

## SPIRITUALITY IN PALLIATIVE CARE IN PEDIATRIC PATIENTS: A LITERATURE REVIEW

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**Abstract: Introduction:** According to the World Health Organization (W.H.O.), palliative care constitutes interventions that focus on patients whose illnesses do not respond to treatment, with the main focus being to improve the quality of life of these individuals and their families, through pain relief, as well as of biopsychosocial and spiritual problems associated with illness. Confirmation of a poor prognosis in a pediatric patient leads to the discontinuation of family planning, a factor that encourages the search for mechanisms that help obtain the best outcome for the sick child's life. In this sense, the role of spirituality in palliative care appears urgent for these patients, in which their family members seek spirituality as a symbol of strength in facing the disease, with the aim of embracing and minimizing the suffering faced. Thus, during treatment, it is possible to observe the appreciation of life and union, with, in most cases, religiosity and faith present as protective factors. **Objective:** To understand in an integrative way the role of spirituality in palliative care for pediatric patients, as well as its influence on the care of these patients based on the studies carried out. **Methods:** Systematic literature review, with data collection from 2013-2023, in the databases: LILACS, SciELO and PubMed, using the descriptors "spirituality", "palliative care" and "pediatrics". **Results:** A total of 05 articles were selected for analysis and through it, it was possible to construct two thematic approaches: spirituality in care and spirituality in palliative care for pediatric patients. In view of the studies listed, it is clear that there is a consensus that testifies to the importance of spirituality in palliative care. **Conclusion:** The study found the relevance of spiritual influence in palliative care for pediatric patients in helping to cope with the illness, as well as the essential need to disseminate knowledge on this topic, and implement a model that

makes the implementation of interventions based on spiritual practices systematic, since that religiosity welcomes and minimizes the suffering of the patient and the family, which helps the importance of carrying out new studies on the topic.

**Keywords:** Spirituality, Pediatrics, Palliative Care.

## INTRODUCTION

According to the World Health Organization (WHO), palliative care constitutes interventions that focus on patients whose illnesses do not respond to treatment, with the main focus being to improve the quality of life of these individuals and their families, through pain relief, as well as of biopsychosocial and spiritual problems associated with illness.

Furthermore, according to the Federal Council of Medicine, Resolution No. 1,805/06 states that palliative care constitutes an approach focused on the quality of life of both patients and their families in the face of problems associated with diseases that put life at risk. Its activities seek to prevent and alleviate suffering, through early recognition and accurate and careful assessment and treatment of pain and other symptoms, and demands, whether of a physical, psychosocial or spiritual nature.

According to the Brazilian Society of Pediatrics (2020), "Palliative Care is that which prevents, identifies and treats children suffering from chronic, progressive and advanced disease" They are essential at any time during the illness, and offer more advantages when offered early, along with other multidisciplinary therapies aimed at curing or controlling the underlying disease. Therefore, Verri and collaborators (2019) also highlight the need for a humanitarian vision by the multidisciplinary team, which involves doctors, nurses, psychologists, psychiatrists

and social workers, physiotherapists and spiritual support, in patient-centered care.

According to Alves et al. (2016), from the moment family members have confirmation of a poor prognosis in the pediatric patient, they find themselves faced with the new and the unknown, a factor that encourages the search for mechanisms that help in obtaining the best outcome for the child's life. sick child. During treatment, the family goes through several changes and, even with the disruption of family planning, it also begins to value life and union, with, in most cases, religiosity and faith present as protective factors, aiming to, thus, the best outcome for the sick child's life.

During the support of palliative care, several needs arise to be met, however spirituality is identified as the most urgent for patients with potentially fatal illnesses, due to the vulnerability they present in the face of the proximity of death.

In this context, Evangelista and collaborators (2016) argue that the role of spirituality in palliative care is considered extremely relevant, since patients are exposed to the fragility they present in the face of the uncertainty of death and the fear of the unknown. Thus, it is believed that the patient can seek spirituality as a symbol of strength in facing illnesses, with the aim of minimizing the suffering resulting from the difficulties encountered or to obtain greater hope of a cure with treatment.

According to the Brazilian Society of Pediatrics (2016), just like adults, children and adolescents need to find meaning in illnesses, transcend beyond suffering and find a sense of connection with themselves, with others or with something significant, especially during difficult periods of life. A child's spirituality can be recognized by behaviors, observing their body communication, such as looks, laughter, crying, paintings and drawings, gestures and facial expressions. This is important for

identifying signs of spiritual suffering that can be reflected by intense crying, insomnia, nightmares, prolonged silence and resistant or regressive behaviors.

In view of the above, this theme aims to understand spirituality in palliative care in pediatric patients in an integrative way, and thus respond to the role of religiosity in the treatment of these patients, as well as understanding comfort in the face of pathology.

