Doi: 10.4025/psicolestud.v22i3.34606

SPIRITUALITY AND RELIGIOSITY IN MOTHERS OF CHILDREN WITH HEMATOLOGIC CANCER[1]

Iara Silva Freitas
Erika Arantes de Oliveira Cardoso[2]
Manoel Antônio Santos
Universidade de São Paulo (USP/RP), Ribeirão Preto-SP, Brazil.

ABSTRACT. Spirituality and religiosity are important sources of emotional and social support for families of severely ill children, specially when it comes to potentially terminal illnesses. Hematopoietic stem cell transplantation is one of the most daring and promising alternatives that have emerged in the last decades to treat onco-hematological diseases. It is a highly invasive procedure and involves risk of death due to its adverse effects, therefore, it requires close involvement of a family caregiver during all of its stages, which exposes this family member to continuous stressors. The goal of this study was to investigate the meaning attributed to spirituality and religiosity by mothers of hematologic cancer patients undergoing hematopoietic stem cell transplantation. This is a qualitative research, with a descriptive-exploratory design and a phenomenological fundamentation. Ten mothers whose children had undergone hematopoietic stem cell tranplantation were interviewed. Individual interviews were audio-taped and later transcribed and subjected to the comprehensive analysis of the reports. Spirituality and religiosity emerged from the speeches of the participants colored by different professed religious beliefs as a source of support and encouragement for family caregivers, helping them to deal with the adverse situation of being companion of a patient undergoing a high-risk procedure. Results corroborated that spirituality and religiosity are important coping resources.

Keywords: Spirituality; family; bone marrow transplantation, phenomenological psychology.

ESPIRITUALIDADE E RELIGIOSIDADE EM MÃES DE CRIANÇAS COM CÂNCER HEMATOLÓGICO

RESUMO. Espiritualidade e religiosidade constituem fontes significativas de suporte emocional e social para familiares de crianças gravemente doentes, sobretudo no caso de doenças potencialmente terminais. O transplante de células-tronco hematopoiéticas (TCTH) é um dos tratamentos mais arrojados e promissores que surgiram nas últimas décadas para doenças onco-hematológicas. Trata-se de procedimento altamente invasivo e que envolve risco de morte em decorrência de seus efeitos adversos. Por isso, exige o envolvimento intenso de um cuidador familiar durante todas as suas etapas, o que expõe esse membro da família a estressores contínuos. O objetivo deste estudo foi investigar o sentido atribuído à espiritualidade e religiosidade por mães de crianças com câncer hematológico submetidas ao transplante de células-tronco hematopoéticas. Trata-se de uma pesquisa qualitativa, de delineamento descritivo-exploratório, com fundamentação fenomenológica. Foram entrevistadas dez mães. As entrevistas individuais foram audiogravadas e, posteriormente, transcritas e submetidas à análise compreensiva dos relatos. Espiritualidade e religiosidade emergiram nas falas das participantes, coloridas pelas diferentes crenças religiosas professadas, como fonte de apoio e alento para a cuidadora familiar, auxiliando-a a suportar as adversidades inerentes à situação de ser acompanhante de paciente submetido a procedimento de alto risco. Os resultados corroboram a importância da religiosidade e da espiritualidade como recursos de enfrentamento.

Palavras-chave: Espiritualidade; família; transplante de medula óssea; psicologia fenomenológica.

---

[1] *Support and funding*: Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq)

[2] *E-mail*: erikaao@ffclrp.usp.br

ESPIRITUALIDAD Y RELIGIOSIDAD EN MADRES DE NIÑOS CON CÁNCER HEMATOLÓGICO

RESUMEN. Espiritualidad y religiosidad constituyen una importante fuente de apoyo emocional y social para las familias de niños gravemente enfermos, especialmente en lo que se refiere a enfermedades potencialmente terminales. El trasplante de células madre hematopoyéticas es uno de los tratamientos más audaces y más prometedores que han surgido en las últimas décadas para enfermedades onco-hematológicas. Es un procedimiento altamente invasivo que implica riesgo de muerte debido a sus efectos adversos. Por lo tanto, se requiere la participación activa de un cuidador familiar durante todas sus fases, lo que expone a este miembro de la familia a continuos factores de estrés. El objetivo de este estudio fue investigar el significado dado a la espiritualidad y la religiosidad de las madres de niños con cáncer hematológico sometidos a trasplante de células madre hematopoyéticas. Se trata de un estudio cualitativo, con diseño descriptivo y exploratorio y fundamentación fenomenológica. Se entrevistaron a diez madres. Las entrevistas individuales fueron grabadas en audio y posteriormente transcritas y sometidas a análisis comprehensiva de los informes. La espiritualidad y la religiosidad surgieron en los discursos de las participantes, coloreado por las diferentes creencias religiosas profesas como fuente de apoyo y aliento a las madres cuidadoras, lo que ayuda a soportar las dificultades inherentes a la situación de ser compañera de un paciente sometido a un procedimiento de alto riesgo. Los resultados confirman la importancia de la espiritualidad y la religiosidad como recurso de afrontamiento.

Palabras-clave: Espiritualidad; familia; trasplante de medula ósea, psicología fenomenológica.

Introduction

Hematopoietic stem cell transplantation (HSCT), better known as Bone Marrow Transplantation (BMT), is one of the most daring and promising treatments that have emerged in recent decades for various onco-hematological diseases. It is a highly invasive procedure that involves risk of death due to its adverse effects (Matias, Oliveira-Cardoso, Mastropietro, Voltarelli, & Santos, 2011). Therefore, it requires the intense involvement of a family caregiver during all of its stages, which exposes this family member to continuous stressors (Laudenslager et al., 2015; Rodday et al., 2012).

The literature indicates that HSCT is a process that psychologically affects patients and their family caregivers (Bevans et al., 2014; Cooke, Grant, Eldredge, Maziaiz, & Nail, 2011; El-Jawahri et al., 2015; Jobe-Shields et al., 2009). Patients undergoing transplantation struggle with a life-threatening disease and, for most of the time, remain hospitalized and are kept in protective isolation because of low immunity. Studies have focused on understanding the psychological consequences of caregivers' efforts to deal with stress related to family member illness, treatment, and uncertainties regarding the possibility of survival (Larsen, Heilmann, Johansen, & Adamsen, 2011).

