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The meaning of spirituality in the transience of life

O sentido da espiritualidade na transitoriedade da vida El sentido de la espiritualidad en la fugacidad de la vida

ABSTRACT

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1. Universidade Federal de Pelotas. Pelotas, RS, Brazil. Objective: This study aimed to comprehend the meaning of the spirituality for integral care to people receiving palliative care. Methods: Qualitative methodology based on the theoretical framework of Viktor Frankl. Participants were nine people receiving palliative care at home. Data were collected through observation and interviews conducted from June to October 2014, recorded, transcribed and converted to text that was interpreted with phenomenological hermeneutic approach. **Results:** The following categories emerged: sense of continuity of life; sense of relief of suffering; sense of naturalness of death, and sense of valorization of life. **Conclusion:** For integral care it is necessary to include spirituality in the practice of health care. The study led to the confirmation of the hypothesis that spirituality provides the existential encounter between the person in palliative care and the professionals that provide integral care.

Keywords: Spirituality; Palliative care; Terminal patient; Nursing; Integrality in Health.

RESUMO

Objetivo: Compreender o sentido da espiritualidade para a pessoa em cuidados paliativos. Métodos: Abordagem qualitativa, fundamentada na fenomenologia existencialista e referencial de Viktor Frankl. Os participantes foram nove pessoas em cuidados paliativos atendidas no domicílio. Informações coletadas por meio da observação e de entrevista realizadas no período de junho a outubro de 2014, gravadas, transcritas e transformadas em texto interpretado com a abordagem fenomenológica hermenêutica. **Resultados:** Surgiram as seguintes categorias: sentido de continuidade da vida; sentido de alívio do sofrimento; sentido de naturalidade da morte e sentido de valorização do viver. **Conclusão:** Para a integralidade da atenção faz-se necessário a inclusão da espiritualidade na prática do cuidado em saúde. A espiritualidade proporciona o encontro existencial entre a pessoa em cuidados paliativos e os profissionais que a cuidam em sua integralidade.

Palavras-chave: Espiritualidade; Cuidados paliativos; Paciente terminal; Enfermagem; Integralidade em saúde.

RESUMEN

Objetivo: Comprender el sentido de la espiritualidad para la persona en cuidados paliativos. Métodos: Estudio con abordaje cualitativo, fundamentado en la fenomenología existencialista y referencial de Viktor Frankl. Participaron nueve personas en cuidados paliativos atendidas en domicilio. Informaciones colectadas a través de la observación y de entrevistas realizadas entre junio y octubre de 2014, grabadas, transcritas y transformadas en texto interpretado con abordaje fenomenológica hermenéutica. **Resultados:** Emergieron las siguientes categorías: sentido de continuidad de la vida; sensación de alivio del sufrimiento; sentido de naturalidad de la muerte y un sentido de apreciación de la vida. **Conclusión:** Para obtener la integralidad de la atención, se necesita la inclusión de la espiritualidad en la práctica asistencial. La espiritualidad proporciona el encuentro existencial entre la persona en cuidados paliativos y los profesionales que la atienden en su totalidad.

Palabras clave: Espiritualidad; Atención paliativa; Enfermo terminal; Enfermería; Integralidad en Salud.

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Submitted on 08/21/2016. Accepted on 12/06/2016.

DOI: 10.5935/1414-8145.20170012

INTRODUCTION

In the health field, conceptual changes have been observed, which are understood as advances that come from the expansion of the health concept through the establishment of new guidelines proposed by the World Health Organization (WHO). Health ceased to be the absence of disease and became physical, psychological, social and spiritual well-being.¹

Combined with these theoretical changes, also comes the awakening of the human being to the values related to spirituality. Studies have frequently demonstrated that spiritual beliefs influence coping with diseases. With the spiritual needs of patients being increasingly difficult to ignore, it is reiterated that health professionals must obtain and document the spiritual history of all patients with chronic, disabling or serious illnesses, as they do with the physical and psychological aspects.²

