

Article

Spiritual Care: The Nurses' Experiences in the Pediatric Intensive Care Unit

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Abstract: Physical aspects of disease management are often more evident than those related to spirituality or spiritual care. Spirituality may appear more crucial in pediatric intensive care units (PICUs) when patients are experiencing serious illness or end-of-life situations. This paper describes the meaning of spirituality according to nurses who had worked in PICUs and how they provide spiritual care to children and their families. It is an exploratory research using a qualitative approach, including interviews with eleven PICU nurses. Data were analyzed using thematic analysis; two themes were identified: meanings of spirituality and religiosity according to nurses, and the provision of spiritual care to children in the PICU and their families. The interviewed nurses recognized the importance and value of spiritual care and are aware that spiritual needs are considered to be of significantly less importance than physical treatments. Spiritual care was mainly focused on the children's families; the nurses justified the absence of spiritual care to children, based on lack of time and children's age and level of consciousness. These results highlight a deficiency in spiritual care in PICUs and demonstrate the need for improved knowledge and demonstrate the need to not only raise awareness of the spiritual dimension of children, adolescents, and their families, but also to enhance discussion and improve general knowledge on the importance of spirituality in the treatment regimen to provide effective holistic care.

Keywords: spirituality; religion; spiritual care; healthcare professionals; pediatric nursing; pediatric intensive care units; nursing care; child; family

1. Introduction

Intensive care units (ICU) are focused on critical patients who are in hemodynamic instability and in need of both specific care and timely interventions [1]. Patients in these units often experience suffering, loneliness, fear, and anxiety [1]. The pediatric intensive care unit (PICU) is viewed as a frightening place associated with severity and death by family members who generally feel anguished by their child's disease and powerless to help their child; children dislike being in the hospital and far from home and parents [2,3].

Spirituality is an important coping mechanism, particularly in times of crisis or disease [1,4,5]. Spirituality is also considered as a protective strategy used by the family in recovering and strengthening themselves to overcome crisis and moments of weakness [6]. Spirituality is widely defined as unique, personal, and dynamic; thus, it may change according to the individual's perceptions and particular stage of life. It is related to the search for meaning and purpose of life in the relationship with God or a higher being, self, others, and nature [7]. When patients and family members start a dialogue on spiritual issues with healthcare professionals, they expect respect for their spiritual needs and beliefs, and seek attention to issues related to meaning, faith, and hope [8]. Both spirituality and religion influence parents and affect their perspectives and decisions concerning the child's treatment. Spirituality can provide parents with feelings of support, peace, and comfort [4].

Children can feel spiritual distress when dealing with physical changes [9]. They have behavioral, emotional, and learning problems when feeling disconnected from themselves, families, peers, and community [10]. The existential dimension of children's spirituality refers to their experience in the present, understanding of time and space, the capacity to understand limitations and symbolisms, and imagination [10]. It is fundamental that the child's physical, psychosocial, and spiritual needs are addressed in order to minimize the negative effects of hospitalization [11]. The family's needs should also be addressed because mothers can feel unsupported when health professionals only focus on their children [3].

Children in the intensive care environment, as well as their families, are in vulnerable situations. Therefore, their spirituality must be evaluated in relation to their needs. Humanized care is imperative to promote recovery and to protect life as a core value [1]. Healthcare professionals frequently focus on the physical aspects of disease management and neglect spiritual care [12]. Patients experiencing severe illness or end-of-life situations often have spiritual needs [12,13]; thus, it is important to have a better understanding of how healthcare professionals can meet these needs in pediatric patients. Hence, there is a need to implement spiritual care in intensive care contexts [14], particularly in the PICU, as well as for more studies on spirituality, in general.

Few studies related to children's spirituality have been performed [15]. Nurses often feel unprepared to promote spiritual care [16]. Organizational, structural, personal, and professional factors have been identified as critical in spiritual care [7,16]. A study involving nurses with different job experiences concluded that intensive care environments are more amenable to the provision of spiritual care than other settings [17]. The nurses' perceptions of spiritual care in different intensive care units have been reported in few studies. However, none focused specifically on the spiritual care of children in the PICU. Thus, the present study is based on the research question: "How do nurses provide spiritual care to children and their families in pediatric intensive care?"

