SPIRITUALITY AND RELIGIOSITY AS COPING STRATEGIES FOR ILLNESS AND DEATH

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ABSTRACT

The objective of the study was to understand spirituality and religiosity as coping strategies for illness and death in youth. This was shaped as a situation study, of a comprehensive approach, through the life history operationalized by the in-depth interview and observation. Interviews and observation reports were transcribed and organized into the research diary. For data analysis, the narratives were grouped into different thematic sets that were reiterated with the agglutination of themes in new sets. For this communication, we highlight the theme related to spirituality and religiosity present in the data corpus. Spirituality and religiosity, strongly imbricated in the young woman’s life, appear as important coping strategies for illness and finitude. Therefore, it is important that the nurse considers beliefs, values of each person, and the many senses attributed to the spiritual and religious experiences of each patient. In short, knowing how to deal with what is not palpable becomes crucial when standing next to the other who prepares to leave this life.

Keywords: Cancer. Nursing. Spirituality. Youth. Death.

INTRODUCTION

Spirituality covers the area of personal beliefs in a relationship with a superior being, which, in turn, has a significant influence on decisions, actions, personality and even the health of a person. Religiosity configures itself as a kind of ritualistic orientation that directs spiritual beliefs and can also be of great importance for improving health.(1)

Health concept occurs beyond the physical, psychological and social well-being, also including the spiritual well-being. In this perspective, the religious faith has been shown as a positive stimulus in coping with terminal diseases, by its potential in giving direction to the process of death and dying(2).

Spirituality, either isolated or connected to religion, has a significant influence on the life of a sick person and of those with whom they share this time, especially in front of the real possibility of death. Spirituality allows the person to give new meaning to illness, pain, suffering and death itself, opening an infinite horizon of meanings, which contributes to better cope with adverse situations in such delicate moments.(3)

In relation to the care, nursing is a profession that requires great proximity between people and this contact requires from the professional capacity and sensitivity to deal with all the human dimensions, such as biological, mental, emotional and spiritual. Thus, regarding the influence of the spiritual dimension over people’s life, the nursing team’s knowledge on about issues related to spirituality and religion becomes extremely important to provide an effective care(4).

Spiritual and religious aspects interact with the illness process, especially in cases of serious illnesses such as cancer. This disease causes changes in all human aspects, especially for placing the sick person in front of the possibility of death(5).

Cancer stands out as a disease whose trajectory is associated to pain, fear, sadness and the possibility of death. Although science has achieved remarkable results in relation to the treatment of the most varied types of malignant tumors, it was not able to undermine the meaning of cancer as devastating.

In this way, cancer generates suffering that goes beyond the physical dimension, because it triggers a breach in the trajectory of the life of those who become ill and those surrounding them, in addition to being a disease capable of mobilizing a wide range of feelings of uncertainty, changing the lives of those who experience it(6). This mobilization occurs especially when the disease installs in the youth phase, a period that generally requires multiple brackets carefully implemented to be able to deal with all the obstacles imposed by this type of illness. When the young person faces a circumstance that
compromises the life, they face feelings of anxiety, fear, unbelief, despair and helplessness. In this scenario, coping strategies are valued, including spirituality, beliefs and faith. These strategies have been shown to be important allies to promote comfort during the most difficult moments of the illness\(^7\). In this way, the following question arises: how can spirituality and religiousness support the process of illness and death of young people with cancer?

We assume that religious and spiritual aspects need to be explored, known and exercised in the healthcare practice and, for this reason, it is necessary to invest in researches that contribute to the improvement of professionals who deal directly with the singularities of illness and death.

Therefore, our objective is to understand spirituality and religiousness as coping strategies for illness and death in the youth.

**METHODOLOGY**

This is a study of comprehensive approach conducted by Study of Situation, which seeks to understand thoroughly the lives of people in their context and the consequences that illness causes\(^8\). This type of study allows the researcher to approach micro-realities and singularities of people, as well as their ways to establish different relations in the course of their lives\(^6\)\(^9\).