It is known that the spiritual needs of people with diseases that threaten life are often not considered by health professionals, due to their lack of preparation. In an Australian study, nurses were mentioned as the closest professionals to meet such needs when, for some reason, are not met by spiritual assistants.³

It should be noted that palliative care provided by the health team consists of a set of multiprofessional actions and attitudes that aim to control the body, mind, spirit and social symptoms afflicting people who are in the process of death. It is necessary that this multidisciplinary team is able to meet their needs in a comprehensive and humane way, articulating and promoting actions to ensure dignified survival and adequate control of the physical, psychological and spiritual symptoms, as recommended by the palliative philosophy, understanding these people and their families in their subjectivity and complexity, who still have much to do.⁴

The *Hospice and Palliative Nurses Association* directs the attention of professionals to the importance of recognizing and supporting people at the end of their lives and their family in their spiritual beliefs and expressions. This support involves a multidisciplinary team and requires an assessment of the spiritual issues of concern to the ill person and his/her family. It is emphasized that spiritual care requires an effective and affective presence from the professional and a willingness to be fully present.⁵

After the incessant reading of authors who write on the subject in Brazil and worldwide, the light to understand spirituality through the search for meaning was found in the works of Viktor Frankl. According to this author, spirituality is inherent in the human species; however, many times this meaning needs to be recovered, and the proximity to threatening situations serves as a stimulus for this search.

This study, which originates from a doctoral thesis, argues that spirituality provides the existential meeting for the person in palliative care. For this, the following objective was elaborated: to comprehend the meaning of spirituality for the person receiving palliative care.

METHODS

This was a qualitative, phenomenological type study, based on the theoretical framework of Viktor Frankl. This is inspired by principles of phenomenology and existentialism, philosophical aspects that strengthened this paradigm as part of the practice of research in the humanities and social sciences. It is due to the nature of the study object that this methodological option is required, considering the comprehension of the meaning of spirituality for the integrality of the care to the person undergoing palliative care, from the framework of Viktor Frankl.

The present study was carried out in the city of Pelotas, in the south of Rio Grande do Sul state, in the Interdisciplinary Oncological Home Care Program (PIDI) run by the Teaching Hospital of the Federal University. This program consists of two interdisciplinary teams that provide palliative care for patients. Implemented in April 2005 in the municipality of Pelotas with one team and extended in 2011 with the two teams, this program added to the care for patients linked to oncology services in the municipality of Pelotas, composing the integral care cycle, from the diagnosis, treatment and cure to palliative care.

Participants of this study included nine people in the PIDI who were receiving palliative care, due to having advanced stage cancer. The inclusion criteria were that participants: be in the PIDI, be aged 18 years or over, and have clinical conditions to respond to the study instrument. The exclusion criteria were: being under 18 or not having the physical condition to participate (very debilitated patients).

In the performance of the study, prior contact was made with eleven people in palliative care, through the monitoring of the team in the home visits, at which time the researcher introduced herself, explained the purpose of the study and invited the subject to participate. After the approach, two of the people said that they did not want to talk about their experiences on the proposed theme. Nine accepted, and then interviews in their homes were scheduled. They were guided by a question of approach and two guiding questions. All information was recorded and transcribed. Data collection took place from June to October 2014. The instruments used were observation, field diary and interview. Thus, the researcher withdrew gradually from the study field, after noting that the data collected presented depth regarding the objectives and theme of the study.

To operationalize this information, the three steps in the hermeneutics of Paul Ricoeu were followed for the analysis and interpretation of the discourse: initial reading of the text (preparation of text - passing the oral text/interview into written text/transcript), critical reading (interpretation of the text) and appropriation (understanding/manifest sensitivity).⁶ Thus, the preparation of the text was started, with the written production from the descriptions of the information collected through interviews with the people receiving palliative care. In the first contact with the text the researcher sought the sense of the experiences of the participants so that this could be existentially comprehended. The next step was the interpretation of the text in order to establish units of meaning, joining units of sense put in evidence. The units of meaning were put into phrases that were related to each other, indicating distinguishable moments in the totality of the text of the description and finally the comprehension, also called manifest sensitivity, was considered in the last stage of the hermeneutics. The emergence of something that was previously unknown occurred through the synthesis of the meanings expressed by the participants, seeking relevant constituents indicated in the description of the experience. Considering what was said and also what was not said during the discourse, the categories were elaborated to comprehend the meaning of spirituality for the people receiving palliative care.

