

POPINVITED: ID# 100951

Title:

Examining Spiritual Support Encountered by Bereaved Parents

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ACCEPTED

Session Title:

Rising Stars of Research and Scholarship Invited Student Posters

Slot:

RS PST1: Sunday, 17 November 2019: 11:45 AM-12:15 PM

Applicable Category:

Clinical, Researchers

Keywords:

Holistic nursing care, Pediatric care and Spiritual care

References:

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Abstract Summary:

This pilot descriptive qualitative study of two families illuminates the lived experience of end of life spiritual care. It identifies the spiritual needs/wishes of families who have lost a child within the modern healthcare system.

Content Outline:

1. Background
 1. Incidence of pediatric death
 2. Code of Ethics for Nurses – ANA
2. Purpose of Study and Research Aims
3. Research Design/Methods
 1. Design - Descriptive qualitative research
 2. Recruitment
 3. Sample and Setting
 4. Data Collection
 5. Data Analysis
4. Sample, Setting, Demographics, and Sample Interview Questions
5. Themes
 1. Relationship
 1. Establishing therapeutic relationship

2. Parental autonomy
 3. Respect
 4. Being present
2. Support
 1. Informational support
 2. Spiritual support
 3. Emotional support
 4. Tangible support
3. Spiritual Concepts
 1. Hope
 2. Love
 3. Prayer
 4. Music
4. Treasuring the child
 1. Proximity to child
 2. Desire to bring infant home
 3. Re-establishing normal family unit
5. Discussion and Conclusions
 1. Importance of holistic care
 2. Importance of therapeutic relationship
 3. Spiritual care embedded within everyday care
 4. Benefits of holistic, pediatric palliative care
6. References

Topic Selection:

Rising Stars of Research and Scholarship Invited Student Posters (25201)

Abstract Text:

Every year the United States experiences the death of over 9,500 children and more than 23,000 infants (CDC, 2016). According to the American Nurses Association Code of Ethics for nurses (2015), nurses are called to promote the dignity and worth of all patients. This is only possible if the spiritual wishes of a child and the child's family are considered and incorporated into care. Through illumination of the lived

experience of spiritual care provided to parents who have lost a child within the modern healthcare system, nurses can better understand the experience of these families, the wishes of the parents, and learn how to be better prepared to provide future spiritual care. A descriptive qualitative design was chosen to provide the researcher a complete image of each family's experience with spiritual care as they endured the loss of their child. Semi-structured interviews were conducted. The interviews were audio recorded and transcribed verbatim. The research team independently analyzed each transcript to identify potential themes and then met as a team to come to consensus on the themes, returning to the narratives for clarification as needed. These themes were then compared to the existing literature.

The setting for this study was the Finger Lakes region of New York State. The sample consisted of two married couples who had experienced the loss of a child at least one year after the death of the child. It is important to acknowledge both couples identified as Christians with an active faith. A list of broad, open-ended interview questions guided each interview.

Review of the interview transcripts developed the four following themes.

1. Parents stressed the importance of establishing a therapeutic relationship with their nurses and healthcare professionals based on a foundation of trust and respect to ensure their wishes would be honored. Parents also wanted to have complete parental autonomy over their child's care.
2. Four areas of support were identified. (a) Informational support indicates parents wanted to receive information regarding every aspect of their child's care. Parents stressed the importance of receiving this information in a clear and direct manner so they could fully comprehend their child's care. (b) Spiritual support was primarily delivered through pre-established faith groups outside the hospital setting. Parents also appreciated receiving care from a nurse or healthcare professional from a similar spiritual background, noting they were able to sense the presence of a spiritual nurse. (c) Emotional support mostly came from friends and family outside the hospital setting. However, some families found emotional support through connections on social media and discussions with other families on the hospital unit. (d) Tangible support refers to practical acts of kindness received from others. Common examples included friends preparing frozen dinners, cleaning your house, or helping assist with the regular needs of the family.
3. The third theme focuses on spiritual concepts that were discussed throughout the parent interviews. Due to the spiritual nature of the study and the spiritual background of both families, many spiritual concepts were discussed. A few were highlighted by both families. Each family discussed hope and how there was a constant hope their child was going to be able to survive. There was hope for a new drug, breakthrough therapy, and for a miracle. Parents also discussed love. Parents had a love for their child, a love for God, and a love for their spouse. Through these three sources of love, parents were able to find some of the support they needed. Parents discussed the importance of prayer and spiritual music to help them feel connected to God and maintain communication with Him.
4. The fourth theme is treasuring the child and is derived from the parents' desire to be with their children as much as possible. In addition to proximity, parents voiced a desire to remove their child from the healthcare setting and bring them back home. Parents discussed a few reasons

for this, mostly the comfort and familiarity associated with home, but also because bringing that child home meant the family was able to re-establish their normal family unit.

Overall, it is important to realize the important role nurses play in providing the spiritual needs of parents experiencing the death of a child, in supporting hope, and creating memories of the child's life. Through the formation of a therapeutic relationship and approaching each patient and family holistically, nurses can identify a family's needs and work towards fulfilling those needs. It is also important to recognize the ability for spiritual care to be embedded in the everyday care nurses provide. Spiritual care isn't always praying with someone or having a chaplain visit with a patient. Spiritual care is multi-faceted and individualized for each patient and family. The overall theme from this research is to encourage nurses to be respectful of families' wishes and beliefs, foster a comfortable environment for the patient and family, be present with patients, and answer any questions in a clear and direct manner.

This research is limited to the two Christian families that participated in the interviews. Future research is important to illuminate the experiences of individuals of different faith traditions and individuals who are not closely connected to a faith community.