Religious beliefs, illness and death: family's perspectives in illness experience

CRENÇAS RELIGIOSAS, DOENÇA E MORTE: PERSPECTIVA DA FAMÍLIA NA EXPERIÊNCIA DE DOENÇA

CREENCIAS RELIGIOSAS, ENFERMEDAD Y MUERTE: PERSPECTIVAS DE LA FAMILIA EN LA EXPERIENCIA DE LA ENFERMEDAD

Regina Szylit Bousso[1], Kátia Poles[2], Taís de Souza Serafim[3], Mariana Gonçalves de Miranda[4]

ABSTRACT

The objectives of this study were to identify predominant themes in religion, illness and death in the life histories of families and examine the relationship between religion creeds, illness and death in the discourse of families that have an ill person. The theoretical framework used in this study was Symbolic Interactionism and the method was Oral History. Participants were seventeen families with nine different religions, who had experienced the death of a relative. Data analysis showed that following a religion is a relevant part of the lives of many families and cannot be neglected in the illness context. Results point to the importance of understanding the meaning that religion has to the families in the health-disease process, so nurses can work on the promotion of health.

RESUMO

Este estudo teve como objetivos identificar temas predominantes sobre religião, doença e morte nas histórias de vida de famílias e examinar a relação entre as crenças religiosas, doença e morte na narrativa de famílias que conviveram com um familiar doente. Utilizamos como referencial teórico o Interacionismo Simbólico e como referencial metodológico a História Oral. Participaram do estudo dezessete famílias de nove religiões diferentes que vivenciaram a experiência de doença e morte de algum familiar. Por meio da análise dos dados, foi possível compreender que a religiosidade é parte relevante da vida de muitas famílias e não pode ser negligenciada no contexto da doença. Os resultados apontam para a importância de se compreender o significado da religião para a família no processo saúde doença, a fim de que o enfermeiro possa atuar na prevenção e promoção da saúde.

RESUMEN

Este estudio tuvo como objetivos identificar temas predominantes sobre religión, enfermedad y muerte en las historias de vida de familias y examinar la relación entre las creencias religiosas, enfermedad y muerte en la narrativa de familias que convivieron con un familiar enfermo. Utilizamos como referencial teórico el Intencionalismo Simbólico, y como referencial metodológico la Historia Oral. Participaron del estudio diecisiete familias de nueve religiones diferentes que vivieron la experiencia de enfermedad y muerte de algún familiar. Mediante el análisis de los datos, fue posible comprender que la religiosidad es parte relevante de la vida de muchas familias y no puede ser obviada en el contexto de la enfermedad. Los resultados determinan la importancia de entender el significado de la religión para la familia en el proceso de salud-enfermedad, a efectos de que el enfermero pueda actuar en la prevención y promoción de la salud.

DESCRIPTORS
Death
Thanatology
Religion
Attitude to death
Family

DESCRITORES
Morte
Tanatologia
Religião
Atitude frente a morte
Família

DESCRIPTORES
Muerte
Tanatología
Religión
Actitud frente a la muerte
Familia

[1] RN. Associate Professor, Maternal-Infant and Psychiatric Nursing Department, University of São Paulo School of Nursing. São Paulo, SP, Brazil. szylit@usp.br
[2] RN. Ph.D. in Nursing from University of São Paulo School of Nursing. Faculty, Centro Universitário de Lavras. Lavras, MG, Brazil. kpoles@usp.br [3] RN, Bachelor's Degree in Nursing from University of São Paulo School of Nursing. São Paulo, SP, Brazil. tais_serafi@hotmail.com [4] RN, Bachelor's Degree in Nursing from University of São Paulo School of Nursing. São Paulo, SP, Brazil. mari_mgm1@yahoo.com.br

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INTRODUCTION

Disease frequently causes suffering and unleashes the search for meanings, in the attempt to understand such as devastating experience. These meanings are molded by beliefs and inserted in histories of faith and understanding of the sacred. According to the authors, the sacred refers to the divine, God, something of higher value or philosophical commitment[1].

Telling stories of suffering can offer relief and opportunity to find different meanings for the experience[2]. For nurses and other health professionals, this is a call to listen to stories patients and their relatives tell, with a view to promoting the relief of suffering[1]. The skill to find meaning and give meaning to their lives is fundamental to understand the process patients and their families experience.