We used the following inclusion criteria: a family with a young member (15-19 years) with serious illness; user of the Unified Health System; resident in Mato Grosso. We considered as potential participants, beyond the young member, other family members, if indicated by the young person and/or by the main caregiver - because they are family members involved in the care. The only exclusion criterion was the difficulty of verbal communication.

Taking into account the criteria, we reunited a network composed by professors and post-graduation and graduation students of the nursing course of a public higher education institution of Mato Grosso. With this strategy, we found a family who met the aforementioned criteria and who agreed to participate in the study.

The participating was composed by Star (fictitious name), young woman, 20 years of age, who had been experiencing cancer since 18 years old and was outside the therapeutic possibilities of cure; her mother; her brother and her stepfather. This is the nuclear family configuration of the nuclear family of the young patient, but two maternal aunts and a cousin, also participated in the study, according to methodological criterion.

For data collection, we employed the Life History once it allows understanding how people experience illness, bringing the memory of what meant by the act of recalling the experience\(^8\). Life History was operationalized by in-depth interviews and by observation.

The in-depth interview was conducted as a conversation with intentionality where participants were invited to talk freely about their experience\(^8\). The observation allowed apprehending beyond discourses, valuing the modulations of the voice, body movement, facial expressions that occur in each narrative\(^8\), as well as attention to events and details of the physical space where the interviews occurred.

The fieldwork took place from October to December 2016, totaling six meetings. The meetings occurred in Cuiabá-MT, where the young patient received treatment and in a city 220 km far from Cuiabá, where the family resides.

Since people have their own understandings and experiences about the illness, the first approach with each participant took place differently. Thus, in order to guide the interview without, however, restricting the young patient, we asked her to tell us her history since her first memories. We asked her mother to tell us the trajectory of illness of her daughter and her own trajectory - so that we could know the life context surrounding Star. We asked the other family members to tell us the personal experience of Star’s illness. Specific issues of each previous narrative guided each subsequent interview, giving us the opportunity to deepen, clarify and raise new questions from the narratives lines.

The full transcripts of interviews and the record of the reports of observation were performed after each meeting and organized in the Research Diary\(^8\). The Research Diary resulted in 153 pages typed in Times New Roman font, size 12 and 1.5 spacing between the lines.

The analysis process began after the first meeting, allowing the deepening of relevant points in subsequent interviews, as previously pointed out. The analysis occurred through detailed readings of the data corpus both individually as in the context of the research group, where there were discussions and reflections that allowed questionings and the drafting of synthetizing drawings that facilitated the understanding of the narratives. In this process, the narratives were grouped into different thematic sets which were repeated with the agglutination of themes into new sets\(^1\) in order to
highlight the issues of greatest relevance, valuing all the richness contained in the narratives. The topics spirituality and religiousness emerged strongly in the narratives of the young patient. Thus, we got deeper in Star’s narratives about spirituality and religion present in her life, illness and death certainty trajectory.

This study is linked to the matrix research “Subsidies for Care Modeling of Families in Situations of Vulnerability” approved by the Research Ethics Committee (671/CEP-HUJM/09 CAAE: 39285114.8.0000.5541). In agreement with Resolution 466/2012 of the National Health Council, all ethical principles were observed, including the use of fictitious names and signing of the Informed Consent Form.

RESULTS

Star was born in an inner city of Mato Grosso, 220 km far from Cuiabá, capital of the state. Her birth resulted from an unplanned pregnancy of teenage parents who remained together until she turned nine months of age. After the couple’s separation, her maternal grandmother raised her until she was five, when she returned to the maternal care, once her mother had acquired better conditions of life.

The family, although self-declaring as belonging to the catholic religion, did not have the habit of attending a religious institution. At age 12, after a friend’s insistence, Star began to attend a church of evangelical denomination - Assembleia de Deus (Congregation of God). Her participation in the church intensified at around 14 years of age when she was charmed with the religiosity of an aunt and decided to follow her example.

The way she [the aunt] served God was so beautiful. That touched me so, so, so much, that I said: ‘you know what? I want to be like my aunt!’ (Star).

Then, Star begins to participate actively in the church, getting involved in different activities, such as: care for children during cults, helping in the kitchen and canteen, among others. For her, her greater involvement with the church turned her into a better person since it had promoted significant changes in her life.