## METHODOLOGY

This is a systematic literature review study, in the databases: Latin American and Caribbean Literature Health Sciences (LILACS), Medical Literature Analysis and Retrieval System online (MEDLINE), and the virtual libraries Scientific Electronic Library Online (SciELO) and PubMed. As a method for selecting articles, Health Sciences Descriptors (DeCS) and the Boolean operator AND were used, namely: Spirituality and palliative care and pediatrics. The inclusion criteria were articles on the topic published in full, in the selected databases, in Portuguese and English, as well as published in the last 10 years (2012-2023) that portray the topic to be researched and articles published and indexed in the databases. of data referred to. As an exclusion criterion, other databases will not be present in the systematics, as well as duplicate articles. 16 articles were found and 05 articles were selected that fit the inclusion criteria that were defined for the selection of articles. Search strategies were carried out according to the databases, highlighting the articles found and selected following the inclusion criteria to be used in the research. (Table 1).

In view of the above, according to the exclusion criteria, which indicates that duplicate articles in different databases are considered only one article for analysis.

Therefore, articles shown in table 2 were used.

## RESULTS AND DISCUSSIONS

### SPIRITUALITY IN CARE

Spirituality can be understood as the search for meaning and meaning in life, in dimensions that transcend the tangible, which lead human feelings to the experience of something greater than existence itself, which may or may not be related to a formal religious practice. (TAVARES, 2013 apud GARANITO; CURY, 2016). In adolescents, spirituality can help some patients, especially those at risk of death and in terminal situations. (VASQUES et al, 2011 apud GARANITO; CURY, 2016).

Faith in palliative care is essential to provide guidance, make sense of your situation, grant permission to make decisions at the end of life and to better deal with the situation (Meyer et al, 2016 apud Wiener et al, 2013). Likewise, according to Superdock (2018), spirituality often serves as a “guide” for decision-making in difficult moments throughout the treatment of the illness. Belief in miracles causes a change in treatment, which may be milder or more complex, in medical procedures, in resuscitation orders and in the suspension of life support therapy. However, despite this assistance from spirituality in decision-making, uncertainty was still present, as they did not think they would be prepared for whatever might happen.

According to Vasques and collaborators (2011 apud GARANITO; CURY, 2016), sick patients give meaning to their pathology in the face of spirituality, and it is noticeable that there is a change in the way they observe their health situation, as well as a way of alleviating the suffering and approaching the spiritual plane, in addition, maintaining contact with the professionals who are in charge of care, and they are more sensitive to patients' reports and are more open to listening, showing that

Search strategy	LILACS		SCIELO		MEDLINE		PubMed	
	E	S	E	S	E	S	E	S
<b>Spirituality and palliative care and pediatrics</b>	02	01	02	01	12	03	00	00
<b>TOTAL</b>	01		01		03		00	

Table 1- Search strategies, according to database. Research carried out with descriptors in Portuguese, using the Boolean operator AND.

Legend: E- Found; S- Selected.

Source: survey data, 2024.

Authors	Database	Title	Newspaper	Year of publication
NAUFEL, Lucas Zambusi; SARNO, Máira Terra Cunha Di; ALVES, Maria Augusta Junqueira	SCIELO	Physicians' Knowledge About Patients' Religious Beliefs in Pediatric Care	Revista Paulista de Pediatria	2019
GARANITO, Marlene Pereira; CURY, Marina Rachel Graminha	LILACS	Spirituality in pediatric practice	Revista Bioética	2016
VERRI, Edna Regina; BITENCOURT, Nathalia Aparecida Santana; OLIVEIRA, Jéssica Aires da Silva; JÚNIOR, Randolfo dos Santo S; MARQUES, Héli da Silva; PORTO, Mariana Alves; RODRIGUES, Debora Grigolette.	MEDLINE	Nursing Professionals: Understanding CarePediatric Palliatives	Revista de Enfermagem UFPE	2019
SUPERDOCK, Alexandra K.; BARFIELD, Raymond C.; BRANDON, Debra H.; DOCHERTY, Sharron L.	MEDLINE	Exploring the vagueness of Religion & Spirituality in complex pediatric decision-making: a qualitative study	BMC Palliat Care.	2018
WIENER, L; MCCONNELL DG; LATELLA L, Ludi E.	MEDLINE	Cultural and religious considerations in pediatric palliative care.	Palliat Support Care.	2013

Table 2- Articles selected according to authors, database, journals and year of publication

they are empathetic. Likewise, Superdock (2018) states that within a community and trust in religious leaders it is possible to have support in these moments of care.

According to Naufel and other authors (2019), doctors must consider spiritual aspects of patients and that beliefs must be discussed, since, often, the cure of their illnesses is associated with prayers, but they do not get this opportunity to questioning.

The service is provided within each specificity, but described in a single document, called a medical record, where notes must be made about the services provided, pertinent information about beliefs, religiosities and other health problems related to the patient. (GENTIL et al 2011 apud GARANITO; CURY, 2016)

On the other hand, according to Naufel

and collaborators (2019), they state that the document contains more information about the clinic than the same interest in the religiosity of the patients they accompany, which is seen both in medical practice and in teaching, thus being little able to deal with these aspects.