According to different authors, religious and spiritual beliefs provide possibilities of attributing meaning and answers to the existential questions that emerge in view of disease and the possibility of death[3-5]. Helping patients and family members to find meanings for their experiences, however, still represents a challenge for health professionals. This is mainly due to the fact that professionals feel unprepared to deal with patients and relatives' religious and spiritual beliefs and, also, the lack of studies on this theme in scientific literature[1].

Getting access to patients' religious and spiritual dimension represents a deeper understanding of their beliefs and values, allowing health professionals to better respond to their needs. Health education still contains a strong objective component and, therefore, many professionals still feel reluctant to address religious and spiritual issues. Today, there is a growing trend to incorporate the spiritual and philosophical dimensions into health care. According to the authors, patients should be holistically understood as persons, and not simply as isolated examples of diseases[6-7].

Getting access to patients' religious and spiritual dimension represents a deeper understanding of their beliefs and values, allowing health professionals to better respond to their needs.

Religion is frequently described as shared, institutionalized values and beliefs and implies involvement in a community[8]. Religion offers emotional and social support, motivation and healthcare resources and promotes healthier lifestyles. In this sense, health professionals need to know the beliefs that make patients and their relatives more or less willing to receive treatment[9].

In an analytic study on the religiosity concept[10], the author affirms that the definition of this concept remains weak, indicating the importance of research in the area. The following attributes were found for the concept: religious affiliation (protestant, catholic, evangelical), religious activities (prayers, activities in church) and religious beliefs (relation with a higher force, religion's system of beliefs).

Although some studies found correlations between religiosity and positive reactions of coping in view of adverse situations[11-12], inquiries on the influence of religion on the disease and death experience from the perspective of patients' relatives are still limited[5].

OBJECTIVES

This study aimed to: identify predominant themes about religion, disease and death in the life histories of families and examine the relation between religious beliefs, disease and death in the narrative of families who lived with a sick family member.

METHOD

The qualitative method is recommended when little is known about a phenomenon or one intends to describe it from the subject's viewpoint, which applies to this study[13]. Symbolic Interactionism was used as the theoretical framework, as fundamental importance is attributed to the meaning of things for human behavior. The meaning of things is seen as a social product originating in symbolic interaction, in which the human being defines and interprets actions through the activities people develop while interacting[14].

In view of the study type and believing in the importance of studying phenomena from people's own perspective in their life context, Oral History was chosen as the methodological framework to conduct this research. Oral History departs from the premise of perceiving the past as something that continues today and whose historical process has not terminated. Thus, the presence of the past in people's immediate present is the reason why oral history exists[15].

Oral history is considered the central study focus and testimonies as the central point of analysis. To reach the methodological value, the researcher focuses on the project elaboration criteria, on the accomplishment of interviews, on the transfer process from oral to written text and on the results fine-tuned with the meaning of the interview. The results are based on the expression of these interviews, as the central point of the research[15].

In this research, thematic oral history was used, which offers the closest approach to the common and traditional solutions for presenting analytic studies in different academic knowledge areas. It almost always considers oral documentation as equivalent to the use of written sources[15].

Regarding sample representativeness, each testimony, each interview is valuable in itself. Hence, it cannot be affirmed that one or some interviews *represent* the set. The

individual version of each phenomenon, however, is important and justified in view of the sum of arguments that characterize the experience as a whole, that is, for oral history, each testimony has an autonomous weight. Thus, one single interview is not considered capable of synthesizing the conception of all family members' experience, but the various interviewees' set of beliefs becomes significant in the search to understand the theme[15].

Selection of collaborators

To select the collaborators, a colony needs to be established. A colony is a group or community of people who are part of the research and display a broad and characteristic behavior. It is defined by the preponderant traits that connect people's trajectories[15].

The selection of the families who were part of the colony was based on the criterion of having experience the disease and death of a relative, independently of the religion. The first family that was selected in compliance with this criterion was acquainted with one of the researchers and, upon that family's indication, access was obtained to another family's experience. As one family was interviewed, the researchers asked to indicate another family that had gone through the experience of disease and death and, thus, a network started to be formed.

