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Spirituality and religiosity in palliative care: learning to govern

Espiritualidade e religiosidade nos cuidados paliativos: conhecer para governar

Espiritualidad y religiosidad en la atención paliativa: conocer para gobernar

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Abstract

Objective: To know the discourses about spirituality and religiosity that circulate in books on Palliative Care, and to learn how these devices operate, producing truths. **Methods:** This is a textual analysis that proposes to make an approach to the field of Cultural Studies. The *corpus* of analysis consists of six books and a manual. The data collection was performed by the interested reading of these books. To perform the analysis, we rely on Foucault's reference, so we use his understanding of discourse, power and government. **Results:** The research highlights the Palliative Care books as important media artifacts that provide circulation of discourses that are considered true. **Conclusion:** The books indicate advantages of be religious and/or spiritualized. We observe people's government through religion and spirituality, in order to drive their behaviors and to influence their mode of being and acting.

Keywords: Religion; Spirituality; Hospice Care; Nursing.

Resumo

O objetivo deste estudo foi conhecer os discursos sobre espiritualidade e religiosidade que circulam nos livros sobre Cuidados Paliativos, e saber como tais dispositivos operam produzindo verdades. **Métodos:** É uma análise textual e realiza uma aproximação com o campo dos Estudos Culturais. O *corpus* de análise é composto por seis livros e um manual. A coleta dos dados foi feita a partir da leitura interessada dos livros. Para realizarmos as análises, apoiamo-nos no referencial de Foucault, desta forma utilizamos seu entendimento acerca de discurso, poder e governo. **Resultados:** A pesquisa destaca os livros sobre Cuidados Paliativos como importantes artefatos da mídia, que proporcionam a circulação de discursos tidos como verdadeiros. **Conclusão:** Os livros apontam vantagens de ser religioso e/ou espiritualizado. Observa-se o governo dos sujeitos por meio da religião e da espiritualidade, de forma a conduzir suas condutas e influenciar o seu modo de ser e agir.

Palavras-chave: Religião; Espiritualidade; Cuidados paliativos; Enfermagem.

Resumen

Objetivo: Conocer los discursos sobre espiritualidad y religiosidad que circulan en los libros sobre Cuidados Paliativos, y saber cómo estos dispositivos funcionan produciendo verdades. **Métodos:** Análisis textual que realiza un acercamiento al campo de los Estudios Culturales. El *corpus* del análisis se compone de seis libros y un manual. La colección de dados se realizó a partir de la lectura interesada de los libros. Los análisis se basaron en el referencial de Foucault, usando su metodología de compresión del discurso, poder y gobierno. **Resultados:** La investigación destaca los libros como artefactos importantes de los medios de comunicación, que proporcionan la circulación de los discursos considerados verdaderos. **Conclusión:** Los libros indican ventajas de ser religioso y/o espiritualizado. Se observa el gobierno de las personas a través de la religión y espiritualidad, con el fin de impulsar sus comportamientos e influir en su modo de ser y actuar.

Palabras-clave: Religión; Espiritualidad; Cuidados Paliativos; Enfermería.

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INTRODUCTION

Spirituality and religiosity are related concepts that, in spite of 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 person's choices[1]. Now religion can be understood as a group or system of beliefs that involve the supernatural, sacred, or divine and moral codes, practices, values, institutions and rituals associated with such beliefs[2].

The World Health Organization defines Palliative Care as an approach that improves the quality of life of patients and families who face problems associated with the 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[3]. In Palliative Care the limit of life is accepted and the objective is the care, and not a cure. Seeking to respect human dignity and must be started from the onset of the diagnosis of severe, progressive and incurable diseases, it is meant to provide comfort and well-being to the individual.

The philosophy of Palliative Care is well established. The dying, death and mourning processes and the bioethical principles applied to palliative care have already been extensively studied. However, there are some gaps when the subject refers to the spirituality and religiosity such as its role in situations of mourning and death, strategies to alleviate the suffering and spiritual ways to establish the dialog concerning these matters[4]. Therefore, we believe that it is important to know about the production of knowledge about the theme, in so far as the health professionals they can take ownership of this issue and apply it in their clinical practice.

