

Exploring the spiritual needs of families with seriously ill children

Betty Ferrell, Elaine Wittenberg, Vanessa Battista and Gay Walker

Abstract

Although we know that families of seriously ill children experience spiritual distress, especially at the end of the child's life, there is little information on the specific spiritual needs of families. In order to develop further training for nurses in paediatrics and help nurses develop skills for communicating about spirituality, this research examined the spiritual needs of families based on nurses' experiences with families of seriously ill children. Nurses' experiences revealed that families' anger with God, blame/regret, forgiveness, and ritual and cultural traditions are salient spiritual needs requiring effective nurse communication skills to support families of ill children.

Key words: ● Nursing ● Spirituality ● Paediatrics ● Palliative care ● Qualitative

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Being a parent or family member of a child facing serious illness or the end of life is understood to be one of life's most devastating experiences (Melin-Johansson et al, 2014). Previous researchers have documented the psychosocial consequences of paediatric illness on families, with numerous studies detailing the financial burden, disrupted roles and relationships, and sibling and extended family member strain (Contro, 2002; Mack and Wolfe, 2006). The literature has also documented parents' common emotional responses including depression, anxiety, anger at God, loss of faith, uncertainty, and grief. Less emphasis, however, has been placed on the spiritual aspects of paediatric illness and the spiritual experiences of the families confronting the imminent death of a child. The growing movement of paediatric hospice and palliative care has begun to explore the spiritual dimensions of paediatric illness. While there is increasing recognition of spirituality as an important aspect of palliative care, there is also literature documenting nurses' lack of competency in communicating with children and families about spiritual concerns and spiritual experiences (Malloy et al, 2010).

The authors of this paper have been involved in two national nurse training programs. The first is the End-of-Life Nursing Educational Consortium (ELNEC) project, an international program preparing nurses to provide care for the seriously ill. The ELNEC project includes a training program specific to paediatrics (End of Life Nursing Education Consortium, 2015). The second program is COMFORT, a communication

course to train nurses in all aspects of communication with patients, families, and professional colleagues, which is inclusive of paediatrics (The Comfort Communication Project, 2015). In both of these training programs, the investigators have observed that spiritual care is the area where nurses are least comfortable in their communication.

The evolving literature has described spiritual experiences of children and their families including positive interventions that support the coping of these people. Nurses working in paediatric hospices or acute care settings have described stories of children and parents, as the children approach death. Some paediatric spiritual experiences involve communicating with relatives who are deceased, being visited by angels, or envisioning themselves in heaven or the afterlife. However, little is known about the specifics of spirituality among family members during this critical time. This study examines the experiences of nurses with ill children and their families to learn more about the spiritual needs of families. A clearer understanding of spirituality in paediatrics can lead to more effective training for nurses.

Literature review

A child's serious or life-threatening illness has a profound impact on the family, including the family's physical, psychological, and spiritual health (Gans et al, 2015). A child's death increases the parents' risk of anxiety, depression, prolonged grief, and poor quality of life, and has been termed the 'ultimate loss' (van der Geest et

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al, 2014). The importance of communication is recognised as a key element of palliative care (van der Geest et al, 2014). In paediatric palliative care, effective communication about death and dying is particularly important to parents who are facing the death of a child and among the health-care professionals rendering care (Harrison et al, 2014). Health-care professionals must be trained in communication and able to convey information in a straightforward, direct and honest way, showing compassion and preserving cautious hope (Contro et al, 2002). As parents face tough decisions about treatment and informing family, friends, and the child about the illness, health-care professionals need to be able to conduct end-of-life conversations that clarify the transition to palliative care and death, in a sensitive way adapted to the needs of the family (Contro et al, 2002).

The American Academy of paediatrics (AAP) has recognised the importance of meaningful communication with paediatric patients and their families, endorsing the following principles as crucial to paediatric palliative care delivery: respect for the patient's and family's dignity, access to competent and compassionate palliative care, caregiver support, improved professional and social support for palliative care, with continued research and education to improve this care (Harrison et al, 2014). The insensitive delivery of critical information to parents has been found to cause long-lasting emotional distress (Harrison et al, 2014) and long-term grief (Mack and Wolfe, 2006). Additionally, studies have shown that parents judge the quality of care by the quality of communication (Mack et al, 2005). Despite the recognition of the importance of communication in paediatric palliative care, many paediatric health-care professionals lack the communication training to render proper care. They need guidance, expert knowledge, and training to help children and their families at this critical time (Reid, 2013).