Initial contact was established by phone, when the families were invited to participate in the study and, after their consent, an appointment was made for the interview. All family members were invited to participate in the interview, in view of the family's definition of itself. Thus, the colony comprised seventeen families from nine different religions who experienced the disease and death of a family member. With the person who had gone through the disease experience as a reference, three sons, two daughters, two brothers, one sister, nine mothers, one father and one maternal grandmother. The participating families themselves chose to hold 15 interviews with one single member and two interviews with two members (mother and maternal grandmother; father and mother). Five catholic, three evangelical, two spiritist, two Baptist, one *umbanda*, one protestant, one Buddhist, one spiritualist and one *Seicho-no-ie* family.

Data collection

In compliance with legislation on research involving human beings[16], the research project was forwarded to the University of São Paulo School of Nursing Institutional Review Board and approved (Protocol No 585/2006/CEP-EEUSP). Interviews were recorded after the authorization and signing of the Informed Consent Term. These interviews took place in a calm and private environment, avoiding interruptions and distractions, with a mean duration of forty minutes.

A script was used, as a fundamental piece to obtain the data investigated in thematic oral history[15]. The script comprised three moments with different foci: (1) religion in the interviewee's life history; (2) disease and religious experiences (when and how their religious beliefs affect their health and how) and (3) the themes religion and disease, religion and death. The script contained the following guiding questions:

- Tell me how religion started to be part of your life?
- How does religion appear in your daily life?
- Think of a disease: How do your religious beliefs affect the disease experiences?
- What does the disease mean to you?
- What does death mean?

Data analysis

The steps of oral history were followed for data analysis purposes[15]: *1) Transcription* – is the rigorous passage from the tape-recorded interview to paper, including the interviewer's answers; 2) *Textualization* – when questions are suppressed and added to the answers. Then, the Vital Tone is chosen, which is a phrase to introduce the oral history because it represents the guiding axis of reading 3) *Transcreation* – Is the phase when the testimony is processed in a broader sense, inverting the order of paragraphs, removing or adding words and phrases.[15] Then, thematic analysis followed, with pre-analysis, exploration of the material for categorization, result treatment and interpretation.

RESULTS

The narratives helped to understand how the families experience different religious cults, with their disease and death perspectives, are incorporated into the experiences of suffering. The families continuously construct and reconstruct the meanings of the events. The data were grouped in three categories, which were: *Religion and the health-disease process; The importance of religiosity in disease and death situations; Death perspective according to religiosity*; and also grouped in sub-categories.

Category 1 – Religion and the health-disease process

Religion or religious beliefs and practices can be determinant in the health-disease process to the extent that it preaches the adoption of healthy habits and behaviors that benefits whoever practices them. Some religious practices entail healthy physical and mental health effects. These practices influence family members and sometimes play an important role in disease prevention.

> My family, thanks God, liked my change because I stopped living my daily life of bars, liquor, they liked it because I got close to religion [...] at least I didn't annoy them with the liquor thing (Family 4).

Thus, religious involvement can be related with a desirable health result for one of the family members. The narrative analysis revealed that, when related with the health-

disease process, the meaning attributed to the corresponding beliefs permeates religious behavior. Consequently, depending on the family's belief, the meaning given to the disease and death makes coping with these difficult situations easier or not.

Religious beliefs and practices that facilitate coping

Religion is an instrument of explanations that help to give meaning to the disease and death experiences. Spirituality, religiosity or religious beliefs reveal to conduct family members' behavior when moving towards a state of adaptation and adjustment to the disease and death. Believing that life does not end at the moment of death appears as a consolation in the narratives, which permits better acceptance of death. Praying shows to be a common and comforting practice in times of difficulty.

> If I didn't hope that everything does not end here, I wouldn't have a reason to keep on living, knowing that everything ends, I wouldn't have a reason to study, to achieve things, I wouldn't have a reason for anything (Family 3).

> Death itself only relates to the material body, this body of flesh, there is no death of the spirit, the spirit is eternal, it just changes bodies in different incarnations. That offers a lot of comfort (Family 2).

> From the moment my son died, we understood that his relationship becomes a project for eternity and not for the days we are here on Earth (Family 10).

> I don't face death as something frightening, if it comes it's because God is going to take us to glory at the right time, but I think death is terrifying for people who do not fear God (Family 15).