A recent study suggests that knowledge about the needs of caregivers and the rest of the family is an important component to be taken into account when planning transplant care (Pennarola et al., 2012). Cooke et al. (2011) carried out a study with the objective of describing the experiences of 56 family caregivers of patients undergoing HSCT, in the period of three to 12 months after the procedure. In this descriptive, correlational study, participants were enrolled in two transplant programs in the United States. Questionnaires were applied to investigate the following themes: quality of the relationship with the family member, object of care; rewards received for care; predictability; stresses as a function of the role of caregiver; tasks related to the care and quality of life of the caregiver. The results indicated a high impairment in the sleep-wake cycle and emotional behavior. The role of caregiver was characterized by family members as very challenging, and as care demands increased, there was a consistent decrease in the caregiver's quality of life. In addition, the researchers pointed out that the most difficult task for caregivers was to provide emotional support to patients. The authors draw attention to the importance of developing interventions focused on the needs of caregivers, as well as incorporating evidence-based best practices into care to prevent or minimize the burden of exercising such a sensitive role.

El-Jawahri et al. (2015) designed a study to investigate the impact of hospitalization for HSCT on quality of life (QOL) and mood in patients and caregivers in the United States. A longitudinal study was conducted with 30 hospitalized patients and 30 caregivers. The results showed that patients subjected to HSCT reported a decrease in QOL and a substantial worsening of the symptoms of depression during the hospitalization. Caregivers, in turn, experienced a decline in vitality and social and emotional functioning, increased levels of depression, as well as impairment of physical functioning and overall health at the time of hospitalization of their family members.

A study conducted in Turkey evaluated the psychiatric symptoms and resilience levels of 51 patients undergoing HSCT and 46 family caregivers (Çuhadar, Tanriverdi, Pehlivan, Kurnaz, & Alkan, 2016). The results showed that the psychiatric symptoms presented by patients and caregivers were negatively associated with the level of resilience. The authors concluded that HSCT is a process that psychologically affects both patients and family caregivers.

Mayer et al. (2009) identified needs and resources of parents of pediatric patients during the first year post-HSCT, through questionnaires answered online. Parents pointed out that the health team had been their primary source of support during the procedure, providing them with information that helped them to handle the challenges of the care experience.

Larsen et al. (2011) investigated the experiences and reflections of the parents about possible changes in the parental role in relation to the care needs of the child undergoing HSCT. Interviews were conducted with 16 participants, complemented by an observational study conducted with some parents in the ward. Based on the data obtained, three main types of approaches that parents experienced in relation to care were identified: the use of rationality, openness to dialogue and the feeling of being socially challenged. The authors point out that parents who used predominantly rationality had a way of interacting with the child in medical knowledge, while those identified as available to dialogue considered important to modulate the emotions by rationality, which in their view would favor caring. Parents who used more the third type of approach showed greater difficulties in adapting to treatment. The authors of this study point out the importance of considering the complex interactions between parents, patients and health professionals throughout the course of treatment, so that the multiprofessional team can more effectively support family members in relation to care the child.

Regarding the sources of social support, although the literature is still incipient, recent studies have provided increasing evidence that religiosity and spirituality are significant sources of emotional support for family caregivers of critically ill patients, especially in the field of potentially terminal illness.

According to Oliveira, Santos and Mastropietro (2010), religiosity can represent a resource that softens the patient’s uncertainty against the inexorability of the chronic disease. More particularly in the context of onco-hematological treatment, this coping strategy is more frequently recurrent, once the discovery of a potentially fatal disease - and still closely associated with death in the collective and individual imaginary, as in the case of cancer - can give rise to reflections and fantasies about the terminality and meaning of life.

According to Boff (2006), the concept of religion refers to an institutional and doctrinal aspect, defined by certain dogmas, beliefs, moral precepts and rituals directed to the dimension of the divine, understood as means to obtain salvation of the soul. *Religiosity*, in turn, is expressed in the subjective scope of religion, that is, it implies the intimate relationship of the individual with the transcendent being. On the other hand, the concept of *spirituality* refers to all experiences capable of producing profound change within the human being and that leads to a feeling of greater harmony with oneself, favoring personal integration and with others (Giovanetti, 2005).

Pessini (2007) adds that spirituality refers to the search for a meaning or meaning of life, not necessarily linked to the belief in a supreme being. Boff (2006) points out that spirituality designates the examination that man makes of himself and as such is related to experience and not to dogmas, celebrations, rites or ceremonies. However, Boff considers that, although distinct, religiosity and spirituality can coexist, but without necessarily keeping one dependent on the other. In this context, Kovács (2007) argues that spirituality presents an essential element of subjective construction and may or not relate intrinsically to the question of religiosity, in addition to encompassing contemplation and reflection about experiences lived on the border with finitude and the sacred.

Once these conceptual distinctions have been established, the present article proposes to focus the meanings attributed to spirituality/religiosity in mothers of children in treatment of hematological cancer. The focus on mothers is justified by the fact that they are the most present informal caregivers in the scenario of hospitalization in oncopediatrics (Arruda-Colli, Perina, & Santos, 2015; Arruda-Colli, Lima, Perina, & Santos, 2016). An informal caregiver is a person - a family member or community member - who, in the hospital or private domestic environment, performs or helps another person with limitations in his autonomy to perform basic and instrumental activities of daily life. The family caregiver provides different types of care to the dependent family member, seeking to meet his specific needs, such as hygiene, food, locomotion, shifting position in the bed and in the chair, among others. In addition, the caregiver acts as an intermediary link between the person cared for, other family members and the health team. The activities carried out vary from providing basic care with personal hygiene to the performance of household tasks and family financial management (Mazza & Lefevre, 2005; Moreira & Caldas, 2007), aiming to guarantee the improvement of the quality of life and the recovery of the condition of the sick person.

Torskenaes et al. (2015), in an exploratory and comparative study, investigated the meaning of spirituality according to the perception of nurses and informal caregivers, as well as comparing the definitions of this term between groups of individuals from two European countries, in which the Western-Christian tradition predominates. The findings indicate that both groups identified the religious perspective of spirituality and emphasized the connection with self, family, nature and with God as the emanation of a superior force. The authors draw attention to the existence of positive and negative energies related to spirituality, the former include feelings of transcendence, completeness and closeness to a superior power, and the latter refer to a sense of anguish experienced after death of someone, and of the inexplicable phenomena that can follow.

Koerner, Shirai and Pedroza (2013) conducted a qualitative study to investigate how Latin American caregivers rely on religious/spiritual beliefs and practices in their daily lives, seeking to know how they help or disrupt their adjustment process to disease. The study included sixty-eight family caregivers, Mexican descent, of patients with diverse needs, such as help with mobility, diabetes mellitus, cardiovascular impairment, cognitive, visual and auditory impairments, among others. The results pointed to positive forms of religious confrontation, with experiences provided by the development of a bond of intimacy with divinity, perception of connection between religion/spirituality and family, feeling of spiritual peace, among other integrating experiences, suggesting that religious/spiritual attachment has a consistent beneficial effect for Latin American caregivers.