Spiritual care is said to be one of the least understood aspects of palliative care (Baird, 2016). Although there have been studies on family's experiences when terminally ill children transition from curative-focused care to palliative care (Mack and Wolfe, 2006), few studies have addressed the emotional and existential issues raised by parents of terminally ill children (Contro, 2002). The spiritual or existential realm is recognised as one of the hardest areas to communicate about. Little attention has been paid to how a child's life threatening illness impacts parents' and family's religion,

spirituality, or life philosophy and how families view a child's serious illness as a spiritual experience (Hexem et al, 2011).

Across the existing studies, there is consistent recognition of the need for spiritual care as parents, children, families, and their professional caregivers cope with a child's death. There has been, however, very little research performed on how spiritual care, effectively rendered, can assist families on this very difficult journey. In order to design training to improve this aspect of care, the purpose of this study was to explore nurses' experiences with children and families facing serious illness to learn more about their spiritual needs. The current research explores nurses' experiences with family spiritual needs when caring for a seriously ill child.

Method

A qualitative approach was used to capture nurses' experiences about spirituality when caring for seriously ill children and their families. A qualitative approach was considered best in order to ascertain what nurses witnessed and to understand their perception of the spiritual needs of families. This approach allows nurses to share their experiences with families in their own words and to share anonymously the details and emotions of their clinical experiences. This study is considered exempt under the Institutional Review Board of the supporting institution.

Instrument

Nurses were asked to relate their experiences communicating with seriously ill and dying children and their families, involving spiritual aspects of the illness journey. Nurses were asked to summarise what happened, what the patient or family member said, and how the nurse responded.

Participants

Nurses who attended one of three end-of-life nursing education courses conducted in the US in 2015 related in writing their experiences with family members of seriously ill or dying children. Course attendees were predominantly registered nurses or advanced practice nurses in clinical roles in paediatric settings. Additionally, nurse experiences derived from an earlier study by these investigators on communication regarding forgiveness (Ferrell et al, 2014), were culled for themes and passages relating to spiritual care and ill children.

Data analysis

Qualitative responses were transcribed and inductively analysed using an iterative process of

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theme analysis (Pinquart and Sorensen, 2005). For this study, the authors identified common themes that emerged related to nurses’ experiences of communication regarding children’s and families’ spiritual experiences during serious illness and end-of-life care.

First, members of the research team, including, researchers and paediatric expert clinicians independently read all of the nurses’ responses and identified unrestricted sections of text, suggesting a theme. Next, research team members met to integrate individual coding and come to consensus through discussion by connecting, collapsing, or associating coding to establish and finalise themes. Quotes were then extracted to illustrate themes.

Results

The nurses in this study ($n=55$) shared experiences that depicted the spiritual needs of families of seriously ill children. Nurses witnessed families angry with God and the need to talk about this anger. Feelings of blame and regret for not finding a cure, or for not seeking care earlier in the child’s illness, revealed the need for apologies between child and parent. Nurses also described families’ need for forgiveness between child-parent or parent-child. Each spiritual need is described in further detail below and summarised in *Table 1*.

Anger

The desire to share angry feelings about God was common among families. Nurses described that parents, in particular, often displayed anger towards God for their situation. One nurse recalled:

‘I took care of a patient on hospice whose mum was torn because she had recently lost a parent and was now losing their child. She believed in God and was so angry with Him ... I think she just needed us to listen and not try to help her get past or through her anger.’

In another case, the father of a seriously ill teen was angry with God, ‘blaming Him for allowing his beautiful daughter to become sick.’ The nurse related that ‘through her [the daughter’s] suffering, he [the father] found his way back to God’, giving his daughter’s ‘life and death purpose.’ The nurse commented that through the daughter’s suffering, the father was able to find redemption and rediscover his faith.

Anger towards God exposed the families’ need for spiritual support. One nurse wrote about a father whom staff had labelled as angry and a ‘difficult parent’. The nurse reported that when she conversed with the father she learned that his

spirituality was based on Voodoo, and (with this knowledge,) she encouraged him to seek spiritual support and counsel with someone who shared his beliefs. His mother in Jamaica shared his belief in Voodoo and the nurse encouraged and facilitated his communication with her. The nurse commented that the father’s demeanour changed significantly thereafter, the nurse witnessing the benefit of the father’s having addressed his spiritual pain with someone he trusted and with whom he shared a spiritual bond. The nurse’s keen observations and facilitation of communication helped that parent cope with the intense stress of his child’s grave illness.