Since the human being is recognized as a thinking being, they are concerned about understanding the meaning of life and death, because of their presence in the world, looking for strategies to deal with the difficulties. Such strategies are usually associated with the topic of spirituality and religiousness and is present in the daily life of people, especially when they are in situations of fragility due to illness.

In a study conducted with elderly, religious practice was reported by 94.27% of the participants. According to this study, spirituality and religiosity are important sources of emotional support, influencing the physical and mental health[5]. according to the literature, during chronic or terminal diseases, patients and family members often are based on religious beliefs or spiritual as a way to face the difficulties, find comfort, hope and strength[6]. Due to this, the spirituality and religiosity are important aspects in the care of people who have diseases without the possibility of cure. On the other hand, such statements generate a discursive network that produces truthful effects.

According to Foucault, the truths are understood as a set of rules through which attaches to the true specific effects of power. Thus, look for these discourses cannot be seen only as an association of things and words, already that arise submitted to a certain set of rules that define its scheme of existence and its correlations with other statements constitute the object and composing a particular discursive formation[7].

We do not intend here to point out the effects of spirituality and religiosity on treatment outcomes, or defining them as right or wrong. To explain how we are from the culture in which we are engaged, we are questioning the knowledge on spirituality and religiosity; how they are organized,and how we are being included in the discourses that we pass through. Thus, the objective of this work is to understand the discourses on spirituality and religiousness circulating in textbooks on palliative care as well, as how these devices operate producing meanings that produce truths.

METHODOLOGY

The study is a textual analysis that proposes an approximation with the field of Cultural Studies, specifically in post-structuralist aspect, which develops from the post-modern perspective. Textual analysis can be understood as one of the investigative paths invented to compose the objects of study, covering disciplines and methodologies to account for the concerns, motivations and theoretical and political interests. In accordance with the Cultural Studies, the discourses and texts has character productive and constitutive of everyday experiences, visions of the world and cultural identities[8]. Culture comprises a network of practices and representations such as texts, images, conversations, and codes of behavior that influence aspects of social life; thus, the Cultural Studies emphasize the issues or the problems in movement between various means of communication[9]. The post-modern perspective proposes an external analytical to the concepts of modern rationality, distrusting the truths of modernity.

The *corpus* of analysis consists of six books and a Palliative Care manual. These publications were chosen because they are often referenced in articles and courses of healthcare professionals and having a wide circulation in our midst. We List below the list of publications:

- Campbell ML. Nurse to nurse: *cuidados paliativos em enfermagem*. (Nurse to nurse: palliative care in nursing.) Porto Alegre: AMGH; 2011.
- *Manual de Cuidados Paliativos*. (Manual of Palliative Care.) Rio de Janeiro: Diagraphic; 2009.
- Santos FS. *Cuidados Paliativos: discutindo a vida, a morte e o morrer*. (Palliative Care: discussing life, death and dying.) São Paulo: Atheneu; 2009.
- Ferrel BR, Coyle N. Textbook of Palliative Nursing. 2ª ed. New York: Oxford University Press; 2006.
- Pimenta CAM, Mota DDCF, Cruz DALM. *Dor e cuidados paliativos: enfermagem, medicina e psicologia*. (Pain and palliative care: nursing, medicine and psychology.) Barueri, SP: Manole; 2006.

- Alvarenga RE. *Cuidados paliativos domiciliares: percepções do paciente oncológico e de seu cuidador*. (Home Palliative Care: perceptions of cancer patients and their caregivers.) Porto Alegre: Moriá; 2005.
- Macmillan K, Peden J, Hopkinson J, Hycha D. A Caregiver's Guide: a handbook about end-of-life care. Otawa: The Military and Hospitaller Order of St. Lazarus of Jerusalem e The Canadian Hospice Palliative Care Association; 2004.

Data collection was carried out from interested reading from the textbooks toevaluate "what we enjoy and what we can dismiss, overlook or put aside"[10:17]. Excerpts from the books that formed the *corpus* of analysis are identified in italics in the body of the Article, in the section on results and discussion. Since this is a study of post-structuralist referential, this selection is considered a hypothesis reading of the authors. Thus, other readings may be made, depending on those who read them.