Fife, Monahan, Abonour, Wood and Stump (2009) investigated the course of adaptation of family caregivers of adults undergoing HSCT, inferred by the level of emotional distress experienced during the acute phase of the transplant. The authors found that a greater sense of attachment to the transcendent and the fullness of spirituality were the main factors associated with low levels of stress and emotional distress.

As can be seen from this overview of the literature, available studies have been carried out in the context of other countries, which indicates a gap in the Brazilian studies. Considering the need to contribute to the expansion of the national literature, still incipient in the area, this study aimed to investigate the experiences of mothers whose children are being treated for serious onco-hematological diseases.

The present research is based on Phenomenology, a philosophical movement that emerged in the twentieth century with Husserl, as a reaction to positivism and rigorous criticism of the experimental method and objectivist psychology (Amatuzzi, 1996; Forghieri, 2004). As such, this philosophical thought starts from the postulate that man cannot be thought of as “a thing among things”, but has to be considered in his inseparable relation to the world, which is “an intentional object with reference to a thinking subject” (Holanda, 2014, p. 46). Phenomenology is, therefore, the science of the phenomenon, seen as that which manifests itself, which shows itself to a certain consciousness (Ambrósio & Santos, 2011).

The phenomenon cannot be separated from the experience, since it is always linked to a particular knowledge (Giorgi & Sousa, 2010). Thus, in the scope of the present study, the sense attributed to religiosity/spirituality by mothers of children under treatment for hematological cancer is privileged. The focus is placed on the experience of these mothers of severely ill children and who have undergone a highly invasive procedure (HSCT), which implies a high risk of death, asking how religiosity/spirituality is revealed in the perspective of those who experience the caring. That is, the phenomenon is always investigated in relation to a given subjectivity (Holanda, 2014).

Following the steps of the phenomenological method, we intend to take the world as it presents itself as a phenomenon (Amatuzzi, 2009; Forghieri, 2004; Holanda, 2001, 2014). This phenomenological attitude demands a “naive look” that makes it possible to see the world as it actually presents itself, practicing reduction, that is, leaving aside the possible representations that already exist. It is not simply to find something about it, but to discipline the look and see, seeking to know a certain experience (Holanda, 2014) as it appears to the consciousness of those who experience it (Ambrósio & Santos, 2015).

In order to expose the sense of religiosity/spirituality for mothers of children undergoing treatment for hematological cancer, it is necessary to assume an *intentionality* of consciousness, that is, to start from the postulate that consciousness does not exist independently from the object (Forghieri, 2004). Consciousness is always a movement, *consciousness-of-something*, because it can only be when it is directed toward something which, by definition, is always in motion.

Considering the above, this study aimed to investigate the meaning attributed to religiosity and spirituality by mothers of children with hematologic cancer subjected to HSCT.

Method

This is a descriptive-exploratory study, with a theoretical-methodological basis of phenomenological inspiration. According to this comprehensive analytical perspective, the phenomenon can be accessed through the discourse of those who experience the situation directly (Bruns & Holanda, 2001).

Participants

The present study included mothers in the role of informal caregivers of children diagnosed with leukemia or aplasia, and who were in the process of HSCT. None of the invited mothers declined the invitation. Table 1 lists a characterization of the participants according to sex, age, schooling, marital status, occupational activity and religion.

Table 1. Characterization of the participating mothers according to age, sex, schooling, marital status, occupation/occupational activity and religion

Name*	Age	Schooling**	Marital status	Occupation	Religion
Clara	42	IES	Married	Rural worker	Catholic
Cláudia	39	CHS	Married	Hairdresser	Catholic
Elisa	34	CHS	Married	Saleswoman	Protestant
Fabiana	31	CHE	Divorced	Nurse	Catholic
Rosa	46	IES	Married	Housewife	Catholic
Hilda	46	IES	Widow	Saleswoman	Protestant
Elza	52	IES	Married	Domestic helper	Catholic
Marta	54	IES	Widow	Housewife	Catholic
Ana	39	IES	Married	Chaperone	Jehovah's Witness
Cíntia	31	CHS	Married	Housewife	Catholic

** = Fictitious names/** = E.F.I.: Incomplete Elementary School; EMC: Complete High School; ESC: Complete Higher Education.*

Data collection

The phenomenological interview was the main tool to obtain the data, based on the guiding question: *"Tell me how you have experienced the care of the hospitalized child for Bone Marrow Transplantation"*.

The interviews were individual, face-to-face, throughout a meeting. They had an average duration of one hour, ranging from 30 to 70 minutes. Data collection was performed in a preserved environment, whenever possible in a reserved room of the hospital, safeguarding the principles of comfort and privacy

Data analysis

After data collection, the recorded audio content was transcribed literally and in full. Data analysis was based on the theoretical-methodological reference of Phenomenology, more particularly on the procedures recommended by the authors who were dedicated to systematizing the phenomenological research in Psychology (Amatuzzi, 2001, 2009; Andrade & Holanda, 2010; Forghieri, 2004; Giorgi & Sousa, 2010; Gomes, 1998, 2007). The model adopted was described by Vidotti (2017), who synthesized the specialized literature in the field of Phenomenological Psychology, and is constituted of four stages: (1) Apprehension of the whole; (2) Description; (3) Reduction; and (4) Interpretation.

The *apprehension of the whole* corresponds essentially to the attentive and exhaustive reading of the collected material. Initially, putting into practice the attitude of phenomenological reduction (Giorgi & Sousa, 2010), a general reading of interview transcripts was carried out, in search of an overview to connect and apprehend the meaning of the experience for the mothers of children with onco-hematological diseases, as a whole (Amatuzzi, 1996). Firstly, an understanding of the language of the one who describes the experience was sought, abandoning the attempt to identify meaningful units in the text (Andrade & Holanda, 2010). In a second moment of this stage, the reading of the material was resumed with the goal of dividing it into smaller parts, from the determination of units of meaning, that allowed a more in-depth analysis.

The *description* corresponds to the second stage of the methodological procedure of analysis, which consisted in ordering and presenting the data obtained according to the assumptions of phenomenological research (Amatuzzi, 2001). The description in Phenomenology can be understood as a means of appropriating reality as shown in the empirical material collected during the interview by returning to the immediate experience of consciousness. At this stage, it is a matter of revealing what was said in the disordered flow of the meeting, but in an organized and clear way, making use of *epoché*, that is, the suspension of assumptions (Gomes, 2007) and everything else that was already known by the researcher regarding the studied phenomenon. This is made possible by the phenomenological reduction, with which the researcher puts aside his immediate thoughts and interests and seeks to remain open to receive the contents that may emerge in the research (Moreira, 2004), seeking to describe the phenomenon as if it had been accessed for the first time, but at the same time it is considered impossible to put the whole experience of the researcher, completely, in parentheses (Gomes, 1998).