The objectives were to describe (1) the meaning of spirituality according to nurses working in the PICU and (2) the nurses' experiences in providing spiritual care to children and their families.

2. Methods

This was an exploratory research based on a qualitative approach [18]. The Ethics Committee for Human Research from the University responsible for the research has approved this study.

2.1. Participants and Setting

The study was conducted with eleven pediatric intensive care nurses from a city in the countryside of São Paulo State, Brazil. The inclusion criterion was having worked at a PICU for at least six months. Participants were selected based on a snowball sampling technique; a direct indication of other participants occurred until the theoretical saturation of data was reached [19,20]. The main researcher recruited the first nurse who participated in the research. All participants signed an informed consent in which the research procedures were explained.

2.2. Data Collection

Data were collected through face-to-face individual interviews, which were audio-recorded and lasted an average of 50 min. Participants were given the opportunity to choose the interview place.

The interview was based on the following questions: “How would you define spirituality and religiosity?” and “How do you provide spiritual care?” Barriers to spiritual care, as well as strategies used in the delivery of spiritual care in the pediatric intensive care context, were explored. In order to preserve anonymity, the participants were identified by the letter N followed by the number in the order they were interviewed.

2.3. Data Analysis

The interviews were recorded, transcribed, and submitted to independent qualitative analysis by four research team members using an inductive thematic analysis [18]. The goal of the analyses was to identify and analyze themes according to the following six steps [18]: first, researchers read each transcript several times in order to comprehend the main idea. Second, excerpts of the discourses were coded and compiled in significant groups. In the third and fourth phases, the codes were organized into comprehensive themes by the four independent researchers, which were later revised in detail to establish equivalence. The fifth phase involved the definition and organization of themes. In the last phase, a report was issued.

Since four researchers analyzed the data, a process was adopted to establish equivalence between codes and themes. This process involved independently pairing and comparing codes. Disagreements were discussed through a second analysis of the interviews until a common coding agreement was reached among the four researchers.

3. Results

All participants were women between 24 and 40 years old. Their working experience as pediatric critical-care nurses in PICUs ranged from six months to eight years, and their total nursing experience ranged from three to 18 years. Two themes were identified from the interviews: “Meanings of spirituality and religiosity” and “Provision of spiritual care to children in the PICU and their families”

3.1. Meanings of Spirituality and Religiosity

The meanings of spirituality and religiosity were described in different ways and were considered as interconnected concepts. Spirituality was described as a subjective, individual, abstract, and broad concept, which pervades the material world. Spirituality was described as a dimension of human life that is related to what gives meaning and strength in life. It was related to transcendence and a higher power, often named God, while religiosity was reported as a doctrine linked to different religions.

“Religiosity is more focused on one religion, on a divine doctrine, while spirituality is broader, related to faith. It means believing in something more, not only earthly, material” (N4).

“Spirituality is something very subjective and what each person brings it along. While some people have more, others have less. I think it has nothing to do with religiosity; each person has his/her spirituality. You cannot develop yourself as an individual without spirituality. It is part of human nature” (N2).

“Spirituality is everything the person believes in, in a higher essence, in what is not concrete to him/her. It is something abstract...Each person has a definition for what strengthens him/her” (N10).

Most of the participants defined religiosity as strongly related to spirituality and as something that may be an individual belief or religion based on principles, conducts, and standards influenced by family or culture. Religion was considered as a route to seek spiritual well-being.

“Religiosity is a bond with something that helps to further accept the situation . . . It is linked to spirituality and is a way, to feel spiritually well through beliefs and culture” (N6).

“Religiosity is for those who follow a certain religion. I use my religion to improve my spiritual dimension. I feel better through my prayers” (N1).

“There is a lot of family influence upon one’s religiosity. I am a Catholic because my parents are Catholics.” (N8).

Some nurses considered spirituality and religiosity not only as similar concepts based on a belief in God, but also as unrelated definitions in which spiritual well-being can be achieved without having a religion.