My grades were not good. Then, they [the grades] improved, because I joined the church. After joining the church, I learnt to talk in public (Star).

Everything indicates that those responsible for the religious institution, realizing Star’s desire and readiness, began to delegate activities that, within her life context brought a transforming potential that made her feel empowered.

This time, Stars begins to have the perception of contacting and communicating with a superior being called God. This communication occurred through voices that talked to her.

God talks to us in many ways. I feel like it is through our thoughts. I know it is Him because it is very different. It is as if I was here and, suddenly, I hear a voice in me, inside myself, talking to me, as if I was talking to myself. But I know that’s not true, because it’s very different, a different peace (Star).

This did not occur in the context of the religious institution, but at her home, in moments of silence/loneliness when she was alone, showing flashes of a spirituality reached by means of religious beliefs and practices.

Despite believing in religious dogma that admits the ability of communication between a person and a superior being by means of voices, images or even dreams, Star used her reasoning to certify the origin of this communication.

I asked Him to Wake me up three times in the dawn, at the same hour (Star).

Since Star indeed awakened in three consecutive dawns at the predetermined hours, she began to understand the voices as of divine origin, i.e., derived from God. Therefore, she began to believe unconditionally in the content of the voices.

When Star was 17 years old, her mother married and the family moved to the city where her stepfather resided, also located in the countryside of the state of Mato Grosso. Star was welcomed in the church of the new city, giving continuity to the activities already carried out previously.

At age 18, Star took the National High School Examination, whose result provided her the opportunity to being admitted into a higher education course at a public university. However, she decided to postpone her plans due to her mother’s pregnancy.

So, I gave up Enem, college, for one year, to stay with my brother, at least for a moment, because it was my dream (Star).

Star continued living based on religious and spiritual experiences, always seeking answers to her life questions in the voices. At certain moment, God told her, through the voices, that she was sick. Despite feeling healthy, she believed that the disease would manifest itself in a short time. The family, more specifically her mother, was concerned with her daughter’s mental health, mainly because of an excessive concern with the disease issue by means of
hyper-valorization of symptoms.

A few months after her brother’s birth, when she was 19 years old, her family was impacted by the appearance of signs and symptoms that culminated in the diagnosis of cancer - non-Hodgkin Lymphoma. This new situation changed abruptly the plans, dreams and family routines. Nevertheless, Star states remaining quiet regarding the diagnosis of cancer, stating that God gave her peace, preparing her for the confrontations.

Two months before, God told me I had cancer, before the diagnosis. Then I got super calm, that was practically to calm me down (Star).

According to Star, God, through the voices, told her that her illness would occur in two phases. The first one would be quiet and painless; however, the second moment of illness would be a very difficult phase and with many pains.

The first phase of the disease was, in her perception and her family’s, the most calm, despite the aggressive treatment of chemotherapy, she felt prepared to face this moment because she believed to be the lightest moment of illness.

After a brief period of remission, the disease relapse occurred more aggressively, as Acute Lymphocytic Leukemia. Nevertheless, Star continued feeling comforted by God to face this new phase of illness, configured in a very difficult way, mainly by pain, by physical decline and the concrete possibility of death.

The leukemia diagnosis was the most difficult moment for me, as it began to be harder for me. Issues such as limitations, pains and I was often hospitalized (Star).

Thus, there arises the need for a bone marrow transplant as an attempt to contain/control the illness. No family member was compatible to be a donor and there was no compatibility in bone marrow banks available. Furthermore, Star and her family received the information that, if the body continued not responding properly to the treatment, the possibility of cure or even of control would be compromised.

Star continued attending church and receiving her comfort and hospitality. Nonetheless, Star states remaining quiet regarding the diagnosis of cancer, stating that God gave her peace, preparing her for the confrontations.

In the last meeting we had with Star eleven days before her death, we could realize that she was strongly rooted in her religiosity and spirituality and that she had accepted death, saying, with a smile and without apparent revolt:

Waiting for God’s will. If God wants me to stay, amen. If He doesn’t, amen (Star).

