

## Spirituality, religion and personal beliefs of adolescents with cancer

*Espiritualidade, religiosidade e crenças pessoais de adolescentes com câncer*

*Espiritualidad, religiosidad y creencias personales de jovenes con cáncer*

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### ABSTRACT

**Objective:** to examine adolescents' perception about spirituality, religion and personal beliefs in their lives due to cancer and a possible strategy for coping with the disease. **Method:** qualitative research, both descriptive and exploratory. The data were collected by means of a personal semi-structured interview, and the categories were analyzed by content analyzes. **Results:** nine adolescents who were undergoing cancer treatment at one of the two institutions located Uberaba, Brazil, participated in the study. Based on the analysis and interpretation of results, it was possible to systematize them according to four categories: spiritual history of the individual; faith and belief; importance of spirituality in their lives, and the community acting as a spiritual supporter. Most adolescents referred to spirituality as being an important tool for dealing with the disease, especially concerning religious rituals and community support. **Conclusion:** spirituality creates hope for adolescents, which helps them to cope with cancer-related difficulties and contribute to the search for the meaning of life.

**Key words:** Adolescent; Cancer; Spirituality.

### RESUMO

**Objetivo:** analisar a concepção dos adolescentes a respeito da espiritualidade, religiosidade e crenças pessoais presentes em suas vidas devido ao câncer e como estratégia de enfrentamento da doença. **Método:** pesquisa qualitativa, do tipo descritiva e exploratória. Os dados foram coletados através de um roteiro de entrevista semi-estruturado, as categorias foram definidas segundo a análise de conteúdo. **Resultados:** participaram nove adolescentes que estavam em tratamento oncológico em duas instituições na cidade de Uberaba, Minas Gerais. Os dados foram sistematizados em quatro categorias: história espiritual do indivíduo; fé e crença; importância da espiritualidade em sua vida; e a comunidade enquanto apoio espiritual. A maioria dos adolescentes referiu a espiritualidade importante no enfrentamento a doença, especialmente a partir de rituais religiosos e apoio da comunidade. **Conclusão:** a espiritualidade gera esperança para os adolescentes, auxiliando no enfrentamento das dificuldades relacionadas ao câncer e na busca pelo sentido da vida.

**Descritores:** Adolescente; Câncer; Espiritualidade.

### RESUMEN

**Objetivo:** examinó la percepción de los adolescentes acerca de la espiritualidad, la religión y las creencias personales en sus vidas por el cáncer y una posible estrategia para hacer frente a la enfermedad. **Método:** se realizó una investigación cualitativa, descriptivo y exploratorio, del guión de la entrevista semi-estructurada sobre la base de las literaturas afines, lo que permitió la definición de categorías, analizadas desde la perspectiva del análisis de contenido. **Resultados:** asistió a nueve jóvenes que fueron sometidos a tratamiento contra el cáncer en las dependencias de ambas instituciones ubicadas en la ciudad de Uberaba, Minas Gerais, Brasil. A partir del análisis fue posible sistematizar de acuerdo a cuatro categorías: historia espiritual de la persona, la fe y las creencias; importancia de la espiritualidad en sus vidas, y la comunidad como apoyo espiritual. La mayoría de los adolescentes informó espiritualidad como acontecimientos actuales e importantes relacionados con la enfermedad, especialmente de los rituales

religiosos y apoyo comunitario. **Conclusión:** la espiritualidad parece emerger como un componente generador de esperanza para los jóvenes, ayudando a hacer frente a las dificultades relacionadas con el cáncer y la búsqueda del sentido de la vida.

**Palabras clave:** Adolescencia; Cáncer; Espiritualidad.

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## INTRODUCTION

Adolescence is a stage of life that, in addition to the normal changes involved, can be even more difficult when it includes life-threatening situations, particularly those involving sickness as, for example, when diagnosed with cancer.

Childhood cancer is associated with a series of stressful experiences and suffering, both for the child and for his/her family<sup>(1)</sup>. Despite not being able to compare the frequency of childhood cancer with the greater number of adult cancer statistics, the incidence of childhood-adolescent cancer has been increasing<sup>(2)</sup>.