According to Gentil and collaborators (2011 apud NAUFEL et al, 2019), with this advance, specialized care tends to avoid ethical conflicts between the professional team and their patients. Doctors are considered managers of multidisciplinary teams, and therefore, it is necessary to understand the main dogmas of each religion, even more so in a country like Brazil which has several religious beliefs. In this regard, Nawawi and collaborators (2012 apud NAUFEL et al, 2019) and Edwards and collaborators (2010 apud NAUFEL et al, 2019)

state that there is a lack of preparation when approaching patients with regard to individual beliefs and existential convictions.

This way, pediatricians and resident pediatricians are not able to deal with the spiritual aspect of their patients in the process of death, and a course on religions must be instituted in Brazilian medical graduation, since it is well known that religion helps in acceptance in the death process (NAUFEL et al, 2019).

According to Saguil and Phelps (2012 apud NAUFEL et al, 2019), there is the possibility of using questionnaires to understand spirituality for medical practice aimed at adult patients, which can facilitate care, they are: FICA Spiritual Tool, HOPE and Open Invite Mnemonic.

According to Sloan and other authors (2000 apud NAUFEL et al, 2019), the use of religion to address patient care must not be denied, with this practice being considered medical negligence and a form of barrier between doctor and patient that involves discomfort and conflicts.

Therefore, according to Serwint and collaborators (2016 apud NAUFEL et al, 2019), guidelines must be implemented that include medical students and residents to understand palliative care in practice, also demonstrating a unique relationship when dealing with patients and their family members, which are often left aside.

## **SPIRITUALITY IN PALLIATIVE CARE IN PEDIATRIC PATIENTS**

In the case of pediatric palliative care, we are not only dealing with the patient, but with their family as a whole. The process of death of a child, even if born with illnesses with poor prognoses, is seen as an unexpected event for their family members, as it will always be considered outside the “natural order”. (GILMER, 2002 apud NAUFEL et al, 2019).

According to Wiener and collaborators (2013 apud NAUFEL et al, 2018), when there is palliative care associated with faith, there is assistance in the death process, such as acceptance and understanding as a whole, at that moment you can have a vision of what is needed thus abolishing more invasive and suffering-prolonging procedures.

According to Santos (2013 apud GARANITO; CURY, 2016), in pediatrics there is no distinction regarding the topic of spirituality or religiosity, but it becomes something positive in treatment, in addition to maintaining care by ensuring respect and a good relationship between professionals-family- patients. According to Freud (1974), there is a replication of how children relate to God and religiosity, considering a contact experienced by the family in moments of inevitable need that they have no control over.

It is clear, in relation to the understanding attributed to Palliative Care, in most responses, that it is seen, mainly, as comfort and care offered to children and their families, using medications to relieve pain and promoting quality of life. (VERRI et al, 2019).

In this aspect, it is essential that specialists in palliative care, as well as general pediatricians and those from different specialties, such as oncologists, hematologists and neonatologists, exercise this care effectively, supported by knowledge of the needs of the child and their family and the recognition of importance of multi- and interprofessional work, aimed at individualized and comprehensive care for each patient (VALADARES; OLIVEIRA, 2013 apud GARANITO; CURY, 2016)

Parents seek to find in their children's end-of-life care: honest and complete information, quick access to the medical team, coordination of communication and care, being able to express their emotions and receive support from the medical team, preservation of the integrity of the parent-child relationship

and support for religiosity through faith in God. (MEYER, EC et al apud NAUFEL, Lucas Zambusi et al, 2019). Families rely on healthcare professionals to understand the decisions they face, and many families also rely on non-medical sources of support, such as religion and spirituality (SUPERDOCK et al, 2018)

Thus, Cartwright (1991 apud NAUFEL, 2019); Mueller and collaborators (2001 apud NAUFEL, 2019), state that religion provides acceptance in the death process, in addition to offering relief to the patient and their families, as it is aimed at improving patients and reducing anxiety in this process.

According to Nawawi and collaborators (2012 apud NAUFEL et al, 2019); Edwards and collaborators (2010 apud NAUFEL et al, 2019), the specialized degree in palliative care and the understanding of spirituality improve the doctor-patient relationship, modifying the vision of the child and their families in the death process, as in the professional sphere they are not prepared to deal with this issue.

According to Naufel and other authors (2019), it is highlighted that there is a need to improve palliative care in pediatrics, as pediatricians and residents are not able to deal with issues related to religiosity, despite having a favorable relationship in the disease process.

and death, in which the patient must be fully assisted and, according to Broeckaert (2011 apud NAUFEL et al, 2019), this care provides quality of life and relief from suffering for the family and the patient himself.

## **CONCLUSION**

In view of the above, the influence of religion and spirituality in the process of accepting death is undoubted, with its positive influence being evident for patients and family members in helping them cope with the process of finitude. This way, it is necessary for health professionals to understand the process of death/dying, as well as religiosity/spirituality in relation to the specificities of each individual and their family members, understanding finitude as a particular, empathetic and sensitive process, as each pediatric patient brings with him a particular vision of the death process added to a vision taught by the people close to him. And in graduations, address this topic, as it will further favor the development of skills to deal with the process, sensitivity and empathy in these cases. Furthermore, it is necessary that other themes are focused on the topic, as there are few studies related to this topic.

Conflict of interest: none

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