The *reduction* is the third methodological step followed in the present study. This step consists in the search for the delimitation of the units of meaning in the speeches of the mothers interviewed, through the exploration and specification of the description, again putting into practice the tasks of phenomenological reduction (Gomes, 1998) and the *epoché*, in order to keep in suspension the natural attitude (Giorgi & Sousa, 2010). The everyday language of the natural attitude is transformed into expressions that allowed to clarify the psychological meaning of the descriptions provided by the interviewees, thus revealing the meaning of the experiences in relation to the object investigated.

Finally, *interpretation* is a stage in which a synthesis of the significant units related to the lived experience of the mothers was sought, resulting in a *structure of the lived* (Giorgi & Souza, 2010). For this, we sought to identify the invariants and variants present in the maternal reports, searching for the relevant constituents of the object, in order to identify the structure of the phenomenon. By means of free imaginative variation, the units of meaning found were transformed into a general descriptive structure, encompassing the more invariant meanings belonging to the units of meaning transformed into psychological language, resulting in a synthesis of the units of psychological meaning (Giorgi & Sousa, 2010). The elaboration of a more comprehensive interpretation of the phenomenon provides a possibility of understanding that allows the researcher to go beyond the particular situations from which the research started. In this step, the intentionality of consciousness is revealed to that particular object of experience, that is, it unveils the sense that that object assumes for consciousness (Amatuzzi, 2009). The researcher's interpretation arises from the exercise of his existential status, since his cognitive, conative and affective capacities are put into action, replacing the subject in the world (Gomes, 1998).

Ethical care

The project was approved by the Research Ethics Committee of FFCLRP-USP (process 618/2011 - 2011.1.2398.59.4). It was stated that the non-acceptance or withdrawal of participation during the study would not cause any harm to the institutional care of the family being treated.

Results

Phenomenology is understood in this study as a method of access to the concrete reality of the world through the clarification of the phenomenon (Amatuzzi, 2001). From the phenomenological analysis of the maternal reports five units of meaning emerged related to the investigated phenomenon, which gave rise to the thematic categories, which will be presented next. To describe the categories, we will use excerpts of speech of the participants, identified by the fictitious names assigned. In this section, we will present the results of the phenomenological reduction, and in the following (Discussion), the comprehensive analysis.

a) Finding sources of support for coping with the disease and the rigors of treatment

All participants reported that they sought support in God, faith, and religion to get through the experience of sickness and treatment of their children. However, they differed in terms of their religious beliefs and of those who clamored for help at the most difficult times. Some mothers, practicing the Catholic religion, prayed for the help of Mary, mother of Jesus Christ, while others mentioned that they address their prayers and cries more to God and Jesus. The participant who defined herself as a student of the Jehovah's Witnesses religion reported receiving direct support from Jehovah.

> *My faith in God is what calms me down, gives me patience, tells me: "Wait for the time for you to speak; calm down, reflect before". It is my faith, my hope in a God that makes me stop a little: "It's not now, it's not that way". It's the one who makes me apologize, the one who gives me humility. So I guess if I did not have faith, I would not be here.* (Claudia)

The mothers who declared to be practicing the Catholic religion say that they asked for the support of Mary, the mother of Jesus, whom they refer to as Our Lady. In this way, they feel identified with the divinity as mothers of a son who experiences states of intense helplessness and physical and psychic sufferings. The fervent approach with the mother of Jesus symbolically evokes the image of the *painful mater* consecrated by Catholic iconography, or the famous Pieta, immortalized in sculpture form by Michelangelo, the mother who welcomes in her arms the body of her dead son after stations of the *via crucis*: *"Then I said: "Oh. Our Lady, all that I can pass on, may the Lady give me much strength. If I have to go through a pain, the Lady give me a lot of strength, and does not let me weaken"* (Marta).

By seeking the protection of the divinity, mothers seek to be strengthened and long for a miracle, as can be seen in the following thematic category.

b) Having expectations of healing through divine intercession

The participants addressed the question of the expectation of healing through God's intercession, and some reported that they cry out directly to God for healing, praying for their child's salvation: *"I bend my knees in the bathroom, I did not want to cry in front of him. I entered the bathroom and said, "Lord, if it be Thy will, someday my son shall be healed"* (Clara).

Some participants reported that God is behind the intelligence and the ability of doctors to heal people. In this way infinite divine goodness would work through the skilled hands of health professionals: *"God does not come down from heaven to do anything, but I believe He uses people"* (Elisa). *"I think all this intelligence that exists in doctors is also the hand of God, because I do not think it's intelligence like that, just men's, no. He is behind everything, even the one that does not have faith"* (Ana).

c) Putting destiny in the hands of God

All participants commented that, given the worsening health of their children, and the awareness of the risks inherent to the HSCT, they deposited their destiny in the hands of God: "I surrender to God"; "I surrendered, I bowed my knees and surrendered"; "That Thy will be done, Father"; "I handed to God, if He gave him to me, he came from the dust, he goes back to the dust"; "Lord, I am in Your hands"; "I gave her into his hand" [Jehovah].

The mothers also affirmed that what they wanted most was to obtain the pardon of the cure and, through it, to obtain the grace to have the son's life back. But if this was not God's will, they spontaneously declare that they would respect His decision, for God is the one who knew what was best for him: *"Then what happened, I surrendered, I bowed my knees and surrendered. "That Thy will be done, Father" What I could do so far I did, You showed me and I followed, then may Your thy will be done"* (Claudia).

d) Intensifying the appeal to religiosity

Participants mentioned that, during the period of illness and treatment of their children, they increased religious attachment, increased their prayers, as well as increased the frequency of visits to religious institutions.

> *It's not that I did not, you see, but I came to believe more. Although it is said that faith moves mountains, right, when you live the situation, you say, "Wow, this is a miracle from God". Because the doctor said, "Gee, I do not know how your son did not die"* (Elisa).

One of the Catholic mothers, unlike the others, said that when she was informed about the recurrence of her son's illness and that he had received an indication for transplantation, she stated that for a moment she rebelled and turned against God. She thought God had lied to her. She thought, then, that God did not exist, but then she calmed down and asked God for forgiveness, again feeling His presence with her. She was then able to restore and keep her faith intact. In this sense, it was noted that, with her son's illness, this participant felt that her faith had been tested and proved and she showed, for a moment, hesitant. It may be thought that the fact that this aspect is not mentioned by other mothers does not mean that there have been no moments of decline of their faith in the divine, especially in periods of greater turbulence.