We chose to read textbooks, understanding them as devices that produce identities and convey discourses taken as true. Therefore, we support in the referential of Michel Foucault, which stands out by thinking of another way processes that are often naturalized, enabling other ways of thinking. Thus, we use their understanding about discourse, power and government. Foucault conceived his books as a toolbox, in which the readers could go in search for what they needed to think and act. In order to approach the intention of Foucault, "it is useful to be willing to question the firmly established social order, to give up all the petrified truths"[11:07].

In relation to the ethical issues we highlight that the publications used for textual analysis are public in nature, being that this research is part of the project entitled "Implementation of the Core of Palliative Care in a teaching public hospital", approved by the research ethics committee at the Hospital de Clinicas de Porto Alegre, under the number 09-320 in October 2009.

RESULTS AND DISCUSSION

Along the reading, we were realizing the texts about Palliative Care as powerful artifacts of the media, which are circular discourses that propagate by professional and academic means. Thus, the texts direct behaviors, teach ways of being and acting, producing subjectivities and defining roles for professional and patients.

The books suggest that religious beliefs are associated with better health - both physical and mental - and quality of life, noting that religious people have less depression. Asserting that being supported in faith in God and in support of the religious community leads the individual to experience greater well-being, sense of belonging, having dignity and peace, as well as the certainty of which will be monitored until the end of their days. It also highlight the fact that knowing that your family will continue receiving spiritual support, helping the sick person and their families to have peace, finding comfort and strength to deal with this situation[12,13,14].

One of the books reports that:

> *Religious beliefs are associated with better health and quality of life. Scientific Studies have identified a contrary relationship between depression and religiosity. These studies claim that having a religion and/or belong to a religious group improves the social support, physical health, reducing expenses related to the illness*[12:239].

The books also reported that many individuals have in religion to help to understand the suffering, the meaning and the uncertainty of their life. Spiritual well-being is associated with lower rates of depression, despair, suicidal ideation, desire to premature death and hopelessness in terminal patients[12,13].

In addition, "it seems that positive spiritual and religious involvement is associated to a longer and healthier life and to a more effective immune system"[14:270]. Studies show that the "negative religious stress can worsen the health status"[14:270] and some scholars put the attention to spiritual aspects in Palliative Care as "greater indicator of good patient care at the end of life"[14:270].

Thus, we can understand the government of the individuals through religion and spirituality. Government is a way of conducting behaviors - of others and of oneself -and governing involves offering reasons by which the governed subjects should do what is said to them[11]. Moreover this is noticeable in the books analyzed, when they say that those who have religion/spirituality will have a life with better quality and less physical and mental problems.

At the end of the 18th century, the idea arose that the State should take care of the population's health. This policy of the modern State is called by Foucault, biopolitics. The health, longevity and the physical well-being of the population in general are to be one of the objectives of the political power. This technology of power, the biopolitics, will deploy mechanisms of forecasts, statistical estimates and global measures, intervening in general phenomena, i.e. arising demographic estimates, calculation of rates and comparisons. The result is the growing State intervention in the lives of people in the most diverse aspects[15]. Biopoliticsis not centered in the body, but in life, it is a technology that brings together the effects of earths own population, which seeks to control a series of fortuitous events that can occur in an earth alive; a technology that seeks to control (and possibly modify) the likelihood of such events in the entire case, compensating their effects[15:297].

The texts make use of mathematical language to highlight the relevance of information, reporting that:

> *95% of Americans believe in some higher power and 93% would like their physicians sensitively addressed these issues if falling seriously ill. [...] Among the elderly, almost all believe in God and 95% consider religion important. Studies with hospitalized patients demonstrate that 77% would like their spiritual values were considered by their physicians and 48%, whereas their doctors praying with*

> *them. Paradoxically, the greater part of the patients said that their doctors never addressed the subject*[12:309].

The statistic is a scientific knowledge essential to good government, because through quantification can probe and sorting people's lives, reaching those who need intervention. The excerpt also makes a comparison to reporting that 77% of the patients would like their spiritual values were considered by their physicians, but that most of the patients stated that their doctors never addressed the subject.