“I think they are the same thing, believing in God” (N3).

“Some people do not believe in any religion because they say they are atheists, but they have other means of being balanced. What is important for you is to be spiritually well, it does not matter how you seek your spiritual well-being” (N1).

3.2. Provision of Spiritual Care to Children in the PICU and Their Families

After exploring the meanings of spirituality, the participants described how they usually provide spiritual care in clinical practice. Aspects of spirituality were more easily integrated into nursing care than other aspects of religiosity because the latter is considered as personal and intimate to each family and the nurses preferred not to address it unless they were asked. Spiritual care was described by nurses as respecting the family’s beliefs and providing them the opportunity to express spirituality or religiosity in the PICU, such as allowing the presence of significant or religious objects that were close to the sick child.

“Some parents bring a rosary and leave it close to the child’s bedside; or they bring a handkerchief that is linked to promises made. Sometimes they bring a written prayer and hang it on the child’s bed. It’s something we allow, it’s their belief” (N10).

“They bring small images of Our Lady, a guardian angel . . . some hang up some phrases at the child’s bed. We always allow that” (N9).

Nurses perceived that when they stimulate and respect the family’s faith, positive thinking, and belief in God they were also promoting serenity and reducing anxiety towards the child’s illness. They believe that it is important for the family to keep the faith because parents without beliefs are more pessimistic about their child’s health condition. They also underscored the relation between the family’s well-being and the child’s well-being.

“We [nurse interviewed speaking] say: ‘Mother, keep having faith! Let us believe in God!’ because I think this calms them [relatives] further. It is a new environment, they see the child with these different things, so you say: ‘Keep having faith, keep having faith! Things will work out!’ They even transmit their anxiety to the child, and when they are calm, the child is calm as well” (N5).

“We [nurse interviewed speaking] see parents here who believe in God and their mood is much better than those who do not and who end up being pessimistic focusing on the disease and not believing in anything. I think it helps a lot when you believe in something” (N11).

Spiritual care was more directly focused on family members than on the child, with mothers being the main beneficiaries from spiritual care because they are primary caregivers, accompanying

the child to the hospital. Nurses considered a child's young age to be a barrier to providing spiritual care. They felt that discussing spirituality with newborns or very young children was complicated because they do not understand the situation. Moreover, it was difficult to talk to children when they were sedated or intubated.

"[...] they are all newborns. It is something complicated, although they have a soul and spirituality, they are not aware of that. Thus, we have a stronger spiritual relationship with the mothers than with the patients themselves" (N7).

"It is very difficult for you to implement that with a child, it is easier with family members, really" (N3).

"The children are in a severe condition, intubated and sedated. Our main contact is with the parents" (N10).

Although a child's age was as a barrier to providing spiritual care, some nurses mentioned that they were able to assess the spirituality of newborns by observing the way they interact. Older children are able to interact, establish a dialogue, and allow assessment of their spirituality and religiosity.

"Generally, babies do not significantly interact but you can interpret that they need this care by the way they are crying" (N11).

"When the baby is very tearful, I pray, I ask God to calm him/her down" (N8).

"An older child showed me some of her religiosity, she was holding a rosary, which was given by her mother... So, we are talking about trying a way to nurture spirituality" (N2).

Participant nurses considered that they primarily provide spiritual care to the family. They also provided spiritual assistance to the child and family by allowing the visit of other relatives and religious leaders at the PICU. However, the request for spiritual assistance generally comes from the family; nurses feel they rarely have the ability to take the initiative.

"Sometimes, we make some exceptions, allowing the grandmother or aunt's presence because we are concerned mainly about the mother's psychological condition. [...] We are always concerned about the family" (N6).

"We rarely turn to the family and say: 'Are you religious? Do you want to bring any minister, or someone else?' The opposite also happens when the family requests 'I would like a minister to come here'" (N4).

The practice of spiritual care was strongly and positively associated with the child's poor health status and palliative care. In those situations, spiritual care was perceived as a way of offering a peaceful death with no suffering by comforting families and promoting the visit of religious leaders to relieve the suffering of children and families through prayer. Praying with children with poor health status and allowing parents' full-time presence with the child were considered other forms of beneficial care.