> *When I received the news, I did not rebel much... Everything I'd done in two and a half years was not worth anything, I felt like a failure. On the day of the news [of the relapse of the son's illness], God lied to me. It was at the time of the revolt that I saw my son in that situation ... But after everything, I calmed down, I stopped, I asked for forgiveness, and today I have God with me* (Fabiana).

e) Betting on the possibility that something positive can be extracted from the suffering

All the participants affirmed that they had extracted some positive lesson from the situation of suffering, emphasizing aspects such as the greater appreciation of the people of their personal network to the detriment of material values,

> *You know, I think my life was very good, but I used to complain a lot, you know, to complain about life. And sometimes it seems like nothing was good for me, you know? And now, going through this, I see that my life was good. I learned, now, through this, that we cannot be complaining at all ... I do not want to complain any more, you know?* (Cíntia).
>
> *I learned a lot. I learned a lot, that we can leave a lot of things aside and in fact we can. How many times did I miss seeing his toy because I had to work. Now I know that all this can be set aside, even for 20 minutes, but it can* (Fabiana).

One of the most significant gains was the redefinition of modes of relationship, from the maturation acquired in the long journey of the child's treatment, accompanied by various learning, such as learning to be more humble and tolerant, to live with people and their differences, as well as the opportunity to strengthen their faith and rethink their way of living, acting and leading in life.

> *This illness of* [name of the son] *came thus to unite the family and lead us to seek more God. Because I had not spoken to my son's father for 11 years. Before I was very far from his father's family, and today we are very close* (Elisa).

Only one participant, who is protestant, approached that the suffering situation represented a life lesson to her, but not in the sense of an opportunity for personal growth, as all other mothers considered, but as a punishment. This punishment promoted a transformation, albeit for the better, through pain. This participant lives in the midst of a belief system that punishment is a consequence of sin, a life governed by excess materialism, or has its origin in the mistakes supposedly made by her and by her own child. In this way, disease acquires a soul purifying power.

> *...I think the disease, I think it's a bit of people's sin, you know? For regret for something we've done, understand? As for me, as for him, who is a son ... And to have something else, you know? It is then that you see, you know, that we need not only material things.* (Hilda)

Discussion

The interviews showed that initial reaction of shock and denial of the mothers in the face of the diagnosis received, followed by ambivalent feelings, permeated by amazement, perplexity, revolt, indecision, attempted bargaining, depression and, later, acceptance. These reactions are expected in the normal mourning process, and are common in cases of anticipatory grief (Fonseca & Fonseca, 2002). The findings are compatible with the findings of other studies (Arruda-Colli, Perina, Mendonça, & Santos, Mayer et al., 2009; Rodday et al., 2012), which allows the characterization of maternal experiences as intense and sweeping, charged with poignant, visceral and unprecedented affections.

In an attempt to alleviate panic at the unpredictability of life and under the impact of the intense suffering revealed by the confrontation with the facticity of the child's illness, mothers use certain strategies to deal with adverse experiences. The present study revealed that the use of spirituality/religiosity is one of the most recurrent ways of dealing with the facticities that mothers find in their way, in an attempt to make sense of an experience that seems inconceivable and inexplicable to them - the diagnosis of a morbid condition threatening the integrity of a child's life and the long and exhausting course of treatment that follows.

It was possible to detect that the most used ways to deal with the illness situation and the uncertainties caused by the HSCT mishaps were: attachment and strengthening of the faith, increase in confidence in the team and search for family support. These data are consistent with the findings of Fonseca (2001), who pointed out religious beliefs and values as very significant aspects in the process of anticipatory mourning, with hope and faith being phenomena observed during almost the entire process. The results also corroborate the findings of Schneider and Mannell (2006), who identified spirituality as the most prominent strategy used by parents regarding the diagnosis of children's cancer. Nevertheless, one aspect that the present study elucidated was that the discovery of the child's illness can also favor not only the intensification but also the distancing of the connection with the divine, although, in the specific case in which this could be perceived, such phenomenon has been transient and, subsequently, surpassed, according to the maternal report.

Regarding the sources of support for coping with the disease and the rigors of treatment, all the mothers interviewed reported that they sought support in God, in faith and in religion, to go through the time of the discovery of the disease and the turbulence of the treatment of their children. Faced with the challenges of an unstable situation, which forces mothers to move to a strange and sometimes hostile territory, as the hospital is usually experienced, it is noted that religiosity/spirituality emerges as a powerful resource also to give legibility to the lived, sewing and ordering seemingly unconnected facts, somehow filling in the absurd and *meaningless* experience of losing the loved one. These results are consistent with those obtained by previous studies (Arruda-Colli & Santos, 2015; Arruda-Colli et al., 2016).

It has been realized that contact with the spiritual dimension offers comfort, especially in moments of more intense and uncontrollable suffering, such as the days before the bone marrow engraftment. Spirituality, as a coping resource used by family caregivers of children and adolescents subjected to HSCT was also pointed out by Andres, Lima and Rocha (2005) as a source of support, helping mothers to feel less lonely and helpless in the struggle for the lives of their children. Fife et al. (2009) also realized that spirituality plays an important role in the positive adaptation of family caregivers, invigorating them so that they could withstand the innumerable setbacks imposed by the long journey of HSCT.

As discussed earlier, it was possible to note in some Catholic mothers that they beg the intercession of Mary, mother of Jesus Christ, in their requests and prayers. Regardless of the fact that this deity is very present and valued by Catholicism - remembering that Our Lady was proclaimed the patron saint of Brazil - one can think of a mechanism of identification of these mothers with the figure of Mary, which, according to the Christian tradition, embodies all divine goodness and mercy. Mary, therefore, as a personification of the ideal of purity, was a mother who accompanied every step of her son's decline and suffering on his way to Calvary, standing firmly by his side during the entire trajectory of Christ's passion. In fact, the word *passion*, etymologically, has the same radical *pathos* that gives rise to "pathological" and "suffering". With infinite patience, Mary was an eyewitness to the suffering of her martyred son and saw him die, but despite all her pain she showed resigned and unshakable in her faith, accepting the designs of God. That is why this saint represents, in the collective imagination, an emblematic being of consciousness of the unspeakable hardships to which the mothers of the whole world experience.

The literature points out that devotion to the Immaculate Mary in Brazil spread from the arrival of devotee colonists of the Virgin, especially, from the seventeenth and eighteenth centuries. As the mother of Jesus the Savior, Mary began to exercise a salvationist role in the Catholic Church (Fleck & Dillmann, 2012). The representations of the Virgin Mary are present in a manual called *Mestre da Vida*, written by João de Castro in 1882. It would be up to the reader of this book to demonstrate his devotion to Mary, for her condition of humility, which would win in return the guarantee of a healthy life and salvation before the death of the body. The manual contained a great number of prayers dedicated to the Virgin Mary, but also the recommendation that the faithful people give their souls to her. Suffering with resignation was recommended to those who desired consolation at the time of death. To the Virgin were the requests formulated in the last moments of life, when a patient in prayer turns to her asking for help, in search of the last grace, which seems to be in agreement with the requests of some of the mothers of the present study, who have shown that they are aware of the possibility of finitude of the child, that is, of the lack of therapeutic possibility of healing and therefore waiting for a miracle for their children.