It is often the nurse at the bedside who listens to and helps grieving parents through the very difficult and intense anger that may accompany their children’s illnesses. In multiple instances, nurses noted the interplay between anger and spirituality, and how anger towards God would permeate to other family members. In some cases, the anger blinded the parents’ spirituality, and in others, it caused them to seek new meaning and support through spirituality. Across all experiences was the evident need for families to talk with nurses about this anger.

Blame/regret

Another spiritual need identified in nurse experiences was the families’ need to express blame or regret, especially at the end of the child’s life. The emotions of blame or regret emerged in parents’ self-questioning and their search to identify what they had done wrong that caused/allowed their children to become seriously ill. Parents and family members blamed themselves for not having sought treatment for their children or follow-up treatment/procedures soon enough. One nurse shared the story of a young couple who took their small child first to a ‘bush doctor’ for an 8-day siege of diarrhoea before finally seeking traditional medical attention. The couple arrived at the hospital with the very ill infant wrapped in a blanket with leaves covering the blanket. The child died while being evaluated by the paediatrician. The nurse described how the family expressed regret for not seeking medical care earlier.

In one instance, feelings of blame and regret resulted in the child’s parents blaming each other for the child’s illness. Miguel (pseudonym), a 17-year-old high school athlete, was dying from cancer. In the course of his hospitalisation and treatment, the nurse witnessed severe strain between the boy’s mother and father. The nurse learned that just 2 years before, the father, due to a bad knee, had stopped working and the family

became financially drained. As a result, the family used a space heater to warm their house, which caused a house fire, and two younger children died in the fire. The father blamed Miguel, the now ill 17-year-old, for not rescuing the younger children, while the mother blamed the father, 'because he wasn't 'man enough' to work through the [knee] pain and keep money coming in.' As the son lay dying, the mother lashed out at the father for their son's suffering and now imminent death from cancer. The nurse witnessed the mother scream at the father across the emergency department, 'It's your fault...'

The inability to find a cure for their child exacerbated the parents' feelings of blame and regret at the end of a child's life. One nurse wrote: 'Parents often have looked at 'what have I done wrong' to cause this death.' Nurses observed this blame and described feeling responsible to personally try and ease the parents' guilt and grief. Nurses depicted how it is the nurse at the bedside who must often explain to parents of dying children that no one is to blame for their child's illness.

Forgiveness

In addition to feelings of blame and regret, there was also evidence from nurses' experiences that seeking forgiveness was a prominent spiritual need for families that brought meaning to final moments. Forgiveness took various forms, from a child asking a parent for forgiveness for being a burden or for causing such grief to parents, or a parent asking a dying child for forgiveness for his

or her behaviour. In the case of a young man who had overdosed on drugs and was very near death, the nurse recalled how he wanted his mother's forgiveness for his drug addiction. His mother continued to deny that he used drugs, even as he lay dying. The hospital staff intervened at the child's request to show her where on his body he had been administering the drugs, so that she could see the truth. Once she was alone with her son, now accepting of the true situation, the mother told her son that she forgave him and within minutes, the son died.

Seriously ill children also forgave family members. In one reported instance, an angry teenager who was near the end of life finally let go of her anger and realised that her family, whom she had railed against throughout her entire illness, had done all it could to help her and care for her. Confronted with the reality of her situation and the dwindling of time, the teenager was able to forgive her family members and died peacefully. Forgiveness of children and/or families forgiving/being forgiven was often associated with a transition through final moments to a peaceful death.

Nurses' experiences also revealed the need for parents to seek forgiveness from their ill children. In one instance, a nurse reported that a mother refused to tell her very ill 13-year-old daughter that her leukaemia was in the terminal stage. The family wanted to spare the child from the painful reality of death and they prolonged futile treatment to keep her alive. In the end, the nurse relayed that the mother regretted not having been

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Table 1. Overview of findings

Theme	Sub-themes	Example from data
Anger towards God	For the situation	One nurse related the story of a grieving mother who was lamenting that her dying son would not live to see the birth of his nephew. The mother expressed anger that 'God took him before he could meet the baby.' The nurse responded to the mother that perhaps the young man was 'holding his nephew in heaven and prepping the nephew for life on earth'
Blame/regret	For not finding a cure	'Sometimes, during the end of life of their child, I hear the parents whisper sorry to their child because they can't do anything anymore'
	For not seeking care earlier	'The child died about an hour after admission... Relatives regretted not bringing the child earlier to the hospital for medical attention'
Forgiveness	Sought by child	'She forgave her family after realising that they were doing the best and she had to go through what was going on'
	Sought by parent	'His father asked for forgiveness to his son that he delayed the follow-ups and the medical procedures that his son needed to undergo'
Ritual and cultural traditions	Differences between health-care providers and families	'A family who recently emigrated from Somalia had a baby girl ... diagnosed with spinal muscular atrophy (SMA) at 4 months old and the palliative care (PC) team was consulted. Because of the parents' Muslim beliefs, they were adamant that only God decides when their little girl will die. They were concerned that the PC team would encourage removing treatment that would hasten death. After long discussions and using the interpreters, they understood that we wanted to ensure that she was comfortable and that their wishes were respected and carried out. She died peacefully in her parents arms a few weeks later'