Thus, there is the comparison of information to identify the priorities and needs of these patients. The comparison is a technique linked to statistical knowledge as technology to govern, already that to lead, regulate and normalize a population, there is need to produce records on it, which would allow monitoring and evaluating interventions. Through the quantification of their characteristics you can extractknowledge so as to becoming a governable population[16].

Biopolitics focuses on healthy living and invests in people. Thus, religiosity and spirituality are useful in so far as they influence the way of being and acting, which is also emphasized by another author, when he says that the spirituality and religiosity are associated with better quality of life, more longevity and less physical and mental disease, because these "associations can be explained by lower consumption of alcohol, tobacco and red meat, greater social support and practice exercises that are influenced by religious-spiritual guidelines"[14:375].

Therefor, religion and spirituality are biopolitical strategies, that while govern behaviors serve as a tool to improve the health of the population, therefore, strategic, utilitarian and productive.

The books also make use of scientific bases and research to convince readers to say that:

> *"... Thousands of articles have been published in medical journals of all the areas of medicine, showing, in their majority, a positive association between spiritual practices and health, whether it be physical, mental*[14:374].

In addition, there are physiological and scientific explanations to clarify the relationship of spirituality and religiosity with a better quality of life. A certain book states that the association between spirituality/religiosity and health can be understood by various biobehavioral paths and

> *the hypothesis today most widely accepted by the scientific community is that the spiritualityact, through of neurotransmitters, in three systems: cardiovascular, endocrine and immune systems. Through the sympathetic and parasympathetic nervous systems, the practice of spirituality would act by decreasing the heart rate and blood pressure, would favor the reduction of cortisol production, better surveillance and function of defense cells*[14:375].

Note that here the approach of physiological issues related to spirituality to reinforce the idea that whoever possesses spirituality/religiosity has a life with more health and quality of life. Furthermore, one can realize that the authors of these speeches are individuals considered important people in the scientific, bearers of knowledge on the subject.

For Foucault[17] what the subject who is in the position of power says becomes a reliable knowledge, noting that there are individuals who are allowed to talk about certain subjects, the so-called "experts". Moreover, it becomes clear that the religious discourse associates with the discourse of health professionals, forming a network of which it is difficult to escape. The texts produce truths that subjectify and govern us, in order to be and act a certain way.

The books suggest the importance given to the religious beliefs stating that they influence the decisions of patients about their treatment, as well as

> *diet, cooperation with the medical treatment, chemotherapy or radiotherapy, accept blood transfusion, vaccination of children, pre-natal care, take antibiotics and medicines, change of life style, accepting the referral to a psychologist or psychiatrist, as well as return to medical consultation*[14:378].

It is perceived that the authors suggest reasons for approaching the spirituality/religiousness, justifying the relevance of these in treatment of patients. The discourses are in power their conditions of existence, where such statements are articulated by people taken as knowledgeable and produce effects of truth about the approach of religion/spirituality with patients.

The books reported that the professional should reap a spiritual history of the patient before you begin to support it in their spiritual needs; they reported that the spiritual and religious issues of patients should be addressed at the beginning of follow-up, to ensure that appropriate measures are taken in order to resolve issues both the patient's and their family. Refer to the "health professionals should reap a spiritual history of all patients with serious diseases, chronic and when the loss of loved ones"[14:378]. Still claim that, during the anamnesis religious/spiritual must be addressed "possible conflicts with the Creator, religious, family, pending issues with relation to rites, sacraments, obligations and promises, loss of meaning greater existence"[12:311].

The books emphasize the spiritual history, as must be addressed and in what moments must be made, such as:

> *During the anamnesis of a new patient; for patients with chronic diseases and severe, as well as when there is death and mourning is present; when the patient is at the hospital by a new problem or exacerbation of a condition former; at admission in a rest home or institution of long permanence; during a check-up for maintenance of*

health; when medical decisions need to be made and can affect the patient's religious/spiritual beliefs[14:381].