Star chose to die in the hospital, next to her mother, stepfather and brother. At the time of death, her mother chose to sedate her, considering the best alternative since her daughter’s suffering intensified in her last moments of life.

DISCUSSION
Personal transformation from active participation in a religious community is evident in some studies(12-13). The religious experience has the potential to develop increased tolerance, improve interpersonal relationships, self-knowledge and empathy, reflecting significant benefits in people’s quality of life(12).

A study(14) conducted in Australia with 65 young people in order to understand the role of the spiritual well-being in strengthening resilience in youth showed that religious institutions allow significant social experiences for young people so that they begin to consider them important communities of belonging. The study concluded that, in the presence of spiritual well-being, young people have less exposure to risk activities(14). Therefore, the involvement with religious institutions may prove to be a milestone in the lives of young people, contributing, in a significant and noticeable way, to their personal training.

In moments of loneliness, silence and deep monologue with one’s own self, the human being naturally assign answers, questions or even solutions found in these moments to a divine being, a phenomenon that is characterized as the existential religare(15). Different religions acknowledge the existence of this phenomenon in which people acquire the perception of hearing voices they attach to a higher being who speaks, guides, shows some ways, answer questions, comforts.

When exercising religiosity, through rites, especially in the establishment of conversations with a higher being through prayer, the person provides a self-experience of existential nature and spiritual depth, as many exemplified by saints, prophets, mystics and martyrs in the course of history(15). It is always difficult to define religiosity and spirituality, because both can become the consolidation of one another: “To rewire the human being in the articulation of their consciousness (soul-his unconsciousness (spiritual) awakens in him the existential dialog of spiritual depth to the discovery of meaning to his life”(15,16).

Spirituality is a universal human phenomenon, but its level of awareness varies, so that some people express it more noticeable than others do(4). However, as already mentioned, there is a fine line between the clear perception of religion and spirituality. Spirituality and religion are often considered synonyms, especially by common sense, which influences some health and education professionals to consider both terms indistinct(16).

The youth is a period marked by a search for identity and personal self-affirmation. Not infrequently, young people seek bonds with cultural and religious organizations, among others, as they seek their self-definition. When facing a chronic disease, many may seek faith or other spiritual connections as a way to face the difficulties of illness(17).

Having to live with the illness from cancer constitutes a milestone in any phase of life, but, regarding youth, some aspects relate to the development needs should be considered. Personal development factors can be significant by the experience of care and treatment of cancer and to the life style of the young person will begin to experience from diagnosis(18).

In the face of numerous conflicts that illness and death proximity bring, there is a strong tendency to use prayers related or not to certain religions to alleviate the anguish that arises in these moments. This habit has gained strength in recent years, being perceived as a way of people to comfort themselves and to be comforted(19).

In our study, Star’s perception validates the prayers made for her by other people, some strangers, as a strategy that helps in coping with the process of death and dying. These prayers somehow were there not as hope for healing, but as consolation so that she could face her own death.

Faith in a higher being can be positive when there is the sense of finitude and the need for transcendence, contributing to a better process of coping and adaptation of the new reality(2). The involvement of young people with the people who are part of their religious environment positively influence on the spiritual well-being, bringing a feeling of peace and contributing to confront the challenges imposed by life(2).

Cancer is a notorious protagonist of many deaths throughout the world. Therefore, cancer, associated with the certainty of death, can lead the sick person and the family members to a state of depression. Nevertheless, there is a relationship between the religious beliefs and better mental health, showing that the religious issue may be a strategy to help in coping with the depression in these delicate moments of life(19).

The human religious side recognizes the existence of a supra-human dimension that cannot be fully understood, but that each person can uniquely experience it, and this transcending aspect helps people to find resilience even when facing big difficulties(19).

When disease evolves to a prognosis whose close futures is death certainty, it influences, in many ways, the faith of the sick person and those next to him/her.
Thus, the faith can be questioned, tested, reaffirmed or even lost. The reports of young Star showed a strong reaffirmation of her faith during the whole process of death and dying. The spirituality and religiosity, so present in her way of being and strongly rooted in her life path, caused a positive impact in the way she began to live her process of death and dying.

