THE MEANING OF RELIGIOUS BELIEFS FOR A GROUP OF CANCER PATIENTS DURING REHABILITATION[1]

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Aquino VV, Zago MMF. The meaning of religious beliefs for a group of cancer patients during rehabilitation. Rev Latino-am Enfermagem 2007 janeiro-fevereiro; 15(1):42-7.

The objective of this exploratory study was to identify how religion influences the survival of a group of cancer patients. The study consisted of an ethnographic case with the participation of six laryngectomized male and female patients between 51 and 72 years old, who had been operated on two to five years earlier. Data were collected by semistructured interviews and analyzed on the basis of the concepts of culture and religion. The results were synthesized into three descriptive categories: the moral representation of cancer, religious beliefs about the cancer trajectory, and negotiation with religion for survival. These categories give rise to the meaning "the hope for a second chance", which emphasizes the importance of religion as part of the support networks that articulate with the patient's coping with the stigma of cancer, with the hope for cure, and with the ways of organizing everyday life, during survival.

DESCRIPTORS: neoplasms; medical oncology; religion; culture; survival; rehabilitation

EL SIGNIFICADO DE LAS CREENCIAS RELIGIOSAS PARA UN GRUPO DE PACIENTES ONCOLÓGICOS EN REHABILITACIÓN

La finalidad de este estudio exploratorio fue identificar cómo la religión influencia la supervivencia de un grupo de pacientes oncológicos. Consistió en un estudio de caso etnográfico con la participación de seis laringectomizados, de ambos sexos, con edad de 51 a 72 años, que habían sido operados de dos a cinco años antes. Los datos fueron recogidos por entrevistas semi-estructuradas y analizados según los conceptos de cultura y religión. Sintetizamos los resultados en tres categorias descriptivas: la representación moral del cáncer, las creencias religiosas en el trayecto del cáncer y la negociación con la religión por la supervivencia. El significado que resulta - "la expectativa por una segunda oportunidad" - enfatiza la importancia de la religión como parte de las redes de apoyo que se encadenan con la conciliación con el estigma del cáncer, con la expectativa de cura y con las formas de arreglar la vida cotidiana, en la supervivenvia.

DESCRIPTORES: neoplasmas; oncologia médica; religion; cultura; supervivencia; rehabilitación

O SIGNIFICADO DAS CRENÇAS RELIGIOSAS PARA UM GRUPO DE PACIENTES ONCOLÓGICOS EM REABILITAÇÃO

Este estudo exploratório teve o objetivo de identificar como a religião influencia a sobrevivência de um grupo de pacientes oncológicos. Consistiu em estudo de caso etnográfico, com a participação de seis laringectomizados, de ambos os sexos, na faixa etária de 51 a 72 anos, operados de dois a cinco anos. Os dados foram coletados por entrevistas semi-estruturadas e analisados segundo os conceitos de cultura e religião. Sintetizou-se os resultados em três categorias descritivas: a representação moral do câncer, as crenças religiosas na trajetória do câncer e a negociação com a religião para a sobrevivência. O significado que emerge - "a expectativa por uma segunda chance" - enfatiza a importância da religião como parte das redes de apoio que se articulam com o enfrentamento do estigma do câncer, com a expectativa da cura e com as formas de organizar a vida cotidiana, na sobrevivência.

DESCRITORES: neoplasias; oncologia; religião; cultura; sobrevivência; reabilitação

[1] Study presented at the 20th Symposium of Scientific Initiation at the University of São Paulo, Funded by the Brazilian Council of Scientific and Technological Development - CNPq, process number 520604/96-2; [2] Undergraduate Student, Scientific Initiation grant holder; [3] Advisor, Associate Professor, email: mmfzago@eerp.usp.br. University of São Paulo at Ribeirão Preto College of Nursing, WHO Collaborating Centre for Nursing Research Development

INTRODUCTION

In Western societies, the symbolism associated with cancer is that of an incurable and mysterious disease that invades the body, causing losses and suffering. This symbolism persists even though the progresses of diagnosis and treatments have increased the patient survival.

The care of cancer patients comprises rehabilitation, a continuous and individualized process that aims at developing and maximizing the individuals' capacities within the limitations imposed by the disease and the treatment[1]. The purpose of rehabilitation is to promote the patient's survival with the best possible quality of life. In this context, survival refers to the period that begins at the time of diagnosis and lasts indefinitely during and after treatment[2].