In relation the expectation of healing through divine intercession, the ten mothers interviewed approached this question, some of whom said that they cry directly to God for healing, for the salvation of the child, while others reported that God acts by mediating the intelligence and capacity of the health team, wisely guiding physicians to heal the sick. In fact, all respondents reported believing that God participates directly or indirectly in all positive events and outcomes that occurred before and after transplantation. These results are in line with the findings of Schneider and Mannel (2006), who described spirituality as a potent resource that can be expressed in many ways in the parent's coping repertoire.

As for the question of destiny deposited in the hands of God, all the participants reported that, given the severity of their children's health and the risks inherent to the HSCT, they deposited their destiny in the hands of God. The mothers said that what they wanted was to obtain a cure for the illness and, through it, they could have the child's life back, but they also asserted that if this was not God's desire, they would respect Him, because He knows what is best in their lives. This apparent resignation before a future that seems to escape completely from human control was also reported by Benites, Neme, and Santos (2017), in a study of oncology patients who experienced the terminal condition.

All participants interviewed mentioned that they had gained something positive from the situation of suffering, emphasizing aspects such as the greater appreciation of people over material values, the redefinition of relationships, acquired maturity, learning to be more humble and tolerant, and living with different people, as well as the opportunity to have more faith, to rethink the way of life and to act in life. Only one participant, who professes the protestant religion, considered that the situation of suffering consisted in a life lesson, not in the sense of an opportunity for personal growth, as the other mothers said, but as a punishment that promoted a transformation, even for the better, both for her and for her son, through suffering.

Importantly, as for the psychological condition of the participants, the transformations that occurred in their way of seeing and living life referred to their existence prior to the diagnosis and the process of the child's transplantation, and also led them, prospectively, into another existence that they imagine to be coming. In this way, it is possible to affirm that the transplantation works like a genuine turning point in their lives. It is a critical event that inexorably divides life into a "before" and a "after".

After experiencing illness and HSCT, the mothers perceived themselves as modified people, who discovered different ways to give way to their actions, with the creation of new ideals and values. Now they are women who privilege contact with each other and who, in their interpersonal relationships, perceive themselves with greater tolerance and acceptance of differences. They also began to value moments of coexistence and the quality of interaction with their children, as well as recognizing the need to seek greater balance in life, working less so as to allow more sharing of children's experiences.

The researcher who chooses to work with the phenomenological method does not intend to verify or establish causal relations, but to elaborate an understanding of something lived (Amatuzzi, 2001). It was possible to perceive that in the course of the HSCT the participants often surprised themselves with a series of acquisitions and learning meant as positive. They realize that they have increased their gregarious longing, learned new interpersonal skills, found themselves stronger than they thought they were at the beginning of the journey toward their children's recovery. Believing in the possibility of the child's salvation and remaining obstinately faithful to this idea contributes to keeping them alive and hopeful. This effort has led them to believe that life has a purpose, which is strengthened by spirituality, and that the commitment to save the life of the other is, in a sense, to save one's life in order to achieve a life full of meaning.

When considering the experiences of caregivers revealed by this study, some recommendations can be made for the improvement of professional practice. It is necessary to sensitize health professionals to recognize the importance of spirituality/religiosity as a source of comfort and support for caregiver mothers. It is also necessary for practitioners to know how to effectively incorporate religious-spiritual care into their health actions. This imposes respect for the religious beliefs and beliefs of caregivers, patients and other family members. But we must go further and create a hospital culture that is authentically open to welcome this issue. A feasible possibility is the offer religiosity/spirituality workshops directed to the team, as suggested by recent studies, which discuss the planning of interventions in chronic health conditions (Backes et al., 2012). Thus, religious-spiritual care may become an important facet in the humanization process of health care (Espíndula, Pontes, Valle, & Santos, 2007).

Final considerations

In the present phenomenological study, we sought to understand the phenomenon as something that demands an unveiling and that can be shown in different ways for the mothers who experience it. Thus, following what the phenomenological method advocates, we sought to have access to the concrete reality of the world through the clarification of the phenomenon. The results were presented and discussed in two moments, related to phenomenological reduction and comprehensive analysis, which pointed out the ways in which spirituality and religiosity are signified by the mothers interviewed.

HSCT is a complex, long-lasting procedure with unpredictable results. Its trajectory is usually erratic and troubled, due to the potential risks of complications that, in some cases, escape the control of the health team, leading to the fatal outcome of the bone marrow receptor. Thus, living with the exhaustive routine of invasive examinations and procedures, remaining in a regime of absolute protective isolation, can affect some domains of the quality of life of the patient's accompanying family member.

In this scenario of permanent tension and stress, the women caregivers participating in this study seek support in spirituality and religiosity, in an attempt to repotentialize the hope of having the child saved through HSCT. In this way, they are obliged to defend themselves against the continuous threats and frustrations they have accumulated since the discovery of their childrens's serious illness. The diagnosis destabilizes the maternal psychic well-being. In this adverse situation, the psychological cost of the overload resulting from the role of the main family caregiver is considerable, putting at risk the physical and emotional health of the mothers investigated.

In relation to the limitations of the present study, we can highlight the fact that participants from only three different religions were included. Taking into account that our country is considered multireligious, a greater openness to the plurality of religious beliefs that characterize the Brazilian people may be relevant to feed future studies. It is important to observe that the topic of spirituality/religiosity has now been approached more frequently in the literature, becoming a focus of research interest in different multidisciplinary fields. In this sense, it would be positive if other scientific investigations were carried out contemplating the participation of caregivers who profess other religious beliefs, in addition to those mentioned in this study, in order to have a more comprehensive view regarding the questioned phenomenon. Another recommendation for possible studies would be to explore the phenomenon from the perspective of parents and siblings, including the perspective of the transplanted child.

The family caregiver's approach by the multiprofessional health team should be systematic, encompassing the multiple dimensions of care, which must be initiated from the patient's admission to the service. Therefore, it is imperative that health professionals recognize the limitations and potential of the family and the person who performs the role of informal caregiver. For health care planning, it is important to know the resources that the family has, respecting their cultural, social and educational beliefs and values, which includes spiritual and religious aspects.