"It is more common when the child dies and then you have to tell the parents. That is the moment when we mostly talk about God, we comfort. It is the moment when we mostly discuss spirituality and religion" (N3).

"When we perceive that the child is dying, we baptize, we pray" (N9).

"[...] with babies in the most severe conditions, we observe that the mothers need not only physical care for their child, but also spiritual care" (N7).

“If the child is at the end of life, there is nothing else to do, parents stay in there, mother or father, not both; they stay in there 24 hours a day if they want to. That is spiritual care” (N2).

Nurses considered the relationship between families and children as fundamental to the assessment of spiritual needs. However, all nurses considered the lack of time and availability due to work overload as barriers to assessing spiritual needs. Hence, lack of time, an organization of work based on the functional position of tasks, and the prioritization of the child’s physical care needs lead nurses to minimize spiritual needs of PICU patients and families.

“Because, when the situation was severe we are so focused on the child, there are so many things to do [...]. Through the daily rush during the shift, we do not even consider that. There is no time because there is a lot to do, there is a lot of bureaucracy; the delivery of care is so busy. [...] There is no time. It is impossible!” (N5).

“What makes it difficult is this lack of bonding with the patient” (N6).

“I think we are strongly focused on the disease, on the procedures we have to perform” (N3).

The daily journey organized in shifts also made spiritual care difficult, mainly during the night because the bond with the child and family was impaired.

“It is even more difficult to offer this care for those who work at night or for those who do not work every day” (N2).

According to some nurses, other barriers for spiritual care were the lack of a definition of spirituality and the subjectivity of both spirituality and religiosity concepts.

“No, I do not provide spiritual care because there are conceptual disagreements between nurses and patients and their families” (N4).

“That is something very particular, each person has his/her own religion and spirituality. I do not know if my spirituality will help the child; the mother’s spirituality helps the child much more than mine” (N7).

The rate of deaths and severity of the conditions of children hospitalized in the PICU turn this environment into a place of suffering for all involved. Spiritual care was considered important not only for patients and families, but also for nurses because it is associated with the search for the meaning of life and the psychosocial strengthening, emotional comfort, and coping with death.

“For them [relatives], the ICU is the place where the child is dying. They get nervous and apprehensive to see the child with those various devices. If you comfort them, have a conversation, speak about God, they will be calm and serene.” (N5).

“That [spirituality and religiosity] removes the ‘weight’ of what this Unit [PICU] is. It is a very complicated service; we lose a lot of children. There are many, many deaths.” (N2).

“With some sicker children, in severe conditions, we ask: ‘What is happening? What has this child done in life?’ We always look for what previously happened that caused him/her to deserve this. We ask that a lot. ‘Where is God, why did He want it to be this way?’” (N4).

4. Discussion

This study describes the meaning of spirituality according to nurses with working experience as pediatric critical-care nurses and how they provide spiritual care to children and their families.

The nurses described different meanings of spirituality, which were generally distinct from the concept of religiosity. Different definitions of religiosity and spirituality have been defined based on

individual perspectives that may or may not be associated with religiosity [4,7,21]. A unique definition is not possible because spirituality consists of concepts connected with, and influenced by, culture as well as individual development, experiences, and perceptions of life [22,23].

Spirituality was described as a characteristic of human beings, which supports the idea that children are also spiritual beings [9]. Spiritual care was considered most important for those with severe diseases and also, their families, and health professionals working in critical care. The PICU is a place that leads to the search for the meaning of life; it is where constant confrontation with death and suffering happens [2,14]. Spirituality is considered a key component to support suffering patients, their families, and is essential to the quality of holistic healthcare [24].

4.1. Provision of Spiritual Care

The results demonstrate the indirect spiritual care provided by nurses when it was performed to the child through their family, and direct spiritual care when the nurses provided care to the child. The nurses' spiritual care was based on relationships and promotion of interactions/connections. In most cases, this relationship was nurtured by permitting extensive visits by family members and/or visits of religious leaders, and when promoting faith in God. This finding corroborates the results of a meta-synthesis study [7] in which the search for meaning was a core component of spirituality, which could be facilitated through relationships. Religion was also described as a component of spirituality, but non-religious patients are also considered spiritual. Hence, spirituality is broader than religiosity and includes believers and atheists [7].

