SPIRITUALITY AND RELIGIOSITY IN PALLIATIVE CARE: PROPOSING A GOOD DEATH

ESPIRITUALIDADE E RELIGIOSIDADE NOS CUIDADOS PALIATIVOS: PRODUZINDO UMA BOA MORTE

ESPIRITUALIDAD Y RELIGIOSIDAD EN CUIDADOS PALIATIVOS: PRODUCIR UNA BUENA MUERTE

ABSTRACT

Objective: recognizing the discourses about spirituality and religiousness circulating in textbooks about Palliative Care, and know how to operating such devices producing senses that produce truths. Method: this is a textual analysis that approaches the field of Cultural Studies. The analysis corpus consists of six books and one manual. Data collection was conducted from the interested reading of textbooks. To perform the analysis we supported on Michel Foucault's framework. Results: the research highlights the books about Palliative Care as important media artifacts, which provide circulation of speeches held as true, so are subject, influencing, disciplining and teaching a correct way of being and acting. Conclusion: the discourse of books is aimed at producing a good death, highlighting the applicant so that the acceptance of death and religious/spiritual assistance are essential.

Descriptors: Religion; Spirituality; Palliative Care; Death; Nursing.

RESUMO

Objetivo: conhecer os discursos sobre espiritualidade e religiosidade que circulam nos livros textos sobre Cuidados Paliativos, e saber como tais dispositivos operam produzindo sentidos que produzem verdades. Método: trata-se de uma análise textual que se aproxima do campo dos Estudos Culturais. O corpus de análise é composto por seis livros e um manual. A coleta dos dados foi realizada a partir da leitura interessada dos livros textos. Para realizar as análises nos apoiamos no referencial de Michel Foucault. Resultados: a pesquisa destaca os livros sobre Cuidados Paliativos como importantes artefatos da mídia, que proporcionam a circulação de discursos tidos como verdadeiros, de forma que constituem sujeitos, influenciando, disciplinando e ensinando um modo correto de ser e de agir. Conclusão: o discurso dos livros se dirige a produzir uma boa morte, destacando de modo recorrente que a aceitação da morte e a assistência religiosa/espiritual são essenciais. Descriptores: Religião; Espiritualidade; Cuidados Paliativos; Morte; Enfermagem.

RESUMEN

Objetivo: conocer los discursos acerca de la espiritualidad y la religiosidad que circula en los libros de texto en Cuidados Paliativos, y conocer el funcionamiento de tales dispositivos produciendo sentidos que producen verdades. Método: se trata de un análisis de texto que se acerca al campo de los Estudios Culturales. El corpus de análisis consta de seis libros y un manual. La recoleción de datos se llevó a cabo a partir de la lectura de los libros de texto interesados. Para realizar los análisis nos apoyamos en el marco de Michel Foucault. Resultados: la investigación pone de relieve los libros acerca de Cuidados Paliativos como artefactos importantes de medios de comunicación, que proporcionan la circulación de los discursos mantenidos como verdadero por los sujetos, que influyen, disciplinan y enseñan de una manera correcta de ser y de actuar. Conclusión: el discurso de libros está dirigido a la producción de una buena muerte, poniendo de relieve al solicitante para que la aceptación de la muerte y la asistencia religiosa/espiritual sean esenciales. Descriptores: Religión; Espiritualidad; Cuidados Paliativos; Muerte; Enfermería.

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INTRODUCTION

Formerly people died in their homes, with families and friends. Their wishes were respected because they were allowed to express them. With the medicalization of health, characteristic of the twentieth century, people began to die in hospitals. Thus, this becomes to be the new location for death, giving a new meaning to the act of dying, quieter and hygienic manner and in conditions for solitude. This transfer of death for hospitals has been referred to as a condition for the emergence of Palliative Care at the end of the twentieth century.

The Palliative Care began with Cecily Saunders and her colleagues to organize the hospice movement, which spread throughout the world a philosophy with two key elements about care. The first is the effective control of pain and other symptoms, and the second is the care with psychological, social and spiritual dimensions of patients and their families. This movement is characterized by strengthening the concept of caring and not only to heal.

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and families facing problems associated with life threatening diseases through the prevention and relief of suffering by means of early identification, proper evaluation and treatment of pain and other physical, psychosocial and spiritual problems.

Palliative care programs have grown significantly in recent years due to the increase of people with chronic diseases, debilitating and life-threatening and the interest of health professionals to meet effectively the population. The philosophy of Palliative Care proposes that health actions are provided by multidisciplinary team, including physicians, nurses, social workers, psychologists, nutritionists, religious counselors, nursing staff and other health professionals. In palliative care, the lifetime limit is accepted and the goal is not to cure, but rather care.