‘Most nurses maintained that across cultures what mattered most was listening, respecting, honoring, being present, and not judging the patients’ and families’ differences.’

truthful with her daughter and ‘not having given the daughter choices about her treatment.’ On the day the young girl died, the mother asked for forgiveness and the child forgave the mother and died in her arms.

In another case, a mother had deserted her family when her daughter was 6-years-old and had very little contact with her daughter for over 6 years. The now 12-year-old daughter was very angry with her mother. As the daughter approached death, the mother rushed in and asked for forgiveness for having left her. She expressed how much she loved her daughter and how sorry she was for not having been there for her. In this story, and many others, nurses reported that the children died shortly after giving or receiving forgiveness.

Rituals and cultural traditions

In recounting their experience with families, nurses reported that a family’s rituals and cultural traditions played an important role in addressing the spiritual needs of families and that it was important to be open and receptive to a family’s orientation. One of the nurses commented on how difficult it was when the health-care professional’s own beliefs differed from those of the patients/families, particularly when religious and cultural preferences dictated that only God decides when a child will die — and prolonged and futile treatments followed. Another nurse acknowledged, however, ‘I believe the family did understand the devastation of their son’s injury, but their spirituality and faith chose the path to leave his destiny in God’s hands.’ One nurse shared a story about the ritual of anointing a Mom’s belly prior to a birth; another was able to connect a family with a religious leader to provide a bedside religious rite. Most nurses maintained that across cultures what mattered most was listening, respecting, honoring, being present, and not judging the patients’ and families’ differences.

Discussion

This study gathered the experiences of nurses who are at the bedside of paediatric patients at the end of life; they hear and bear witness to and, in turn, can relate the spiritual care experiences of these families. Common themes emerged as families confront and live through this difficult time. In sharing these experiences and themes, professionals can begin to identify the spiritual care needs of the families and how best they can assist them to cope during this critical time. Clearly, the health-care professionals who care for these children and

families need effective communication skills in order to be present, listen, and respond to spiritual needs.

Research on paediatric palliative nursing has identified communication as an essential skill to providing care (Reid, 2013; Rodrigues and King, 2014). Nurses working with seriously ill children have noted the importance of sensitive communication with the family (Reid, 2013). Understanding the specific spiritual needs of seriously ill children and their families may aid nurses in communicating with families and children about their spiritual experiences. The current study identifies the spiritual experiences and spiritual concerns of families as an essential component of nurse communication in paediatric palliative care. Nurses with an understanding of the spiritual needs in paediatric palliative care are best suited to provide essential communication with families about anger towards God, feelings of blame/regret, and forgiveness. These findings reflect the communication topics vital to quality care.

As part of family-centered care in paediatric settings, nurses work with families to revisit goals, assess their understanding of information, and explore the child’s illness trajectory (Rodrigues and King, 2014). This study illustrates that spirituality is a theme across all of these communication goals, especially as the nurses work to reconcile child and parental wishes by advocating on behalf of the child (McCloskey and Taggart, 2010). Spiritual experiences and concerns are prevalent in paediatric care and personal spiritual beliefs are one way nurses cope with the emotional toll of caring for dying children (Forster and Hafis, 2015).

Families often self-identify key staff members with whom they develop caring relationships and close bonds (Rodrigues and King, 2014). In paediatric settings, these relationships often include the nurse. Nurses need to engage in solid listening skills, providing family members with a safe place to talk about their anger at God, admit blame, or the need for forgiveness. The relationship between the nurse and the child’s family can be difficult and family anger is a stress for nurses caring for ill children (McCloskey and Taggart, 2010). Proactively addressing family anger and broaching topics that address the family member’s spiritual angst may serve as nurse communication skills that aid families and reduce stressful situations for nurses. Feelings of blame or regret can place parents at risk for negative bereavement outcomes (Lichtenthal et al, 2016) and nurses should be taught how to solicit these feelings.