Changes in the daily life of adolescents with cancer result mainly from their hospitalization and treatment to which they will be submitted. Chemotherapy and radiotherapy, which are the most commonly observed medical-pharmacological treatment processes, can cause physical, psychosocial and emotional adverse effects that can vary in their symptoms, frequency and intensity and will almost certainly disrupt or change the life of the adolescent.

Throughout the oncological treatment process adolescents are forced to change their routines, roles, habits and daily activities.

Adolescent cancer completely alters the life of the sufferer and that of his/her family. The diagnosis, therapy and news regarding whether or not the treatment has been successful causes people to develop certain expectations during each of these steps<sup>(3)</sup>.

However, the way that this process can be less stressful for everyone is to face the reality and propose measures to relieve pain and suffering, for the adolescent as well as the family and health team<sup>(3)</sup>.

The process of dealing with a chronic illness has been a focus for research in terms of the influence of factors that act as additional resources to treat and approach the disease, such as personal and family beliefs<sup>(4)</sup>.

Caring for an oncological patient is more complex than caring for those with other diseases, since it involves people's spiritual aspects as well as their physical/biological and socio-cultural aspects<sup>(5)</sup>.

The families of children with chronic illnesses have used spirituality and religion as mechanisms to cope with these kinds of diseases<sup>(4)</sup>. Spirituality is therefore a field that has been widely discussed as a possible complementary resource to combat chronic diseases, such as cancer, and as an additional way for families to find resources to help deal with the day-to-day difficulties that are faced when caring for a child or adolescent going through treatment.

It is worth mentioning that using the words faith, belief, religion and spirituality as synonyms is not uncommon. However,

contrary to what is understood based on common sense, these words have specific meanings in this study.

Spirituality is regarded to have a philosophically guiding nature that results in behaviors and feelings such hope, love and faith being produced; and that provides a meaning in people's lives<sup>(6)</sup>.

Religion is having a belief in the existence of a higher power that would have the divine ability to create and control the universe<sup>(6)</sup>. Religion serves as a vehicle through which individuals can express their spirituality, based on values, beliefs and ritual practices<sup>(7-8)</sup>.

Belief is something that results from life experience and whose convictions are not based on rationality; whereas having faith is taken as something inspired by God<sup>(9)</sup>.

The changes that occur as a result of disease encourage people to search for meaning and strategies to cope with this affliction, which are both often found in spirituality, religion and personal beliefs.

The aim of this study was to analyze cancer suffering adolescents' perception of spirituality, religion and personal beliefs as well as to evaluate how these could be possible strategies for combating the disease.

## METHOD

Nine adolescents who had been diagnosed with cancer participated in the research. These were individuals of both sexes, aged between 12 to 18 years, and currently receiving care or oncological treatment at the two institutions located in the Brazilian city of Uberaba (MG), which deal with adolescents suffering from cancer.

This was a qualitative piece of research, both descriptive and exploratory in nature. The data were collected by means of personal identification and a semi-structured interview, which consisted of open-ended and closed-ended questions. The interviews were recorded and then transcribed. The data were subsequently interpreted by means of content analysis.

The interview covered issues related to spirituality, which was made up of the following topics: spiritual history, importance of spirituality in his/her life, spirituality in the religious community and the involvement of spirituality in care.

Individuals excluded from the study were those who were not in the aforementioned age group, who were undergoing treatment or follow-up by at least one of the cancer clinics in Uberaba, who had lost or were experiencing problems with their memory and adolescents whose legal guardians do not provide a free and informed consent term.

This research was submitted and approved by the Research Ethics Committee at the Federal University of Triângulo Mineiro, according to protocol 1783/2010.

## RESULTS

A total of nine adolescents participated in this study, whom are referred to here as s1 through s9, with 5 of these individuals being female and 4 male. Most of the participants were Catholic. Most of the participants had been diagnosed with Acute Lymphoid Leukemia, followed by Hodgkin's Lymphoma.