Since the human being is recognized by a thinking being, he is concerned to understand the meaning of life and death, the reason for his presence in the world, looking for strategies to deal with the difficulties. Such strategies are usually associated with the theme of spirituality and religiosity and come to doing this in daily life, especially when they are in fragile situations due to illness. Patients with severe, progressive and incurable diseases tend to feel the need of spiritual or religious support. Thus, Palliative Care propose also perform this care.

In Brazil, most of the population is religious and spiritual beliefs, reaching 90% to Brazilian rate declaring go to church, worship or religious services. According to the literature, for chronic or terminal diseases, patients and families often support in religious or spiritual beliefs as a way to face the difficulties, find comfort, hope and strength. Because of this, spirituality and religiosity are important in the care for people who have diseases without possibility of cure. Moreover, these discourse set forth generate an actual network that produces effects. According to Foucault, truths are understood as a set of rules by which it attributed to real specific effects of power. Thus, these discourses are not only association of things and words, since arise undergo a certain set of rules that define their existence regime and correlations with other statements constituting the object of talking and writing a particular discursive formation.

Spirituality and religion are related concepts, but despite often being used as synonyms, do not have the same meaning. Spirituality encompasses the universal human needs, it may or may not include specific religious beliefs and provides a philosophy or perspective that guides the choices of the person. In turn religion can be understood as a group or belief system involving the supernatural, sacred or divine, and moral codes, practices, values, institutions and rituals associated with such beliefs.

Spirituality and religiosity have been receiving attention in health care, because they constitute important coping strategies in situations that impact on people's lives. In addition, authors report that they would have shown positive influence on physical health, acting in
disease prevention and reduction of deaths, including noting that people who have spiritual and religious practices seem to have better emotional support, tending to develop healthy lifestyle habits, lower stress and depression rates and give more meaning to life; stressing positive aspects.\textsuperscript{10,11}

Authors show that recognize spirituality or religiosity as coping strategies and identify the individual spiritual gaps to make health professionals can plan and provide comprehensive care to the patient,\textsuperscript{12} highlighting the importance of professionals to understand patients and how deal with the disease, their beliefs and values, and understand the influence of these relations on the quality of life of that individual. Other authors point out that the patient should be understood in his entirety and have his beliefs respected, which could contribute to a better relationship between the team and the patient.\textsuperscript{11}

Studies report that the philosophy of Palliative Care proposes the right to decent life until the last moments of the patient and health care professionals should be alert to try to reduce the suffering and anxiety and can religiosity and spirituality be important allies for some patients.\textsuperscript{11} Accept the patient, respecting his beliefs about spirituality and religiosity, is one of the foundations of Palliative Care.

The Philosophy of Palliative Care is well established. Die processes, death and mourning and bioethical principles applied to palliative care have been extensively studied. However, there are gaps when it relates to spirituality and religiosity, such as their role in situations of mourning and death, strategies to relieve spiritual suffering and ways to establish dialogue regarding these matters.\textsuperscript{13}

We do not intend to show the effects of spirituality and religiosity on treatment outcomes or, to judge whether practicing them is right or wrong. By exposing as constitute ourselves from the culture in which we operate, we question the knowledge about spirituality and religiosity and the way they are organized and how we will be challenged by the discourses that run through us. For this we mention Foucault's ideas,\textsuperscript{14} which considers discourse as something that runs through us and constitutes us. Thus, the objective of this work is to know the discourses on spirituality and religiousness circulating in textbooks on Palliative Care, and know how to operate such devices producing senses producing truths.

\textbf{METHOD}

Article compiled from the completion of course work \textit{<< Palliative Care: an analysis of discourses about spirituality and religiousness >>} submitted to the Nursing Course at the Federal University of Rio Grande do Sul Porto Alegre-RS, Brazil; 2012.

The study is a textual analysis that approaches the field of Cultural Studies, especially the post-structuralist strand, which develops from the postmodern perspective. Textual analysis can be understood as one of the investigative paths invented to make the objects of study, covering disciplines and methodologies to account for the concerns, motivations and theoretical and political interests. According to cultural studies, speeches and texts have productive and constitutive character of everyday experiences, world views and cultural identities.\textsuperscript{15} Culture comprises a network of practices and representations such as text, images, conversations, codes of behavior that influence aspects of social life, and cultural studies emphasize the issues or problems in circulation among the media .\textsuperscript{16} The postmodern perspective proposes an external analytical to the concepts of modern rationality, suspecting the truths of modernity.