'A family-centered approach must also be culturally appropriate and include the existential aspects of a child's illness. It is a profound communication responsibility for nurses to address cultural beliefs about truth-telling and cultural beliefs about end of life with families of seriously ill children. A nurse's failure to take into account a family's or child's beliefs and culture may create a barrier to nurse-parent communication in that such communication lacks cultural awareness and sensitivity (Wiener et al, 2013). An especially salient area of spiritual communication is the search for the meaning of pain, illness, suffering and death, all of which are not static across cultures (Wiener et al, 2013). Cultural communication, and more specifically language barriers, has been identified by paediatric palliative care providers (nurses and physicians) as one of the major barriers to end of life care for children and their families (Davies et al, 2008, Davies et al, 2010). Spiritual dimensions of language and cultural differences are currently missing in nursing curricula.

Recommendations for practice

With often limited formal training in spiritual care, nurse often rely on their own experiences and spirituality to inform their responses to patients and families. Coursework in communication should be made available to nurses and spirituality should be one of the key topics introduced in paediatric palliative care training. Nurses should learn how to engage in conversations about spiritual suffering, including anger towards God, and be taught the importance of reminding parents that they are not to blame for their child's illness or death. Children's nurses should understand that family rituals and cultural traditions may be different from their own, requiring patience, flexibility, and a non-judgmental attitude.

Limitations and future research

In addition to the sample size of this study, findings are limited by the absence of demographic information on the nurses who shared their experiences. Although participants in the study were all working in similar clinical settings, generalisations cannot be made as international contexts with different health-care structures may differ. On the other hand, the voluntary nature of the study suggests that nurses who did share had memorable experiences that may have had deep meaning and impact on their clinical practice or their own spirituality. Thus, data may represent some of the most challenging spiritual concerns among families. It is important

to note that this study was limited to nurses' experiences with seriously ill or dying children and their families. The participants were nurses attending a palliative care course; accordingly, these nurses may have greater knowledge and experience than other paediatric nurses. The nurses' experiences with the families are recalled events and are more likely to include the nurses' own words, rather than the actual words spoken, by family members.

Limited literature exists about seriously ill children and the families of those children. Additional research is needed to learn about spirituality in paediatric palliative care, including potential variation across clinical settings (e.g. rural and urban) and among health-care professionals. With continued emphasis on interprofessional care teams, further work is needed to identify how teams collaborate to provide spiritual care and align with the goal of 'family-centered care' in paediatrics. Further research in this area is warranted to develop sound spiritual care curricula for nurses.

Conclusion

Often, families facing a child's serious illness or death draw on religion and spirituality to cope with this 'ultimate loss'. By hearing and considering their spiritual experiences, nurses can use this analysis to shed light on how families use spirituality as a resource to cope with and process grief. The experiences with families, as shared by nurses, indicate critical opportunities for nurses to hear these stories, offer support, and bear witness to these profound emotions and experiences. The themes identified in these narratives, anger at God, blame and regret, forgiveness, and cultural and religious traditions, each provide distinct and rich opportunities for nurses to be involved both by addressing distressing emotions (i.e. anger or blame), and also by supporting positive experiences (for example forgiveness or finding the way back to faith). Nurses' communication with regard to spirituality and spiritual care can help identify families' unmet needs, resolve conflicts, and coordinate care with spiritual care professionals, such as chaplains. National guidelines in the US have identified spiritual care as one of eight essential domains of quality palliative care. Nurses, as the predominant professionals across settings of care, can contribute greatly to ensuring that spiritual care is provided to children and their families throughout their illness journeys and at the end of life. 

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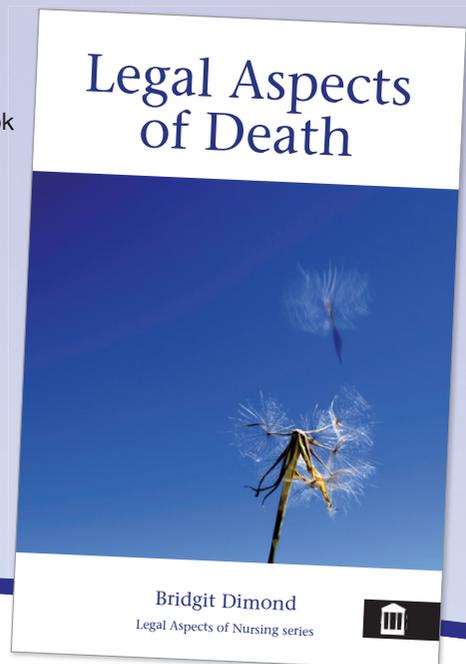
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