The ethical principles for Research with Human Subjects were followed at all times of the study, as required by Resolution No. 466 of 12 December 2012 of the National Health Council,⁷ Ministry of Health, as well as the nursing professional code of ethics.⁸ All the participants were guaranteed anonymity and are identified by the letters CP followed by numbers according to the order of data collection. The study was approved by the Research Ethics Committee of the Faculty of Medicine of the Federal University of Pelotas under authorization number 668.915.

RESULTS AND DISCUSSION

The study included nine people, six males, aged between 44 and 72 years, and three females, aged between 36 and 68 years. Of these, three were retired and the others were on sick leave. Regarding religion, one reported being Spiritualist, two Evangelical and four Catholic, while two declared no religion.

Sense of continuity of life

For people who are receiving palliative care, spirituality gives a sense of continuity when they express that life does not end with the death of the body, including pointing out that with the physical weakening they feel the strengthening of the spirit and envisage death as a passage to another place.

> [...] as there is incarnation, nothing changes, it continues (...) life never ends. We are not the body, we are infinite, the flesh is a tool to bring us here on earth (CP1).

> [...] what dies is our body, we are flesh here, but what God wants from us is the spirit. With the disease the body is weakening and the spirit strengthening [...] (CP5).

For Frankl the person transcends him/herself both in the direction of the other human being, as well as in search of meaning. From the perspective of the people receiving palliative care only physical death occurs, considering that life continues. As there is something beyond human life, it is understood that there is a relationship with the instinct of preservation of the human being that prevents them from believing that there is an end of everything.⁹

Seeking meaning for death in spirituality is common to the great diversity of religions that exist in the country. All religions preach the continuity of life: for Christians death takes the soul or

spirit to another dimension or, to be with God; while the spiritual doctrine of Buddhism, Hinduism and Taoism considers the possibility of reincarnation, that is, the spirit returns to earth with the birth of a new being. Regardless of religion, this is a way to give meaning to death, seeing it then as a continuation of life in another dimension.¹⁰

However, it is emphasized that in this study religiosity and spirituality are different concepts. The first is related to the beliefs and tenets of a particular religion, while the second is broader and is related to the existential process, the search for meaning to life and for transcendence.

The continuity of life is also understood by Frankl when he says that the spiritual dimension remains intact despite the illness, with the subject remaining free to choose how you will experience your illness, either in the psychic or organic dimension. Even though it is blocked, the spiritual faculty continues, potentially, even though it may not have constant expression through the other dimensions of the being. This is not only an ontological clarification, but also a matter of great therapeutic relevance, considering that the role of the professional is to mobilize the spiritual existence, with this being the only one that will remain after the physical and psychic death.¹¹

Sense of alleviating the suffering

Frankl believes that a person, even on the verge of death, can find a positive meaning for the suffering resulting from this situation. This is characterized by finding an aim or explanation for the situation and may refer to the work activity, life projects, experiences and positive attitudes faced with this existential reality, preventing the suffering from being destructive because, according to the author, it is not the suffering itself that destroys the person, but suffering without meaning.¹²

Through spirituality, meaning is assigned to the suffering, alleviating it. When considering faith, prayer and meditation as supports for coping, even an improvement in symptoms can be perceived and it is observed that with the disease the faith is intensified. This fact can be identified in the reports of the interviewees.

[...] those seeking spirituality improve a lot, really improve, because I improved [...] (CP3).

[...] I have more faith, it helps me a lot, after a prayer I feel relieved, more relaxed, I do not get depressed when I pray, I get better [...] (CP4).

[...] when I discovered the disease it was my religion and my faith that strengthened me more [...] (CP5).

[...] for me, my faith is very important because it helps me improve. I had faith before, but after I got sick my hope increased [...] (CP9).