Religious beliefs and practices that hamper coping

Questions about who is guilty or the reasons for the disease were present in the narratives. The family can associate the disease with something negative based on its beliefs, and this type of association can determine the extent to which the disease is accepted and guide the way the family deals with the situation. Believing that the disease derives from the person's own attitudes can cause feelings of guilt and even hamper treatment. The moral aspect also emerges when the explanation presents the disease with punitive connotations.

> His disease was a consequence, although he converted, the Bible is clear, you will harvest the fruits of everything you plant (Family 3).

> We were raised, born and bred in sin, the Bible says that the salary of sin is death (Family 10).

Category 2 – The importance of religiosity in situations of disease and death

In stressful situations like disease and death, the family can get closer to religious institutions or religiosity in search of emotional support, answers to its inquiries, or in search of religious beliefs and practices that facilitate coping with these difficult situations.

Search for emotional support

Disease and death can turn into situations of approximation with the divine, attempting savior or problem solving. The more attached to spiritual aspects, the more the family identifies resources and maintains its energy to keep up the stressful situation of disease. Religion or religiosity cannot solve the situation instantaneously, but to gradually renew energies to allow the family to identify resources and learn how to deal with the situations.

> It is an opportunity to approach spirituality, we get more sensitive, and more attached to God. At these times, we seek hidden forces to recover and religion represents this approach to spirituality... it's the strength we need, it's great support (Family 6).

> Spirituality was a way to keep going, the feeling of knowing that I was being helped is beyond description, by people, by friends, by their prayers (Family 11).

> My faith got much stronger after my son's illness, we definitely know that someone's watching out for us and that's comforting, someone up there, some higher force, I think we have to know how to ask and thank and believe in that (Family 12).

Search for answers

The family uses religious resources to understand the disease and death and deal with them. Thus, religious beliefs and values are used to help and give meaning to the disease and death event. The religious strategy is sought to provide an explanation for the unavoidable, seeking support for its affliction.

> This loss of my mother, this piece God took away from us, was for our growth, for one to help the other, because perhaps, if she were here, everything was just the same old thing, each person thinking of himself (Family 7).

> God used this for me to stop a little, to give me maturity in this area which I didn't have yet and, if I hadn't gone through all this, I wouldn't be such a good mother, it was a very painful moment, but it was a moment when I learned things about me I didn't know yet, I learned about my daughter and learned for my life really (Family 8).

> I think these are phases we have to go through and which serve to strengthen (Family 13).

One essential component in the family's assessment of the relation between religion, illness and death comprises the beliefs and values that guide the family's life. The support resources found in different religions help to comfort the families during unexpected experiences of disease and death, offering explanations that these experiences entail positive consequences for the family's life as a form of growth, regeneration or evolution.

> It happened with my mom for everyone to grow. Each person grew in a way, but everyone had to grow... We're down here only to grow, it's a school here, we are here to learn, to get a diploma (Family 7).

Sometimes, the explanation religion provides does not answer all inquiries of people who experience the disease and death situation. They start to seek more convincing answers or explanations in other religions. Hence, without an explanation that gives meaning to the suffering experienced, the family can easily move between different cults and religions.

> As I didn't find answers in Catholicism, I started to research... I went to evangelical churches, I went to Seicho-no-ie and I started... I looked for someone who would show me answers, intelligent answers! [...] and after looking I found spiritism and the rational answers I was wanting (Family 2).

Category 3 – Death perspective according to religiosity

Religion imposes itself as the social institution that controls the rituals and knowledge associated with death. It does not only offer comfort during these times of suffering, but also, at least in some beliefs, offers a promise of life after death and reunion with the lost family. The different religions and beliefs offer the family several perspectives of death. Like disease, death was also associated with something positive or negative, depending on the type of belief of the person experiencing the situation.

Death as something natural

It is common for the family to adopt a biological perspective on death – as something natural. It should be highlighted that all families referred to older people who had died: parents, grandmothers, aunts. Perhaps this perspective was not that present in the death of children or young people.

> For me, death is a phase of life, that quite biological things, I think everything has its start, middle and end. The human being, we human beings are embedded in that, you are born, grow up and die. It's just that I also have this view of something that is like an evolution, that I'm going to an eternal life, a life different from what I live here, I have a notion. I believe that I'm not here in the world at random, that I have a mission to fulfill, that I'm not present at times and in places where I am at random for me it doesn't exist, coincidence does not exist (Family14).

