by most Iranians. They typically believe that death is part of God's plan and that terminal illness is an opportunity for prayer. The basis of the social structure is family. Most family is nuclear and extended. The concept of family is more private than in many other cultures. A Muslim family may want to see their family and friends when a loved one is dying or is in a bad situation or crisis because their relatives may help provide support and a sense of peace.

In the study by Meert et al.,<sup>12</sup> spiritual needs are mentioned by parents in connection with their child and also truth, compassion, prayer, ritual, sacred texts, connection with others, and bereavement support.<sup>12</sup> Cobb et al.,<sup>16</sup> in a review article, mentioned that often

the term "spirituality" is used with regard to religious and sometimes used in other articles to mean spirituality/religiosity. In this review article, a belief in God was reported in Hindu, Muslim, and Sikh, but there was no explanation about the content of this belief. The most important feature of spiritual needs in Islam is based on human nature and relationship with God, according to religious concepts. These factors must be taken into consideration in each community.

The purpose of this study was to explore the spiritual needs of Iranian families at the end of their baby's life and through bereavement, from families' and professional health care providers' perspectives in the NICU. The research question was "What are the families' spiritual needs at the neonate's end of life in the NICU from family and professional health care provider perspectives."

## Methods

### Study Design

In this study, the conventional approach of qualitative content analysis was used.<sup>17</sup> Qualitative research methods are appropriate for studying spiritual care and bereavement, where qualitative researchers interpret events in terms of participants' points of views.<sup>13</sup>

### Setting

The research environment was the NICUs in five educational and noneducational medical centers in the city of Isfahan, Iran. Isfahan is a religious city, and most people in the area are Muslim and believe in Allah, a Doomsday, life after death, Ramadan, an imam or religious leader, and prayer five times a day facing Mecca. The term "religious" is more familiar than "spirituality" in Iranian daily lexicon.

### Participants and Interview

In qualitative research, participants are considered as research samples.<sup>17</sup> Sampling was done with a purposeful sampling method and considering maximal variation. In this method, the researcher for diversity selects a small number of units or cases with maximum variation relevant to the research question.<sup>18</sup> In maximum variation, heterogeneity in cases is important.<sup>19</sup>

Inclusion criteria for families, nurses, and physicians were having experienced at least one newborn death in the last six months in the NICU. The study data were collected from June 2013 to March 2014 with face-to-face, semi-structured, in-depth interviews. All participants (family) were identified in the NICU and informed about the purpose of this study. The first author stayed in the NICU for the length of the study and communicated with families who had an infant at the end of life. The head nurses at each NICU helped identify families that met the inclusion criteria.

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