Data collection was conducted from the reading of textbooks to assess "what we enjoy and what we can discard, pass or put down".17-17 Since this is a study of post-structuralist framework, this selection is seen as a chance to read the authors. Thus, other readings can be taken, depending on those who read.

We chose to reading textbooks understanding them as devices that produce identities and convey speeches considered true. Therefore, we support in reference to Michel Foucault, which stands for thinking otherwise processes that are often naturalized, allowing other ways of thinking. Thus, we used their understanding of speech and disciplinary power. Foucault conceived his books as a toolbox, in which readers could go in search of that they needed to think and act.18

Regarding the ethical aspects, remember that the analyzed publications are of a public nature and highlight the extracts from books that formed the corpus of analysis identifying them in italics in the article, referring to the authors of the works analyzed.

RESULTS AND DISCUSSION

Man is an autonomous and rational being, product of unconscious cultural forms and practices beyond his control, being composed of a complex network of social practices and historical facts.18 Thus, he is influenced by the speeches, such as the texts of books on Palliative Care. Throughout the reading of books, we realized these texts as powerful media artifacts that circulate speeches that produce subjects and subjectivities, teaching ways of being and doing, influencing patients, caregivers and health professionals.

The analyzed books describe how should be the attitude and posture of the professional who will make the spiritual assessment. Indicate criteria to conduct an effective spiritual assistance, including: listening carefully, empathizing and supporting, recognizing and responding to the suffering of others, to identifying and addressing ethical and conflict issues and seek additional resources, such as chaplains and spiritual care providers when needed.8 They also reported, attitudes expected of nurses such as: respect the spiritual history, rites and traditions of the patient and allow the visit of religious.8

The nurse spends more time with the patient than any other professional. This fact gives him a broad visibility and access to know and meet the social life needs, psychological distress and spirituality of the patient.4-6

The books claim to be necessary for the professional making observations while questioning and listening carefully to the patient’s response. These questions must be open to elicit information about faith, religion, spiritual beliefs and practices. The best open questions begin with ‘how, what, who, when’ or phrases like ‘tell me about […]’. Generally, questions beginning with ‘why’ are not useful, patients are often muddled with the perceived threat or challenge (eg, “because you believe that?”).19-20

The evaluation will be effective only if the trader previously established trust and rapport with the patient, as it may not feel comfortable when disclose intimate information to a person unknown.19 Another book ensures that it is necessary to listen to the patient in order to understand, show respect for the beliefs or unbelief, and support the beliefs.20

Professional books instigate certain behaviors and attitudes to perform spiritual assistance. These are instructed to act in a certain way, and therefore disciplined for it. The disciplinary power acts on the bodies of the subjects, establishing permissions and restrictions. It is a power that contain appropriate rules to act, to behave, to relate, linking those who escape from the norm and moral propositions.21

All texts encourage certain attitudes and ways of doing, pointing out that it is appropriate to do this or that for the nurse be not be misinterpreted to asking questions that would be the privacy of patients. One book says it is polite to the
nurse start the spiritual assessment with the explanation of why such a review is necessary because the spirituality and religiosity are intimate and personal topics. In addition, it must be attentive to nonverbal communication and the environment the patient, since these factors are sources of great information, which will help the nurse in spiritual assessment. For the environment, it can be observed:

- There are religious objects on the bedside table? Are there religious illustrations or crucifixes on the walls? Improves cards or books with spiritual themes? Are there indicators that the patient has many friends and family with love? The curtains are closed and pulled the quilt over his face? The patient seems to be angry or agitated?

Books discipline nurses directing what to observe, orient and listen. Thus, the discourses produce certain type of professionals that when engaging in this order of discourse, performing certain practices and acting in a certain way and not another.

Another text recalls the importance of language, which should not be offensive. To avoid this problem; the nurse should start the review with general issues, not related to spiritual and religious matters. A question example would be: “What is giving strength to cope with their illness now?”

The text points out that the nurse must be aware of language that the patient uses to formulate continued issues. If the patient responds, for example, “My faith and prayer help me”, then the nurse knows that faith and prayer are words that do not offend this patient. If the patient states that “great spirits guide”, then the nurse will not respond to “talk to me like Jesus is your guide”.

This text is also referred to the importance of listening to the patient’s response, remembering that silence is appropriate and directing that should be heard more than words: hear the symbols, listen to the patient’s energy places and hear the emotion beyond cognition.

While the nurse asks the patient about his spirituality, he is assisting the patient to reflect on the most intimate and important aspects of the human being. The nurse is also indicating the patient to confront spiritual matters is normal and valuable. The nurse also offers spiritual care during an evaluation for being there and witnessing what is sacred to the patient.