The death event was associated with a form of family growth, as a means to get closer to the family and not with a negative meaning of abandonment or something insurmountable. The family seeks a meaning for the death event and, based on that, tries to reconstruct life or construct a new life. The explanation of death as natural and unavoidable also appears as a positive form of attributing meaning to the event.

> For me, death does not mean anything, because death does not exist, what exists is a continuation. So it was better for her to go than stay and suffer like that (Family 4).

Death as a determinant of the divine

In the disease and death situation, the family attributes not only the cause of the event, but also, sometimes, the possibility to overcome the experience, a way not to lose hope, to God or hidden forces. When assuming submission to God and acceptance of situations of suffering, it becomes easier to keep going, thus eliminating the weight in accountability regarding the disease or death.

> The Lord took her away from Earth so that I can learn to seek God more (Family 16).

> I don't see death as something frightening, I believe that, if it comes, it's because God will lead us to glory at the right time (Family 15).

Religious faith, associated with the support the spiritual community, grants the family better internal control. All religions offer *solutions* for the death problem, a control that belongs to God. Religious practice is a strategy to recover strengths lost during the suffering experience. In this context, religious beliefs and practices respond to the emotional need of having future expectations.

> My religion has always given me support, even more than others, because we even end up feeling carried on the lap by spirituality (Family 2).

> There's no doubt that my faith was what helped me to win all this (Family 8).

> The feeling of knowing that you are being helped, by people, by friends, by their prayers (Family 12).

DISCUSSION

The family deals with the suffering as it can at that given moment, as coping actions are limited by the pressure of the event, by the system of predominant beliefs and by the assessment of resources available to cope with them[17].

The relation between religious symbols and social life is established in the course of disease and death events, during which individuals appropriate themselves of, confront and reinterpret the symbols in the light of certain goals and interests[18].

When studying the religiosity concept[9], the author evidenced that the disease experience is one of the antecedents of the concept, that is, when people are confronted with adverse experiences, religiosity appears as a resource to overcome the crisis. One of the consequences of religiosity refers to positive coping with the stressful events of life, such as disease and death situations, as evidenced in the present study.

Various studies have demonstrated the influence of religious beliefs on the construction of meanings in stressful events. These studies have also permitted a better understanding of individual needs in the construction and reconstruction of these meanings and realities, seeking to overcome the suffering the experience imposed[19]. By attributing meaning to stressful experiences, the family manages to transcend the experience[2]. The families' narratives also demonstrated the search for meanings for the experienced events, based on their respective religious beliefs.

The range of religions included in this study was restricted and, therefore, these results cannot be generalized. The study about religions and their relation with disease and death in the families' perspective deserves further research and different research strategies.

CONCLUSION

The narratives raise important questions on the functions of religions in disease and death experiences for the families. The data permitted the construction of categories that relate religion, disease and death in the family's life history. In general lines, it shows us that the benefit of religion and spirituality in these experiences depends on the interaction among factors in the context of the disease event.

It is obvious that religion can offer benefits for this experience, such as social support, emotional support, motivation and hope. These are coping strategies the family uses in stressful situations of disease and death.

Religiosity is a relevant part of many families' life and cannot be neglected in the context of the disease. This is not about defending the use of religiosity in coping as an instrument or resource, but about its valuation when the family has religious beliefs and already uses these in life.

This study reveals the importance, for nursing, of understanding and accepting that the other is a being permeated with beliefs based on his/her respective religions. These beliefs influence the way the person copes with the situations of loss, and also influences the meaning of the disease and death for the person and, often, determines the extent to which these situations affect the family.

Despite some study limitations, this study does not lose its potential to encourage future research, to equip health professionals in the attempt to learn how to deal with families' different reactions towards situations of loss, which can be positive or negative, but play a determinant role in family contacts and extra-family relations.

This study presents the idea about the importance of religion and the religious group as a source of support in disease and death situations and even a form of coping with them in the best possible way, as the meaning of the disease and death for people varies according to their beliefs and religion.

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Correspondence addressed to: Regina Szylit Bousso
Av. Dr. Enéas de Carvalho Aguiar, 419 - Cerqueira César
CEP 05403-000 - São Paulo, SP, Brazil