Thus, presenting items for which the team must be attentive. Through this, we intend to know the maximum possible, so that the patient can govern them.

The books relate several methods for the patient's spiritual assessment. Wenoticed, as well, the importance that is given to these instruments, because through them we will be able to know how to govern the patient, since in order to govern is necessary to know the people with whom you are dealing. This scientific gaze cast upon the subject aims to scrutinize and categorize their characteristics and behaviors to make them amenable to government action, being thus constituted as a governable population[18]. We offer the following three examples of instruments reported in books that suggest an initial approach to the assessment.

The instrument called FICA is presented as capable of assessing the areas of,faith, importance, community and approach. To address such issues the following questions are proposed:

Do You consider yourself a religious or spiritualized person? Do you have a faith? If not, what gives meaning to your life? Is faith is important in your life? How important? Are you part of a church or spiritual community? As we (team),we can address and include this issue in your care[1:52.12:310,13:584,14:273]*?*

Other books describe the instrument SPIRIT that corresponds to the respective areas: spiritual belief system, personal spirituality within spiritual community integration, ritualized practices and restrictions, implications for medical care and terminal events planning. Within these areas are addressed the following issues:

What is your religion? Describe the beliefs and practices of you religion or spiritual system that you accept or not. Do You belong to any church, temple or other form of spiritual community? What is the importance you give to this? What are the specific practices of your religion or spiritual community (example: meditation or praying)? What are the meanings and restrictions of these practices? Which ofthese aspects spiritual-religious you would like that I'd be aware of? In planning the end of your life, how does your faith interfere in your decisions[12:310,13:584,14:273]*?*

Finally, we present the instrument HOPE that corresponds to the following domains: source of hope, organized religion, personal spirituality or kirem practices and effects on medical care and/or end-of-life issues, being made the following questions to assess these areas:

What or who is it that gives you hope? Are you are part of a group of faith? What does this group do for you as a person? What personal spiritual practices, such as prayer or meditation, help you? Do you have beliefs that may affect how the team of caregivers' health cares for you[13:585]*?*

The instruments reported in publications serve to guide patient care, according to their authors. However, all have virtually practice the same approach. In general, they guide that professionals ask the patients if they have faith or spirituality, which their religious practices/spiritual and how the faith/religion influence the way of facing the end of life. Namely, it is assumed that are equal and have the same needs.

An instrument seeks to normalize the patients and professionals and represents them in a particular way. These instruments are intended to normalize bodies and attitudes, producing modes of thinking and acting that does not allow us to think about life/death outside of faith, religiosity and spirituality. Moreover, they introduce a system of truths that produces a certain type of professional and patient.

A certain book reports, also, that if the patient is not religious you can address the existential meaning through the following items:

How is the patient dealing with the disease? What is the meaning or purpose in the current disease situation? Who or what cultural beliefs are used and that can influence the treatment? What are the social resources available to support you at home or in hospital[14:380]*?*

The books show various methods for religious/spiritual approach, using provided tools for easy storing and application, general approaches, simplified assessments until the self-assessment of the patient. Also for those who have no religion/spirituality, there are questions that need to be made, because the subject must be addressed. Everyone must be included, even if they have different conditions, ie, no one can stay out of power networks[18].

Bring terminal patients to a Palliative Care unit has made it possible to know individuals who before were far apart, segregated and, often, excluded from social life. To include these individuals they become observable, explained and controllable. Such inclusion, in addition to bringing the subjects, develops knowledge about this population to know where intervene in order to govern them[18].

A certain book cites that "nurses are in the front line position, in the coordination role, have intimacy with the concerns of patients, and has a holistic view of care"[13:582]. Thus, the nurses "are the ideal professional to carry out the spiritual assessment"[13:582]. Another book says that we should not make assumptions about the beliefs and habits, and that if we are not aware, we must ask. It indicates some suggestions for communication, such as:

Is There any ritual or custom of his family that I need to know? Your mother has a rosary. Is she Catholic? Does she want to receive the Sacrament of the Sick? I noticed

> *that you are with a Bible. Do you want our chaplain to say a prayer*[1:137]*?*

In This way, they are taught strategies to scrutinize details of the personal lives of patients that would help to better care for them.