As you can see, the books are right kind of professional setting standards, ways of being and acting, functioning as an instrument at the same time regulating and normalizing, acting on the bodies to regulate the conduct of individuals, establishing a standard of which subjects cannot escape.

The books also described the difficulties of health professionals to address the issue religiosity/spirituality with patients. In another book is pointed out that the perception of our finitude brings issues and needs that can be addressed by the health professional; but these professionals many times fear or cannot handle such issues. Talk of the finiteness can be a conversation about spiritual matters, and professionals may have difficulties such as:

- Lack of knowledge about the subject, training and time; discomfort with the subject; afraid to impose religious views or offend the patient; believe that knowledge of religion is not relevant to medical care and find that it is not within its jurisdiction the approach to such matters.

The professional can begin to talk more generally, asking, for example, “Must be very difficult for him or her to cope with this. How are you feeling?” In another passage is referred to as a “barrier to spiritual assessment is the fear of offending the nurse in nonreligious patient using religious language.” Make therefore more general questions, make communication easier on spiritual matters; however, the texts show that nurses must recognize that they are not experts in the evaluation of spiritual care and that many nurses did not receive adequate training to perform evaluation and spiritual care, and this may be due also to role confusion or lack of time. Thus, when the judgment indicates nurse need for a more sensitive assessment and expert care must refer the patient to a specialist.

Spiritual care requires both recognition of the value of assistance as unconditional willingness to provide spiritual care. Employees need to know how to identify their own limits/restrictions and determine when there is need for the aid of chaplains or spiritual care providers. This includes...
It is “essential that the nurse try his own journey, visiting the intense emotions surrounding the dying process and the act of witnessing the suffering”19:617. So the professionals who wish to address the spirituality of the patient must apply themselves the FICA professional, which is an instrument that aims to providing greater security for the professional to address this issue in patient care.20 Below are some questions:

- I have spiritual beliefs that help me dealing with stress and with the end of life? These beliefs are important to me? They influence the way I take care of myself? My spiritual life is integrated in my personal and / or professional life? If not, why not? I belong to a spiritual community? What is my commitment to this community? What should I do in my practice in order to grow spiritually? What better way to integrate my spiritual life in my personal and / or professional life? 20:381

We perceive that this instrument reinforces the idea that spirituality/religiosity help dealing with the end of life; it is difficult to think otherwise. In general, the texts report the importance of professional self-knowledge about spiritual and religious matters, as only allowing it to provide effective patient care. To suggest questions to ask you in order to know better and provide better patient care. Therefore, to provide adequate patient care, the provider should be evaluated, look inward, pass an examination of conscience. Here we see professionals as target discipline. The discipline that acts on the bodies of these individuals, […] is a power technology that operates in detail, which scans an entire field of vision to control individuals. A control that increases the effects of disciplinary power, for nothing escapes his permanent surveillance, continuous observation, of seeing without being seen.21:36

In accordance to the books, evaluation and spiritual care should be introduced in the early care and reassessed continuously. In addition, it is essential that nurses establish a reliable and good communication relationship with the patient to facilitate spiritual care.19 Spiritual care aims to increase the opportunity for reconciliation with the superior power and itself. The goal is to relieve spiritual suffering, but the goal in the spiritual care is not to provide a personal response to key issues or make the patient achieve a particular belief.
“Most of the interventions can be applied to people of any faith, or even for people without faith”, 19,396 for even those with no religion/spirituality can and should receive spiritual care, as the discourse is constituted in such a form that includes everyone.

Two basic interventions of spiritual care can be offered by the nurse or other team members. The first is the fact of being with the patient, to hear him; the second would be praying. 19 States that “prayer is very well documented in the literature as having meaning for patients and families, representing not only connect with God, but also a relational link with the other”. 19,613 “Prayer, invited and offered heart is a powerful means of care for the patient, the family and the nurse”. 19,604

Health professionals should help the patient finding passages of sacred books of their own religions and discussing these passages to answer the questions about the meaning of suffering and death. If the patient is unable to read, nurse or other caregiver can do the reading. The cult, ritual, prayer and meditation can be part of spiritual care, and encourage participation in such actions is important, both for patients and for the family. When it becomes difficult for the patient to visit a place of worship, because of physical limitations, clergy visits should be considered. A nurse or other caregiver should call the priest to perform the visit. 19 The nurse can explore the authentic history of the patient; especially times when faith and connection to something higher were strong and when they were weak and which influenced these changes. The act of watching “fear, suffering, and isolation may be the only possible spiritual care - not to mention, the best spiritual care available”. 19,601