The suffering of the person is an important component in healthcare and with the increase of chronic diseases in the world, suffering was included as a focus of the International Classification for Nursing Practice (CIPE), making it relevant to analyze the perception of the cancer patient in palliative situation regarding this meaning.¹³ From the perspective of the participants, spirituality promotes support through faith, prayer, trust in something greater than themselves, giving them strength to cope and giving meaning to life.

In situations of extreme inevitable suffering, the person hopes for support for the inability to rationally comprehend that life has an unconditional meaning, regardless of the circumstances. This unconditional meaning is called supermeaning. It is only grasped through faith, trust and love.¹⁴ That is, the super-meaning cannot be understood by reasoning that answers the question of "why?" (why did the terminal illness, the natural disaster, the unexpected situation happen?) but by the potential meaning of life, which is unconditional and can only be found through faith.¹⁵

Sense of naturalness of death

It is understood that the uniqueness of the human being makes the process of dying an individual occurrence that can be experienced in different ways by each person, depending on the social, historical and cultural environment in which they are included. However, non-acceptance of this process as part of the life cycle is related to the fear of the unknown and lack of meaning. It is important that the processes of dying and death are addressed as sublime moments, endowed with spiritual elevation, expression of feelings, acts of courage and solidarity with the other.¹⁶

From the Frankliana perspective, the meaning refers to the whole life of a person, as well as the present moment. It also relates to an ultimate, broader meaning, which the author refers to as the meaning of the totality of the life of everyone. This can be exemplified by the following metaphor: a film is made with thousands of photos, each one has a meaning, however, the meaning of the whole film will be understandable only at the end of the display. Therefore, the meaning of a person's life as a whole can only be comprehended at the end of this life, or after its closure.¹⁵

It is known that the great facilitator of this process is the work of an interdisciplinary palliative care team with an effective and affective bond between its members and the patients and their families who are experiencing the death process.

The presence of the diagnosis of a disease that threatens life, especially when this is cancer, inevitably leads the person to think about death. With this, a lot of expectations about this process arise; however, it is clear that with the evolution of the disease and with the care and management of the symptoms resulting from this expectation, it is common for these people to understand the naturalness of death.

This sense of naturalness of death is mentioned by the participants who see it as a turning of the page or a sleep, a feeling that is intensified with the disease. They realize that it is inevitable for all living beings, however, it is calmly seen as a process that is part of life. [...] I was never afraid of death, after I had knowledge, through reading and contacts with other dimensions when I closed my eyes to sleep, it confirmed what I thought, death to me is the turning of a page as if I lay my head on the pillow and sleep [...] (CP1).

[...] when I was not sick I thought death was a heavy thing, different, then when I became sick that fear that I had before I did not have anymore [...] (CP4).

[...] I never was and I am not afraid to die, I know that one day I will have to go, we have to leave it in the hands of God, I do not want to be suffering or for those who are by my side to suffer. I'm not afraid, I'm calm [...] (CP5).

[...] I'm not afraid of anything. I talk to my wife, talk to her, she is sometimes angry with me because I want to talk about it, and I say, we have to think of the past and the future. You have to know that I can die from one day to the other, we have to leave everything ready [...] (CP7).

In the statement of CP5, death means relief from suffering for both him and his family, and he still attributes his tranquility facing this moment to the trust he placed in God.

It was observed that trust in God is the conductor of this tranquility that leads these people to not feel afraid of death, and even allows the issue to be addressed by the patients with their families, allowing certain preparations for this moment, as expressed by one participant when he mentioned the need to "leave everything ready". This preparation can also be understood as a way to find spiritual comfort, because the people know that those who they have affection for, or are their dependents, will be protected. In this sense, diseases such as cancer allow this planning, as things do not happen acutely, abruptly, and this brings some form of comfort.