Therefore, the nursing needs to consider religious and spiritual aspects, since they can positively contribute to a better development of the treatment, whether palliative, or not, bearing in mind that people are indivisible beings in a way that their dimensions interact, reflecting and giving a new meaning to the way they live their personal experiences. Health professionals’ comprehension of spirituality may contribute considerably for them to be able to attribute sense to are provided in the end of the life, in such a way they allow getting closer to the needs of the person they care for.

CONCLUSION

This study showed that, in the life of the young participant, spirituality and religiousness were important strategies she used to cope with the illness and the certainty of death. Therefore, we can add that this study reinforces the importance that religious and spiritual aspects have on the lives of people in a situation of illness and death; reaffirms the importance of considering spiritual and religious dimensions during the care offered, mainly by the nursing team; and highlights the need for qualifying nursing professionals to a care that goes beyond techniques and protocols.

Taking care considering the subjective dimension of the person is of extreme relevance in a moment when the cure is no longer possible. It is necessary to consider the beliefs, values, and the unique way of feeling/seeing the world and the many attributes each person give to their spiritual and religious experiences. Finally, learning to deal with what is not palpable becomes crucial when standing beside the other who is preparing to leave this life.

The care offered to people in severe illness should provide the best possible welfare, which includes the support to meet and consider the spiritual and religious needs by ensuring that the person is fully welcomed in their process of illness and death. We believe that this study has as limit the fact of having explore a single case, which awakens to the importance of further studies, addressing the topic, especially with young participants.

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RESUMO

O objetivo do estudo foi compreender a espiritualidade e a religiosidade como estratégias de enfrentamento do adoecimento e da morte na juventude. Este moldou-se como estudo de situação, de abordagem compreensiva, por meio da história de vida operacionalizada pela entrevista em profundidade e pela observação. As entrevistas e os relatos de observação foram transcritos e organizados no diário de pesquisa. Para a análise dos dados, as narrativas foram agrupadas em diferentes conjuntos temáticos que foram reiterados com a aglutinação de temas em novos conjuntos. Para essa comunicação, destacamos o tema relacionado à espiritualidade e à religiosidade presentes no corpus de dados. A espiritualidade e a religiosidade, fortemente imbricadas na vida da jovem, surgem como importantes estratégias de enfrentamento do adoecimento e finitude. Reafirma-se assim, a importância de que o profissional enfermeiro considere as crenças, os valores de cada pessoa, e os muitos sentimentos que são atribuídos às experiências espirituais e religiosas de cada enfermo. Enfim, saber lidar com o que não é palpável torna-se crucial no momento em que se coloca ao lado do outro que se prepara para deixar essa vida.

Palavras-chave: Câncer, Enfermagem, Espiritualidade, Jovem, Morte.

LA ESPIRITUALIDAD Y LA RELIGIOSIDAD COMO ESTRATEGIAS DE ENFRENTAMIENTO DEL ENFERMAR Y MORIR

RESUMEN

El objetivo del estudio fue comprender la espiritualidad y la religiosidad como estrategias de enfrentamiento del enfermar y de la muerte en la juventud. Estudio con abordaje comprensivo, realizado por medio de la historia de vida operacionalizada por la entrevista en profundidad y por la observación. Las entrevistas y los relatos de observación fueron transcritos y organizados en el diario de investigación. Para el análisis de los datos, las narraciones fueron agrupadas en diferentes conjuntos temáticos que fueron reiterados con la aglutinación de temas en nuevos conjuntos. Para esta comunicación, señalamos el tema relacionado a la espiritualidad y religiosidad presentes en el corpus de datos. La espiritualidad y religiosidad, fuertemente imbricadas en la vida del joven, surgen como importantes estrategias de enfrentamiento de la enfermedad y finitud. Se reafirma, así, la importancia de que el profesional enfermero considere las creencias, los valores de cada persona, y los sentidos que son atribuidos a las experiencias espirituales y religiosas de
cada enfermo. De todas formas, saber lidiar con lo intangible se vuelve crucial en el momento de ponerse al lado del otro que se prepara para dejar esta vida.

**Palabras clave:** Cáncer, Enfermería, Espiritualidad, Joven, Muerte.

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