The nurses in this study considered their spiritual care for children and families as insufficient. In general, the families themselves promoted spiritual care by requesting the visit of religious leaders, and praying or performing some form of religious ritual with the child. Visits and prayers have been reported as part of some patients' routine for adults and children hospitalized in the ICU [1,4]. Parents reported praying for their children, reading the Bible, and participating in a religious community as religious practices [4]. Promotion of the family's manifestation of values and beliefs without judgment was highlighted by the nurse participants; this attitude is also reported in other studies that underscore the importance of religious groups [5,7]. Religious and spiritual leaders help families use their beliefs and spiritual resources for positively coping with stressful situations; this motivates the health team to include spirituality and religion in patient care [5,14].

The nurses' spiritual care was also represented by their tolerance of family member visitations beyond designated visitation times and allowing parents to remain overnight in the PICU. A study [2] of the experiences of parents with a child in palliative care demonstrated the importance of extended visitation times [2]. The presence of parents offers comfort, security, and makes the environment less hostile, which favors the child's recovery [11]. Moreover, the family's presence allows the team to identify the child's spiritual needs [9,11]. Some aspects of religion, spirituality, or life philosophy displayed by the child are derived from the parents' belief [4].

Nurse participants considered that the suffering of family members and their children is interrelated. Therefore, promoting faith and belief in God was a potential intervention that nurses in this study used to improve the parents' coping strategies and positively influence the child's well-being. Emotional support and care for the family are also important [3]. The belief in a higher power is a source that promotes and maintains hope, and that is strongly related to the search for meaning in life [5]. Trust in God may result in feelings of peace, comfort, and patience making faith-based decisions less difficult [4].

The spiritual care evaluated in this study was empirically provided and based mainly on previous experiences in the health care practice and the nurses' religious and spiritual values. This aspect may question ethical aspects of care because nurses may transfer their own beliefs to patients [13].

According to these results, spiritual care was seen as more frequent among family members and older sick children than younger sick children and babies. The main reasons for not providing spiritual care to young and baby patients were age and the stage of development not enabling dialogue.

Children have more limited experiences than adults, and their developmental stage can directly affect the interpretation of their experiences [25].

In addition, the nurse participants report that spiritual care could not be provided to older sick children when they have a decreased level of consciousness, a situation which compromised dialogue. This is described in other studies in the intensive care context in which the level of consciousness is reported as interfering in the team's interaction and bonding with patients [1,12]. When verbal communication is impossible, nurses should heed the children's expressions of crying, posture, and facial, and hemodynamic changes in an attempt to identify their needs [11].

A few nurses in this study argued that children mainly express their spirituality through behaviors. The literature underscores that children reproduce rituals, symbols, and the expression of values. Nevertheless, adults have a limited understanding of these expressions of spirituality [9]. Through behavior, the child can express feelings of joy, despair, and spiritual distress. This can happen through dancing, art or storytelling, episodes of extensive crying, difficulties eating or sleeping, silence or not wanting to interact, and resistant behavior [9].

Some studies highlight the nurses' difficulties to acknowledge and tend to patients' spiritual needs, particularly when the patients are children [14,17,23]. This is often the result of insufficient training to assess spiritual needs [16,26,27]. To attend to children, nurses need to understand their developmental stage in faith as well as their cognitive, psychosocial, and moral development. The theories of Jean Piaget, Erik Erikson, Lawrence Kohlberg, and the faith's stage of James Fowler can provide nurses with additional information to help promote spiritual care for children and their families [28]. Other strategies, that were not used by nurse participants that may promote spiritual care and expression of spirituality in children and adolescents include art activities with materials such as paint, clay, cloth, story-telling, writing texts and poetry, use of imagination, games, theatre, music, dance, and videos [29–31].