In this study, it is considered that God is a supreme force that never lets the person down that seeks this through the exercise of transcendence, which is characterized by the uniquely human ability to seek something outside of oneself. This occurs through the relationship with God through prayer, petition, or simply a conversation. Frankl defines God as "the partner of our most intimate conversations with ourselves". For the author, when we are totally alone with ourselves, when we are dialoguing with ourselves in the final solitude and honesty, it is legitimate to name the partner of these soliloquies as God, whether we consider ourselves atheists or believers in God.¹⁵

From the concept of Frankl, regardless of the length of existence, it has a meaning, and the person starts to seek it when faced with the transience of his life.¹⁷ Death and dying would not be something that would deprive life of meaning, as the transitory nature of life is what drives the human being to seek a way to perform a certain task. In other words, the finitude gives meaning to life, awakening in humans the sense of responsibility, because death makes life unique and impossible to reverse.¹¹

Sense of valorization of life

The valorization of life is common with the proximity of death. It can be observed that every day of life becomes precious when the person is facing imminent death, every moment now has another dimension: some cling to the fact that they do not want to leave their children, others refer to appreciating the simple fact of waking up, the possibility of staying alive for one more day, enabling the performance of everyday actions.

The possibility of death in this aspect is the main driver of specifically human acts, like love. Furthermore, linking the human existence to life, especially to the experiential values, therefore, valorizes the existence.¹⁸ Frankl found that the transience of life should be an incentive to carry out responsible actions in the human existence.¹¹

Thus, the sense of valorization for the time of life that remains, demonstrating gratitude for each day more, hoping to stay longer, showing, however, trust and surrender to God should be highlighted.

[...] I give thanks for the day, it is difficult, if you think about material goods, we managed to get almost everything, but there are the children and my wife that will be left behind [...] (CP4).

[...] when the day dawns I thank God because I woke up, that I'm here [...] (CP5).

[...] I just have to give thanks for everything I went through and I have had, I am grateful every day for being alive, for having passed through that day, I put my day in God's hands, every morning everything is with God my father [...] (CP6).

In the period of the proximity of death, the time starts to be comprehended with great importance with regard to the existence. Being aware of the imminence of one's finitude, one's physical death, is what gives urgency to organizing the remaining time for closing the life cycle with as few things pending as possible.

The confidence and the possibility of the patient having someone who listens and understands without judgment, and considers all their demands and pains important, and that can give attention to everything that expresses a meaning to their existence, certainly contributes so that, once the demands have been met, the person can accept death with more tranquility. Thus, the people can calmly talk about what they would like done after their departure, in relation to their family and also about what their preferences would be regarding the funeral ceremony. Debating death leads us to value life, even if it is only the few days that still remain.¹⁹

FINAL CONSIDERATIONS

For people who are receiving palliative care, spirituality gives a sense of continuity when they express that life does not end with the death of the body, including pointing out that with the physical weakening they feel the strengthening of the spirit and envisage death as a passage to another place.

Spirituality offers preparation to face death naturally, being therefore important to keep this relationship active with a thought that refers them to spirituality. That is, from the cultivation of this value, it is understood that the terminality of the life is just the physical death of an individual, and that there is something beyond human living.

It is observed that tranquility faced with the end is related to trust in God. The fact that the people do not feel afraid of death, even allows the issue to be tackled with their families, allowing a preparation for this moment, as expressed by one participant when he mentioned the need to "leave everything ready".

The valorization of life is common with the proximity of death. Faith and support promoted by spirituality provide better internal controls against the terminal situations through the sense of God's presence, which is experienced by people receiving palliative care in different ways that are felt through love, strength, faith, tranquility, protection, ability to overcome and surmount obstacles.

The philosophy and practice of palliative care again brings the possibility of humanizing death. The focus of palliative care is on the possibility of offering patients what is called a good death, in which relief of the symptoms, comfort, systematic monitoring by an interdisciplinary team and the continued presence of their families are considered, preferably in their own home.

The results of this study confirm the hypothesis that spirituality provides the existential encounter for the person receiving palliative care, suggesting that this be included in all health scenarios. The contributions of hermeneutic phenomenology for this study are also highlighted, as it enabled the comprehension of the phenomenon investigated, through the interpretation of life, revealing the meaning of spirituality for people undergoing palliative care.

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Arrieira ICO, Thofehrn MB, Milbrath VM, Schwonke CRGB, Cardoso DH, Fripp JC

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