We followed up cancer patients who participated of a support group called GARPO (*Grupo de Assistência à Reabilitação do Laringectomizado*, Group for Support to the Rehabilitation of the Laryngectomized). The frequent references that the patients made to their religious beliefs led us to resume our previous work that focused on the meaning of being laryngectomized. For these patients, the religious practice was a strategy for recovering the strength lost with the disease and the treatments[3]. Thus we started the present study with the objective to evaluate how religion influences the survival of cancer patients, using an interpretative-cultural approach.

THEORETICAL AND METHODOLOGICAL BACKGROUND: CULTURE, RELIGION AND ETHNOGRAPHIC CASESTUDY

Culture is a body of meanings transmitted historically within the social group, by means of which the individuals develop their knowledge and the activities related to life. As a social construct, culture provides a way of seeing and interpreting the world, framing the cognitive and the affective life, and as a consequence influences the individual's attitude to health and disease. The experience of having cancer is particularly challenging to the patient, who looks for means to confront it, and in the Western culture religion is viewed as a valuable strategy to cope with disease and its treatments[4].

The ethnographic case-study[5-6], a traditional tool of the anthropological research, was the methodological strategy selected to approach the problem, since it allows to consolidate the religious experience of the cancer survivors and at the same time recognizes the singularity of each individual and his (or her) point-of-view.

The study included six patients (three males and three females) who had been submitted to total laryngectomy between two to five years before the study, who did not present physiological complications, and communicated by esophageal speech, vocal prothesis or electronic larynx. They were from 51 to 72-year of age, three were married, two widowed and one single; two had retired before the surgery, two after the operation and two were still working.

Data were collected on the monthly meetings of the support group and in the patient's home, by means of semi-structured observations and interviews oriented by the question: "how the religious faith helps you to cope with your condition?" The interviews were recorded and transcribed, with the subject's permission. A mean of three interviews per participant were carried out, lasting an average of 20 minutes each, during a period of eight months.

The research was approved by the institutional review committee. All the patients agreed to participate, signed a term of free and informed consent and their names were coded by letters to preserve their identities.

Data analysis was performed in two steps. Firstly, by reading repeatedly the interview transcriptions, we constructed descriptive categories that descibe the contents or meanings given to the theme. Then, on the basis of the theoretical references, we constructed analytical categories that revealed religion as a coping strategy for the oncologic patient[5-6].

RESULTS AND DISCUSSION

The descriptive categories recognized were: the moral representation of cancer, the religious beliefs in the cancer trajectory, and the covenant [compromise, dealing] with religion for surviving. These categories summarize the meanings that the participants of the study attach to the religious beliefs as a strategy for surviving to cancer. On the basis of the anthropological concept of religion and of the social

and cultural characteristics of the participants, the above categories were integrated into the meaning "the hope for a second opportunity".

The moral representation of cancer

The moral and religious punitive connotation of cancer as a fatal disease, prevailing among the lower social strata, was emphasized by the participants of both sexes and all ages.

"God chooses strong persons for the trial of this disease. It is not a punishment. God tries people because some need to be molded, transformed. God draws a good from the evil!" (B., female, 51 years). "Now, after all this suffering, I understand that my life was not so good! I think that I didn't do the right things. I think that I am paying for what I've done. This disease makes us think about the life, what was right and what was wrong... Smoking and drinking were not the cause of the disease; it's something else, the improper lifestyle...." (D, male, 62 years).

This connotation is characteristic of the Western christianity that relays the idea that the individuals are subject forces of a fate divinely determined, which highlight the relation of punishment and redemption[7]. From this point-of-view, the religious interpretation of health-disease conveys the understanding that the world has an order in the sacred-profane field. By submitting to God and accepting the chaotic situations of life, it is possible that the sacred submit the profane. In this way, the divine entity dominates the human life, the unexpected (i. e., the disease) may be foreseen, the haphazard may be explained, fate is substituted by the divine providence[8].

The experience of a chronic disease and its therapies envisages [conceives, assumes] a symbolic bridge that links the body, the self-image and the society. This chain inter-relates the processes, the meanings and the relationships, in such a way that the social world is connected to the personal experience. This world is defined by [limited to?] what is of interest for the individuals and the social groups[9-10].

The religious beliefs in the cancer trajectory

The subjects emphasize their religious beliefs and behavior before the beginning of the disease.

"I've always been a catholic, but before my disease I used to pray alone" (C. Female, 56 years). "I've always been a catholic, like everyone else! But I didn't go to the church, I didn't talk to God" (D., male, 62 years). "Before the surgery I followed the catholic religion, went to church every Sunday, but I didn't pray the rosary" (A, female, 51 years). "I am a catholic. I don't go to church, don't practice, but I'm a catholic" (E., male, 72 years).