In summary, our findings invite healthcare professionals to provide care that recognizes the meanings that religiosity/spirituality acquires for family caregivers. It is considered that knowing, respecting and legitimizing their religious convictions are the first steps in integrating religious and spiritual care into the preventive and intervention actions promoted in the transplant scenario.

References

Amatuzzi, M. M. (1996). Apontamentos acerca da pesquisa fenomenológica. *Estudos de Psicologia, 13*(1), 5-10.

Amatuzzi, M. M. (2001). Pesquisa fenomenológica em Psicologia. In M. A. Bruns & A. F. Holanda (Orgs.), *Psicologia e pesquisa fenomenológica: Reflexões e perspectivas* (pp. 15-22), São Paulo, SP: Ômega.

Amatuzzi, M. M. (2009). Psicologia fenomenológica: uma aproximação teórica humanista. *Estudos de Psicologia, 26*(1), 93-100.

Ambrósio, D. C. M. & Santos, M. A. (2011). Familiares de mulheres com câncer de mama: vivências diante da possibilidade de morte. *Psicologia: Teoria e Pesquisa, 27*(4), 475-484*.*

Ambrósio, D. C. M. & Santos, M. A. (2015). Apoio social à mulher mastectomizada: um estudo de revisão. *Ciência & Saúde Coletiva*, *20*(3), 851-864. https://dx.doi.org/10.1590/1413-81232015203.13482014

Andrade, C. C. & Holanda, A. F. (2010). Apontamentos sobre pesquisa qualitativa e pesquisa empírico-fenomenológica. *Estudos de Psicologia (Campinas), 27*(2), 259-268.

Andres, J. C., Lima, R. A. G., & Rocha, S. M. M. (2005). Experiência de pais e outros familiares no cuidado à criança e ao adolescente após o transplante de medula óssea. *Revista Brasileira de Enfermagem, 58*(4), 416-421. Recuperado em colocar data de http://www.scielo.br/pdf/reben/v58n4/a07v58n4

Arruda-Colli, M. N. F. & Santos, M. A. (2015). Aspectos psicológicos da recidiva em Oncologia Pediátrica: uma revisão integrativa. *Arquivos Brasileiros de Psicologia*, *67*(3), 75-93.

Arruda-Colli, M. N. F., Perina, E. M., & Santos, M. (2015) Experiences of Brazilian children and family caregivers facing the recurrence of cancer. *European Journal of Oncology Nursing, 19*, 458-464.

Arruda-Colli, M. N. F., Lima, R. A. G., Perina, E. M., & Santos, M. A. (2016). Child cancer recurrence: a study about the mother's experience. *Psicologia USP, 27*(2), 148-155.

Arruda-Colli, M. N. F., Perina, E. M., Mendonca, R. H. & Santos, M. A. (2015). Intervenção psicológica com familiares enlutados em oncologia pediátrica: revisão da literatura. *Psicologia: Teoria e Prática, 17*(2), 20-35.

Backes, D. S., Backes, M. S., Medeiros, H. M. F., Siqueira, D. F., Pereira, S. B., Dalcin, C. B., & Rupolo, I. (2012). Spirituality workshops: alternative care for the comprehensive treatment of drug addicts. *Revista da Escola de Enfermagem da USP, 46*(5), 1253-1258. doi: 10.1590/S0080-62342012000500030

Benites, A. C., Neme, C. M. B., & Santos, M. A. (2017). Significados da espiritualidade para pacientes com câncer em cuidados paliativos. *Estudos de Psicologia (Campinas), 34*(2), 269-279.

Bevans, M., Wehrlen, L., Castro, K., Prince, P., Shelburne, N., Soeken, K., & Wallen, G. (2014). A problem-solving education intervention in caregivers and patients during allogeneic hematopoietic stem cell transplantation. *Journal of Health Psychology*, 19(5), 602-617. doi: 10.1177/1359105313475902

Boff, L. (2006). *Espiritualidade: um caminho de transformação*. Rio de Janeiro: Sextante.

Bruns, M. A. T. & Holanda, A. F. (2001). *Psicologia e pesquisa fenomenológica: reflexões e perspectivas*. São Paulo: Omega.

Cooke, L., Grant, M., Eldredge, D. H., Maziaiz, R. T., & Nail, L. M. (2011). Informal caregiving in HCT patients. *European Journal of Oncology Nursing*, *15*(5), 500-507. doi: 10.1016/j.ejon.2011.01.007

Çuhadar, D., Tanriverdi, D., Pehlivan, M., Kurnaz, G., & Alkan, S. (2016). Determination of the psychiatric symptoms and psychological resilience levels of hematopoietic stem cell transplant patients and their relatives. *European Journal of Cancer Care, 25*(1), 112-121. doi: 10.1111/ecc.12219

El-Jawahri, A., Traeger, L., Kuzmuk, K., Eusebio, J., Vandusen, H., Shin, J., K., ... Teme, J. S. (2015). Quality of life and mood of patients and family caregivers during hospitalization for hematopoietic stem cell transplantation. *Cancer, 121*(6), 951-959. doi: 10.1002/cncr.29149

Espíndula, J. A., Pontes, A. C., Valle, E. R. M., & Santos, M. A. (2007). Bioética e profissionais de saúde: algumas reflexões. *Bioethikos, 1*(1), 68-75.

Fife, B. L., Monahan, P. O., Abonour, R., Wood, L. L., & Stump, T. E. (2009). Adaptation of family caregivers during the acute phase of adult BMT. *Bone Marrow Transplantation, 43*(2), 959-966. doi: 10.1038/bmt.2008.405

Fleck, E. C. D. & Dillmann, M. (2012). "A vossa graça nos nossos sentimentos": a devoção à Virgem como garantia da salvação das almas em uma manual de devoção do século XVIII. *Revista Brasileira de História, 32*(63), 83-118. doi: 10.1590/S0102-01882012000100005

Fonseca, J. P. (2001). *Luto antecipatório: as experiências familiares diante de uma morte anunciada*. Dissertação de Mestrado, Pontifícia Universidade Católica, São Paulo.

Fonseca, J. P. & Fonseca, M.I. (2002). Luto antecipatório. In M. H. P. Franco (Org), *Estudos avançados sobre o luto*. Campinas, SP: Livro Pleno.

Forghieri, Y. C. (2004). *Psicologia fenomenológica: Fundamentos, método e pesquisa* (2ª ed.). São Paulo, SP: Pioneira.

Giorgi, A. & Sousa, D. (2010). *Método fenomenológico de investigação em psicologia.* Lisboa, Portugal: Fim do Século.

Giovanetti, J. (2005). Psicologia existencial e espiritualidade. In M. M. Amatuzzi (Org.), *Psicologia e espiritualidade* (pp. 129-146). São Paulo: Paulus.