The books remind us that health professionals should be trained to accept the different religious and spiritual values. The professional's values may not be imposed on patients. They must respect and encourage the participation of the patient and their family members in their own spirituality[12]. In addition, they claim that in these conversations the key is knowing how to listen and observe the patient's values and the possible differences religious or spiritual that exist between the healthcare professional and the patient[14]. Therefore, we can also understand the government on the healthcare professionals, who must behave in a certain way.

The texts also mention that the spiritual care requires the evaluation and monitoring of various aspects of the life of the patient and his family, and may include review of life, meanings, guilt, forgiveness, fears, and beliefs in life after death. This care

> *Appreciates the uniqueness of each individual. Recognize and respect the beliefs, values, practices and rituals of each one, being totally open to reformulation, revelation and experimentation. It deals with the issues of the end of life in a manner consistent with the cultural and religious values and spiritual of the terminally ill. Patients and their family members are encouraged to display their spiritual and religious symbols and should be able to practice their own spiritual and religious rituals in an atmosphere of acceptance. The use of religious symbols per employee and the institutions must be sensitive to cultural and religious diversity*[1:230].

The books analyzed reported, also, the importance of performing a proper spiritual assessment in the patient, because

> *[...] identify needs spiritual can enhance the patient's ability to cope better with the disease, to improve the patient-professional relationship, strengthen the membership and belief in the treatment, increasing the support and monitoring in the community; therefore, improving the increasing satisfaction with the care and accelerating the recovery of disease*[14:382]

In addition, "the spiritual suffering can externalize or increase the intensity of physical symptoms. It happens when the individual is confronted with the challenges that threaten their beliefs, their meanings or purposes"[1:230].

The analyzed texts reveal how the control and government of individuals occurs. First we must know them, i.e., we must search them out them and remove knowledges for that in this way we can govern them and cares for them in the best way possible. Note that it is a thread of discourses, which support and end up producing the same truths with which we subjectified, causing us to think and behave in a certain way and not another.

FINAL CONSIDERATIONS

The textbooks on Palliative Care put the religiosity and spirituality in order of discourse about the care the person at the end of life, by constructing a network of knowledge about the theme that represents patients and professionals. In this study we aimed put under suspicion of such discourses that we are experiencing, i.e. those truths that are circulating about the spirituality and religiosity of people at end of life. We try to show that such discourses, accepted as natural, resulting from a trauma that proposes to educate patients and nursing professionals. By analyzing the discursive truths, that network tried denature these discourses, launching a different perspective on this subject at the same time old and new.

The books disclose that patients are at the end of life should be questioned about how they felt at the time, and nurses are encouraged to find ways to help them at this stage. Healthcare professionals should be prepared for this activity and must perform it, even if only to provide an initial approach afterwards forwarding them to a specialized person. Thus, the books claim that professionals should collect the spiritual history of the patient at the beginning of monitoring. For this, we show how this approach should be, at which point it should be done, items that staff should be alert and report instruments to perform spiritual assessment.

We highlight the association of religious discourse with the discourse of health professionals, because, according to the texts, the patient who has religion/spirituality has a life with fewer problems related to health and, therefore, with better quality. The texts produce truths through countless tricks, such as statistics, research outcomes and repetitions. We report a series of assessment tools that scrutinize spiritual life of patients in order to govern it Thus; there is the government of the subject through the devices of religion and spirituality in order to drive their behaviors and influence their way of being and acting.

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ERRATUM

The article "**Spirituality and religiosity in palliative care: learning to govern**", DOI: 10.5935/1414-8145.20140020, published in the periodical Escola Anna Nery, 18(1) 2014, pages 136-142, was inserted in page 142 the following note of end:

"the article Spirituality and religiosity in palliative care: learning to govern is one of the categories of the end-of-graduation course paper with the title of Palliative Cares: an analysis of the discourses on religiosity and spirituality, presented to the Escola de Enfermagem of Universidade Federal do Rio Grande do Sul, in the year of 2012, authored by Aline Fantin Cervelin, under the advisor of Maria Henriqueta Luce Kruse".