Women stressed more emphatically their religious links then men, but all pointed out that they were christian, in order not to stray from the social patterns of the group.

They started to look for the religious strategy at the time of diagnosis, searching for an explanation for the inevitable.

"I went to the religious feast, entered into the church and started praying the rosary. Then I asked God to show me the way. The doctor had not yet told me that it was cancer. I found the rosary and started to pay. When the doctor told me that I had a malignant tumor, it was incredible. It seemed that I was waiting for that ..." (A, female, 51 years).

In the search for religious support for their affliciton, a participant lived an unexpected situation.

"One week before being operated I went to the church and talked to the minister. I went there because it is near my house and I already knew that particular religion by the television. He told me that if I had a true faith in Jesus, I should not submit to the operation, because Jesus would operate me without need to do any surgery. But my niece said to me: Don't believe that! You will loose your turn in the operation list and then you'll need to wait your turn again. I was feeling very badly and thought: I will go through with the surgery. For me, Jesus is the doctors' doctor." (D, male, 62 years).

This account shows how the proposal for treatment by religious intervention caused a conflict to the patient, which was however solved by the family's intervention that helped her to decide for the medical treatment.

This image of suffering gives the oncologic patient a distinctive identity within the social group, an identity that simultaneously evokes strength and weakness, vulnerability and determination, resignation and courage. This way of interpreting a severe disease derives from common sense among different social groups[11]. In this situation, the individuals turn to God for the first time in their lives, or more often and fervently then before, *because God always help*.

Expressions such as *"God willing, God will help me, I ask God",* and *"I thank God"* that the particpants used frequently are learned very early in life in the family surroundings, and help to understand the influence of religion. However, these expressions are not related to the organic dimension, but rather reflect a relationship of the individual with the society,

elicited by the stigma associated with the profane image of the disease.

Thus, the search of religious support by means of ritualistic parctices or by invoking God, in the chaotic situation represented by the disease, is a practical strategy, especially because in the urban environment a large variety of religious services are available, and the members of the support network incentivate the patients to use them[11].

The covenant with religion to survive cancer

From the time of diagnosis and the surgery, survival is constantly threatened by the possibility of relapse. Although the participants were going through a particularly good period when they were interviewed, owing to the good physical conditions and the psychosocial rehabilitation, there was a permanent dread of relapse, revealed by the comments that circulated during the group meetings, about the patients who were not in remission any more. In this context, religious beliefs fulfill the need for hope in the future.

"I believe that God draws good from the evil. It is important that people do not give in to death, Jesus give us a lot of strength" (B, female, 54 years). "I truly believe in God. If you believe in Him, you may go through difficulties but He helps you" (C, female, 56 years). "Of course I changed! After all this, we get more attached to God. When we are well, we forget Got. I think God is one and the same, whatever the religion. Considering the type of operation that was submitted to... If you have strength and faith in God, He will help you!" (F, male, 53 years). "I don't go to the church, don't practice, but I am a catholic. I have always prayed and continue to pray... This helped me, because I asked God to get better, for everything to go well, and everything went well, God be blessed!" (E, male, 72 years).

The search for religious support involves the whole social network of the patient and the community, as revealed by the accounts.

"I've gone to various churches, the friends invite me and we go there to pray... they are always helping us..." (F, male, 53 years). "When I was operated, my brother asked a brotherhood to help me, to pray for me. The whole church helped me, the brethren prayed for me... When I was discharged from the hospital I went to the church; I went to the Universal Church, then to the International Church of the God's Grace, to which my sister belongs, and now I'm frequenting the Brazilian Christian Congregation. God is only one, always the same, only the churches are different. It is worth to be on God's ways; if you have faith, you'll succeed" (D, male, 62 years). "My wife helped me by praying for me in the church" (E, male, 72 years).

The majority of the participants report acceptance and attention by the church community during the periods of greatest severity of the disease, in this way approximating the religion with the disease setting. Family and the religious practices are part of the social networks that provide support to the patient, in particular in the cognitive, normative and affective domain[7].

There are several studies that emphasize the role of religious influence in the care of patients with severe diseases such as cancer. Some authors have pointed out that the rehabilitation of the patients who have religious beliefs is associated with a sense of hope and satisfaction with life and less depression. For this reason, religious belief is recognized as a coping strategy for survival in cancer, especially in lower social classes, independently of age and sex[11-14]. The power attributed to the divine entity permit the satisfaction of needs that escape the human control, avoiding the sentiments of fear of the future.