4.2. The Difficulties in Performing Spiritual Care in the PICU

Although the nurses believe that spiritual care is essential at the PICU, it rarely occurred in their daily activity. The main justifications for this absence included work dynamics which includes prioritizing physical needs, and lack of time for spiritual care. Literature shows that even in adult ICUs, professionals prioritize physical and technical care to the detriment of other dimensions as the result of the number of tasks that need to be accomplished [1]. The turnover of professionals [11], night shifts [2], and organizational factors, such as a large number of patients, heavy work load, rapid shifts, and lack of continuity of spiritual care, are other factors described to justify the absence of spiritual care in the clinical practice [8]. In addition, personal factors, such as lack of training to assess spiritual needs and to intervene, emotional burden, and religious and cultural beliefs, were also highlighted as barriers to providing spiritual care in other studies [7,16].

The PICU management should ensure time and space for compassion and empathy [2] in order to allow nurses to absorb the patient's suffering, recognize their spiritual needs, and provide spiritual care. Nurses are in privileged positions to promote and help families; therefore, they need to become involved and establish ongoing communication, which requires knowledge about culture, spirituality, and religiosity [5]. In addition to technological and biological information, nurses must understand the family's needs and allow time for relatives to be with the child as family love and support contribute to a positive care environment that allows for the child and the family to cope with the child's hospitalization [32]. Communication is important to acknowledge spiritual needs and allow patients and family members to be able to share their feelings and experiences [3]. Therefore, in order to attend to spiritual needs in the PICU, nurses should consider families, their children, and their spiritual and religious beliefs. Healthcare professionals need to be aware of the existential, spiritual, and religious aspects of care, which are as important as physical needs [5]. In addition, nurses must display sensitivity to verbal and non-verbal communication with children and families that are essential for providing spiritual care in the PICU.

5. Limitations and Future Studies

The participants' characteristics, such as affiliations and religious practices, could have been explored. Although Brazil is considered a predominantly religious country, the lack of assessment of how the participants' religion could have influenced clinical practice and the meanings attributed to spirituality that was reported in the results are limitations in the study. The participants directly indicated other participants because of snowball sampling, and consequently, some values or behaviors may predominate in the study. We acknowledge that studies with other strategies for data collection, such as participant observation in the intensive care contexts, could expand the understanding of this phenomenon.

This study focused on nurses' experiences in the PICU. The investigations of spiritual care in other contexts of children's health care and study designs that consider the inclusion of other health professionals are important to evaluate facilitating factors and barriers to including spirituality in health care. Additional contributions to the body of knowledge in this area could result from studies that explore the spiritual dimension of children and experiences of health care professionals who incorporated spiritual care in their clinical practices.

6. Conclusions

This study analyzed the experience of nurses in providing spiritual care to children at the PICU and their families. The results show that the nurses understood spirituality as an important part of caring for children, families, and health professionals in critical care settings. Most participants did not consider the meaning of spirituality for the child. Young age and decreased level of consciousness were described as factors that affected the provision of spiritual care directly to the child. The poor clinical condition of children in intensive care along with a palliative care diagnosis were factors that motivated the nurses to provide spiritual care, which was addressed mainly to the families. The success of spiritual care necessitated establishment of a preliminary relationship with the child and family, which was mainly hindered by a lack of time during the working shift.

In a critical analysis of the PICU context, the results suggest that nurses experience insecurity in dealing with the children's spiritual dimension. Practices that prioritize physical and measurable aspects of the disease are still predominant, compared to subjective aspects and the spiritual dimension. These findings highlight the challenges and opportunities related to the inclusion of spiritual care to children and their families. Thus, the need to implement and consolidate teachings on spiritual care in academic contexts is also underscored.

These findings strengthen the value of the spiritual dimension on holistic care in the PICU. Interventions that characterize the spiritual care of children and families are described in this study, as well as the importance of observing non-verbal communication in children, when assessing spiritual needs. These strategies can encourage the promotion of spiritual care in the PICU and other pediatric settings, as well.

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Abbreviations

The following abbreviations are used in this manuscript:

ICU	Intensive care units
PICU	Pediatric intensive care unit

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