The data transcription produced four categories – The Spiritual History of the Individual; The Faith and Belief of the Adolescent; The Importance of Spirituality in his/her Life; and the Community acting as a Spiritual Supporter.

### Spiritual History

The "Spiritual history" category refers to beliefs acting as sources of comfort/stress and as an aspect that could possibly influence medical decisions; in addition to addressing whether or not adolescents participate in a spiritual/religious community and the possible spiritual needs of each individual. The vast majority, i.e. 8 of the 9 adolescents, think that beliefs are a source of comfort when facing the disease, with the exception of one adolescent (s4), who considered belief to be a stress factor, since there are conflicts between their values and those imposed by the adolescents' parents.

During this research it was found that praying was the strategy/resource most used by the interviewed adolescents as a source of comfort in their fight against the disease, which was preceded by their own belief in God.

For 4 of the adolescents (s2, s3, s5 & s8), spiritual beliefs had an influence on their medical decisions during treatment, referring to the frequency in which they attended church or a group including people who prayed for them, in addition to their belief in God's support. These beliefs were the main considered factors in order to make therapeutic decisions and recover from the disease. Despite continuing to practice praying, five adolescents reported that these beliefs did not have any influence on their therapeutic decisions.

In regards to participation in religious or spiritual communities, 7 adolescents (s3, s4, s5, s6, s7, s8, s9) reported attending them. From these 9 adolescents, 4 reported that they assiduously attended their spiritual community (s3, s4, s7, s9) and 5 reported that they stopped or reduced the frequency in which they attended, mainly as a result of starting of chemotherapy or radiotherapy, the social restriction from which is unavoidable. One of the adolescents (s1) had no defined religion and therefore did not attend any spiritual community. All of the interviewed adolescents reported receiving some kind of support from their spiritual community, except (s1) due to the previously mentioned circumstances.

The participants expressed no willingness, interest or need for any other types of spiritual support, whether they are related to their set of beliefs or not. They expressed satisfaction in regards to the spiritual support offered by the community to which they belonged.

### Faith and Belief

The "faith and belief" category refers to the adolescents opinion of themselves as spiritual or religious people; using beliefs

to combat stress or not; and what it is that gives meaning to their lives. When the adolescents were questioned about their own perception of whether they see themselves as being religious or spiritualist, 5 adolescents (s1, s3, s4, s5, s8) gave a prompt and affirmative answer, with no other related expression. Four adolescents reported themselves as partially religious or spiritual, with three of them (s2, s6, s9) justifying this perception in accordance with their rare attendance to their spiritual community, and one (s7) due to the need that this individual felt to give time to other aspects of life, which are not necessarily related to God or their spiritual community.

Most of the adolescents, i.e. 8, felt that their beliefs help them cope with the stress caused by the disease and those by its implications, with prayers such as Our Father and Hail Mary being cited as the principle source of help, followed by conversations with God and their families, the benefits from which being a sense of calm and tranquility. Only one teenager (s7) did not assign emotional support to their beliefs, stating that beliefs make you reflect on your life, thus providing relief from stressful situations.

While identifying what teenagers ascribe as being of value in their lives, 5 referred to their family and friends. The others reported that their beliefs are enough to make sense or meaning of their lives, stating that these are also totally and fundamentally important in their treatment (s3, s5, s6, s9).

### Importance of Spirituality in his/her Life

Considerations regarding the level of importance of spirituality or religion in the participants' lives can be seen in the "importance of spirituality in his/her life" category, as can the influence of these aspects on self-care and recovering health. When asked about the importance that faith or beliefs have in the lives of each person, all the adolescents considered these aspects to be of fundamental importance in each of their lives. All participants assigned grades (0 to 10) to demonstrate how important this was to them, with 0 meaning zero importance and 10 utmost importance.