Gomes, W. B. (1998). *Fenomenologia e pesquisa em Psicologia.* Porto Alegre, RS: Editora da Universidade/UFRGS.

Gomes, W. B. (2007) Distinção entre procedimentos técnico e lógico na análise fenomenológica. *Revista da Abordagem Gestáltica, 13*(2), 228-240.

Holanda, A. F. (2001). Pesquisa fenomenológica e psicologia eidética. In M. A. Bruns & A. F. Holanda (Orgs.), *Psicologia e pesquisa fenomenológica: reflexões e perspectivas* (pp. 15-22), São Paulo, SP: Ômega.

Holanda, A. F. (2014). *Fenomenologia e humanismo.* Curitiba, PR: Juruá.

Jobe-Shields, L., Alderfer, M. A., Barrera, M., Vannatta, K., Currier, J. M., & Phipps, S. (2009). Parental depression and family environment predict distress on children prior to stem-cell transplantation. *Journal of Developmental & Behavioral Practices, 30*(2), 140-146. doi: 10.1097/DBP.0b013e3181976a59

Koerner, S. S., Shirai, Y., & Pedroza, R. (2013). Role of religious/spiritual beliefs and practices among latino family caregivers of Mexican descent. *Journal of Latina/o Psychology, 1*(2), 95-111. doi: 10.1037/a0032438

Kovács, M. J. (2007). Espiritualidade e psicologia: cuidados compartilhados. *O Mundo da Saúde,* 31(2), 246-255. Recuperado de http://www.saocamilo-sp.br/pdf/mundo_saude/53/12_Espiritualidade.pdf

Larsen, H. B., Heilmann, C., Johansen, C., & Adamsen, L. (2011). An analysis of parental roles during haematopoetic stem cell transplantation of their offspring: a qualitative and participant observational study. *Journal of Advanced Nursing*, *67*(7), 1458-1467. doi: 10.1111/j.1365-2648.2010.05587

Laudenslager, M. L., Simoneau, T. L., Kilbourn, K., Natvig, C., Philips, S., Spradley, J., Benitez, P., McSweeney, P., & Mikulich-Gilbertson, S. K. (2015). A randomized control trial of a psychosocial intervention for caregivers of allogeneic hematopoietic stem cell transplant patients: effects on distress. *Bone Marrow Transplantation, 50*(8), 1110-1118. doi: 10.1038/bmt.2015.104

Matias, A. B., Oliveira-Cardoso, E., Mastropietro, A. P., Voltarelli, J. C., & Santos, M. A. (2011). Qualidade de vida e transplante de células tronco-hematopoéticas alogênico: um estudo longitudinal. *Estudos de Psicologia, 28*(2), 187-197. doi: 10.1590/S0103-166X2011000200006

Mayer, D. K., Tighiouart, H., Terrin, N., Stewart, S., Peterson, E., Jeruss, S., & Parsons, S. K. (2009). A brief report of caregiver needs and resource utilization during pediatric hematopoietic stem cell transplantation. *Journal of Pediatric Oncology Nursing, 26*(4), 223-229. doi: 10.1177/1043454209340409

Mazza, M. M. P. R. & Lefevre, F. (2005). Cuidar em família: análise da representação social da relação do cuidador familiar com o idoso. *Revista Brasileira de Crescimento e Desenvolvimento Humano, 15*(1), 73-84.

Moreira, M. D. & Caldas, C. P. (2007). A importância do cuidador no contexto da saúde do idoso. *Escola Anna Nery Revista de Enfermagem*, *11*(3), 520-525.

Moreira, V. (2004). O método fenomenológico de Merleau-Ponty como ferramenta crítica na pesquisa em psicopatologia. *Psicologia: Reflexão e Crítica, 17*(3), 447-456.

Oliveira, E.A., Santos, M. A., & Mastropietro, A. P. (2010). Apoio psicológico na terminalidade: ensinamentos para a vida. *Psicologia em Estudo*, 15 (2), 235-244. doi: 10.1590/S1413-73722010000200002

Pennarola, B. W., Rodday, A. M., Mayer, D. K., Ratichek, S. J., Davies, S. M., Syrjala, K. L., Patel, S., Bingen, K., Kupst, M. J., Schwartz, L., Guinan, E. C., Hibbard, J. H., & Parsons, S. K. (2012). Factors associated with parental activation in pediatric hematopoietic stem cell transplant. *Medical Care Research and*

Review, 69(2), 194-214. doi: 10.1177/1077558711431460

Pessini, L. (2007). A Espiritualidade interpretada pelas ciências e pela saúde. *O Mundo da Saúde,* 31(2), 187-195. Recuperado de http://www.saocamilo-sp.br/pdf/mundo_saude/53/06_a_espiritualidade.pdf

Rodday, A. M., Pedowitz, E. J., Mayer, D. K., Ratichek, S. J., Gien, C. W., & Parsons, S. K. (2012). Parental caregiving of children prior to hematopoietic stem cell transplant. *Research in Nursing & Health, 35*(4), 328-339. doi: 10.1002/nur.21485

Schneider, M. A., & Mannell, R. C. (2006). Beacon in the storm: an exploration of the spirituality and faith of parents whose children have cancer. *Issues in Comprehensive Pediatric Nursing, 29*,(1) 3-24. doi: 10.1080/01460860500523731

Torskenaes, K. B., Baldacchino, D. R., Kalfoss, M., Baldacchino, T., Borg, J., Falzon, M., & Grima, K. (2015). Nurses' and caregivers' definition of spirituality from the Christian perspective: a comparative study between Malta and Norway. *Journal of Nursing Management, 23*(1), 39-53. doi: 10.1111/jonm.12080

Vidotti, J. F. (2017). *Descobrindo o câncer de mama: uma compreensão fenomenológica das vivências do processo de comunicação diagnóstica.* Dissertação de Mestrado, Faculdade de Filosofia, Ciências e Letras de Ribeirão Preto, Universidade de São Paulo, Ribeirão Preto, Brasil).

Received: Dec. 20, 2016
Approved: Jul. 18, 2017

Iara Silva Freitas: Psychologist by the Faculty of Philosophy, Sciences and Letters of Ribeirão Preto, University of São Paulo (FFCLRP-USP).

Erika Arantes de Oliveira Cardoso: Master and PhD in Psychology. Psychologist, Department of Psychology, FFCLRP-USP. Member of the Laboratory of Teaching and Research in Health Psychology - LEPPS (FFCLRP-USP-CNPq).

Manoel Antônio Santos: Associate Professor, Graduate Program in Psychology, FFCLRP-USP. Coordinator of the Laboratory of Teaching and Research in Health Psychology - LEPPS (FFCLRP-USP-NPq). CNPq Research Productivity Scholarship, level 1B.