In these passages we can see that the speeches try to meet all dimensions and possibilities of patients at the end of life and their family, prescribing correct ways of living this life stage, establishing what would be right with an incentive to work for that has certain conduct and not others. There are practices that turn the disciplining of individuals in order to adjust their behavior according to moral principles which are appropriate for life in society. These practices are embedded in complex power games that manufacture values, judgments, interests, and ways of being and drive. 21

To assist the terminally ill to reframe the pain of symbolic death, were developed psychotherapeutic interventions integrating techniques of mental relaxation and mental imagery with elements that make up the spirituality. Among the proposed actions, we highlight the following interventions:

Direct suggestion to bid farewell to this life and enter into a beautiful spirit world and peaceful; statement to the patient view spiritual beings of light that provide support, protection and radiate unconditional love, kindness, affection; statement to the patient view Our Lady protecting him and wrapping him in his blue cloak; and affirmation for the patient to feel the love of Christ wrapping him. 21,344

Again, the patient is encouraged to see the spiritual/religious side, even if he is not Christian or religious / spiritual, so that such speech is naturalized in order to produce a good death should all explore their spirituality, to value these aspects to have a final life with quality.

Another book recommends the following interventions of spiritual assistance:

Listen to the concerns, feelings and beliefs of the patient; provide a private room and listen carefully so he can express feelings and experiences associated with the disease, stress and death; provide opportunities for him to express regret, anger, despair, sadness, happiness, joy and confusion; suggest contact with people who can help you; refer you to professional spiritual care providers; suggest spiritual practices such as yoga or meditation; support rituals, sacraments; support the prayer; encourage reading of sacred texts; encourage reflective readings of poetry or literature; encourage patients and their families to write a blog or journal. 8,52

It is noticed that the books have “recipes” of how to offer spiritual assistance. The requirements are broad and reach various activities that would be producing a good final moment, a good death. Professionals, patients and their families are encouraged to write, speak, pray, meditate, listen and read. It's the discipline of professionals to have certain behaviors and pay attention to certain items in offering spiritual care to patients.

When patients and families request that the nurse pray with them, this must be understood as a sign of respect and attempt to include it in this unique time. 8

English/Portuguese

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Cervelin AF, Luce Kruse MH.
The nurse fails in this, the nurse turn its back on its intrinsic promise to relieve suffering, so nursing can no longer exist. Instead, the nurse becomes simply the technique and the planner, the nurse becomes part of the problem. She violated the code of Nurses reporting - "Nursing care is directed to the prevention and relief of suffering usually associated with the process of death [...] and emphasizes human contact."19,612

Note in this excerpt emphatic language that highlights the impossibility of existence of nursing outside the relief of pain and suffering and encourages professionals to assume the role of spiritual caregivers, even if you know they are not prepared to do so, since such knowledge are not part of the professional curriculum. Nursing is a profession that appears related to religion, and the nurses took the spiritual care, perhaps under the influence of Florence Nightingale, who had religious education and was the founder of modern nursing. On the other hand, should also be considered that the purpose of the hospitals was the imprisonment and death to those who had nowhere else to die, and its main objective spiritual assistance. The nurse took this care, more than any other professional, due to his constant and direct presence with the patient,26 enabling the creation of a greater bond and verbalization of patients about their intimacy.

CONCLUSION

The textbooks on Palliative Care praise religiosity and spirituality in order of discourse about patient care at the end of life, building a network of knowledge about the subject is that patients and professionals. In this study we attempted impugning such discourses that run through us, that is, the truths that are circulating about spirituality and religiosity of people in later life. It sought to show that such discourses accepted as natural the result of a plot that aims to educate patients and nurses. By analyzing the truths this discursive network tries to denaturalize these speeches, casting another look at this issue.

The texts proclaim that there is a right way to approach spirituality and religiosity, as well as a correct way to die. Although prescribe an individualized patient care, end up emphasizing the same behavior for all. It is observed as well, a standardization of care and the
way he died. There are rules and regulations for all situations that seek to make death as natural as possible.

We observed that the discourse of textbooks on Palliative Care is directed to produce a good death, i.e. a death with the minimum possible suffering. And, according to these speeches, the acceptance of death and religious/spiritual assistance are essential. Therefore, the books resort to various methods, guidelines, strategies and behaviors in order to teach how the health professional should behave and how to act in caring for terminally ill patients in relation to spirituality and religiosity. It is noted so the discipline practitioners, in order to produce a certain type of behavior.

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