From the 9 participants, 6 regarded faith or beliefs as being of the utmost importance in their lives, justifying this idea by saying that everything in life has a relationship with God. Two adolescents said that they would not give a 10 grade, the given reason was that there are other factors, besides religion, that are equally or more important in their lives, such as their families (s3, s8). Another aspect that was used as a reason not to give the highest 10 grade of importance was the low visit frequency to their religious or spiritual community, and practice of their customs, as was reported by one participant (s2).

Two of the adolescents (s2, s4) did not consider that their beliefs could have an influence on self-care in relation to their disease. Seven of the adolescents mentioned an increase in some types of feelings, such as strength, confidence, peace of mind and greater self-care following the disease, relating these aspects to the beliefs and rituals of each one.

With no exception, all the adolescents thought that their beliefs had some influence on their recovery, which they mainly attributed to their prayers and a growing sense of confidence to face the disease.

### Community Acting As a Spiritual Supporter

The "Community acting as a spiritual supporter" category presents data about belonging to a religious or spiritual community and the possible support that these can provide, as well as the group of people in the adolescents' lives who are most important. With the exception of one adolescent (s1), who had no defined religion, the other 8 individuals stated that they were part a spiritual or religious community, despite their not regularly attending such.

Most of the adolescents, specifically eight of them, mentioned that their community mainly provides support through rituals and prayers directed towards them, as well as through emotional support. They also mentioned financial support offered to help face the situation (s3). Even the adolescent (s1) who had no specific religion said that support was received in the form of prayers. Only one adolescent (s2) reported not having received support from the community, the reason for which was that this individual stopped going to church even before the disease.

There were no exceptions in terms of how important the adolescents' families are as a source of support in life and during their treatment, all regarded these as of utmost importance. The mother is the family figure who appeared most frequently in adolescents' reports. In addition to the family members, 5 adolescents (s3, s5, s6, s8, s9) referred to their friends and others from their religious or spiritual community as also being of great importance.

### DISCUSSION

In relation to spiritual history, the adolescent participants believed that belief and faith are essential sources of comfort and support when facing the stresses that accompany illness. For these individuals, believing in God and ritually praying are strategies that provide sources of comfort. They state that going to church, believing in support from god and people praying for your health influence decisions and medical care designed to improve your health. All the participants showed their satisfaction regarding the spiritual support offered by their community.

Spirituality or religion can bring spiritual comfort, provide feelings of hope, as well as be an additional factor of acceptance, in the treatment of chronic diseases such as cancer, in addition to acting to reduce stress factors and increase quality of life<sup>(4)</sup>. Therefore, unpredictable events, such as illness, are explained by the Divine Providence, which provides security and replaces fate<sup>(5)</sup>.

Spirituality may involve a belief system that can sometimes be associated with traditional religions and their rituals<sup>(10)</sup>. If prayer or other rituals connected to spirituality or religion have the power to produce a calming effect, love or a sense of belonging for the individual involved, then these should be considered healthy practices that can provide benefits to health. However, if these practices are moralist or conflict with personal interests, then they should not be considered healthy<sup>(11)</sup>.

Many people place the responsibility of resolving their health problems on God and believe that being part of

religious or spiritual communities will bring them closer to this superior Being. Therefore, being part of such communities will be a process that works to solve problems, while not avoiding confronting the disease<sup>(12)</sup>. One study performed in 2007 shows that people who attend religious communities have significantly reduced mortality, i.e. they live longer compared to people who are not part of any religious communities<sup>(11)</sup>.

Faith is fundamental in life and in the process of this illness for all the adolescents involved in this research. For these individuals, belief and spirituality may influence self-care in regards to the disease, and may even have an effect on their recovery and return to health. They believe that the benefits of spirituality are related to feeling stronger, calmer and more confident.

These adolescent participants recognize the importance of spiritual support that is offered by their community, which is expressed through rituals and prayers designed to support the cancer sufferer as he/she fights the disease. In addition, the importance of emotional and financial support during the course of the disease was also recognized by the adolescents.

In relation to being part of religious or spiritual communities, this is a practice that enables experiences to be shared and mobilizes support for these adolescents, which in turn promotes greater interaction and social support for them and their family members<sup>(4)</sup>. Therefore, this aspect can be considered a positive one in the fight against the disease.

During this research, spirituality was principally found to be related to religion and associated with prayers and participation in community events. In addition, despite the adolescents' religions and beliefs being very different and each of these religions having its own way of addressing God, the universal Christian prayer "Our Father" was found to exist in the the discourse of most of the participants.

Spiritual practices consist of actions whose objective is to relieve subjects from suffering and help them focus on hope<sup>(13)</sup>. The form of these practices are according to what belief means to each person and may or may not be religious in nature<sup>(12)</sup>. When such nature happens to be religious, as was the case in this research, the main coping strategy for relieving suffering is prayer. However, over time, these practices can emerge as other forms of expression such as promises, penances, adoration and contemplation of a higher Being<sup>(12)</sup>.

Nonetheless, religious and spiritual practices are not the only way for the participants to confront their suffering. Despite adolescence being characterized by these individuals pursuing new social roles, defining their personality and seeking independence, it is common for them to fall back on parental support in situations where adolescents finds themselves in vulnerable situations<sup>(14)</sup>. In addition, the importance of support provided by social networks that adolescents use was noted.

When experiencing a serious illness such as cancer, people are driven to understand themselves better, as they are compelled to rethink their lives and rediscover its value, casting themselves as the main character in their story<sup>(15)</sup>.

In situations that are life threatening, as is the case with cancer, the belief in a God or Supreme Being intensifies and the search for a miracle bestowed by the power of faith is regarded as the most important, and perhaps the final, of all the available resources for reversing the pathological outlook. People believe that nothing is impossible for God<sup>(15)</sup>. Furthermore, adolescents are not emotionally prepared to deal with death itself, which can intensify their search for a miracle cure/form of healing<sup>(14)</sup>.

Thus, when there is this belief and at the same time overcoming the difficulty for which made the individual seek support from the superior being in which he/she believes, this can make the individual have even more faith and strengthen their sense of closeness with God. This can also be used to rescue and recover their spiritual side<sup>(15)</sup> and possibly make a contribution when confronting new controversial situations.

Faith in God is a feeling that is rooted in the Brazilian culture and is equally as important as the other ways of coping with illnesses. The spiritual dimension occupies a prominent place in people's lives. Therefore, it is extremely important to understand the nature of a patient's spirituality when planning his/her treatment<sup>(5)</sup>.

By understanding how each adolescent deals with their cancer experience, as well as their life contexts, meanings, roles, routines and beliefs, it is possible for those professionals, who are directly linked to their treatment, to understand, help and maintain this demographic's health practices in an individualized and meaningful way.

The hope is that this study can make a contribution to the scientific community and to health professionals, as well as prompt new research in this area in order to correlate the

cancer patients' quality of life who are not always in search of a cure, but in search of general well-being<sup>(5)</sup>.

## FINAL CONSIDERATIONS

Adolescence, when lived alongside a life-threatening situation, such as cancer, can lead to feelings such as fear, anxiety, nervousness, disbelief, despair and helplessness. It is important that we understand how these people deal with the disease process and how their contexts of life, beliefs and customs can assist in this battle. Spirituality has been the subject of several pieces of research related to health. Based on the statements made by the adolescents interviewed, it was possible to affirm that spirituality seems to emerge as a component that generates hope for them, which helps tackle the cancer-related challenges and search for meaning in their lives.

For the adolescents who were involved in this study, spirituality, belief and faith are essential as tools to provide comfort and help deal with the stress that accompanies this illness. According to these individuals, practicing spirituality during illness, which includes their beliefs, values, rituals and differences, can bring about the following benefits: increased feelings of strength, calmness and confidence; promotion of self-care to aid recovery and health restoration; promotion of spiritual and emotional support, including that of a financial nature from their respective community; contribution to sense of belonging to a community; giving meaning of life to friends and family.

In addition, despite there being an increasing number of studies performed aimed at proving that spirituality is a resource for coping with disease, it is possible to observe that there are few publications based on its practical application.

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