Meaning: The hope for a second opportunity

When the patients connect the disease with a religious design, the individual actions are reconciled with the sacred, acquiring a quality of moral or spiritual superiority that do not allow the separation of their health condition before and after the treatment. From the accounts of all the participants emerged the magic-religious belief that the divinity can control the worst situations.

"God helped me to accept well... When God closes a door, He opens a window. It is by God's mercy that I'm well. Now I can go out, take care of my affairs, do the cleaning up at home. It was a God's miracle. I thought that my life had come to the end. It's been four years since my operation... This must be a sign of God's help" (A, female, 51 years). "After all that, God teaches us everything... We loose the fear of the dying. I told Mary, the Mother of God: now I won't hold Your hand any more, I'll just lay my head on your bosom and let you do Your will" (B, female, 54 years). "God doesn't punish anyone. He helped me, because when I was going to the surgery I said: I'm going to die. However, when I woke up from the surgery I said: my God, I'm still here, thank you! You need to thank... I often ask for God's forgiveness for my errors, and He forgives me" (C, female, 56 years). "I thought: I'm nothing, I'll follow the path of the church. I want that Jesus protect me in all senses. There are some days that I wake up breathless because of the emphysema, which is severe and has no cure. Then I think: God suffered more than that, and He succeeded! I am sure that if it was not for Him I

wouldn't have learned to speak again. I'm sure that I owe everything to God. I can be cure any moment. I do my part…" (D, male, 62 years). "It's because I have a will, I don't give in. Religion teaches you to be patient, to have hope… the worst thing is to give in to the disease. Then, you must make an effort, it's not easy" (F, male, 53 years).

Cancer elicits two established images of cancer in the popular culture: diagnosis of cancer is equivalent to a death sentence, leading to fear; the understanding that diagnosis and treatment lead to a change - the opportunity of a second life. Within this context, the search for religion should not be seen as a means to escape form reality, but rather as a perspective for the future because of the suffering usually associated with cancer. This view helps to understand why the religions offer results of a symbolic efficacy, in relation to well-being and self-control. Culturally, religions play various role: to create an identity of cohesion between the people, to gain new strength in the fight for survival, and to reinforce a cultural resistance that by itself reinforces the search of religion as a solution, as related by one of the participants of this study[15].

Although some of the patients have attended services at several religious denominations, the form by which they refer to the religious faith is characteristic of Catholicism. Indeed, all the different religious practices that these patients attended share common aspects with popular Catholicism in relation to cure for a severe disease: the belief in a magic power, a kind of gravitational circle of energy that links all the believers who share the same expectations, and the feeling of a social order that derives from the miraculous intervention[12]. We need to consider, however, that faith, a central value for the religious system, is a personal experience or adhesion to the sacred. We observed that the participants follow a popular church denomination, such as the Catholic Church, for convenience or tradition, rather than by conviction derived from doctrinal knowledge. As a consequence, the form of practicing the religion is individual, although all the participants refer to attend some forms of cults or rituals, such as collective or individual pray. Thus, despite the personal involvement with the religion being only partial, it is sufficient to give the feeling of participating of a religious community, contributing to lessen the discriminations of the profane life in relation to cancer[11].

The apparent facility with which the participants move between different church denominations suggests that the social practices are disconnected from the projects of the different religious denominations. This means that the models that we use to understand the religious world of the individuals must evaluate the relationship between the symbols of a religion and the practices of its followers. The analysis of religion is then approached from the perspective of the religious experience, i. e., how the religious symbols are utilized and continuously gain novel meanings, as a consequence of the interaction between individuals and groups[11].

CLOSING COMMENTS

This study allowed us to understand that the cancer survivors live with a transition identity, owing to the long time since the operation and the good emotional and physiological conditions: they are not "normal" socially - because of the sequels - and symbolically they are human beings with differences. This creates ambiguity and uncertainty for their identity, and increases the need to respect the cultural tradition of religious beliefs and practices. Thus, the participants, who belong to the popular strata of society and to the age group above 50 years, behave as they feel appropriate to the situation of illness and survival to cancer, independently of their sex.

Spirituality is a construct of the personality of each individual - an expression of his/her identity and purpose at the light of the personal history, experience and aspirations. For this reason, religion lessens suffering, since it permits to change the subjective perspective under which the patient and the community experience the severe disease. Owing to the meanings of cancer, the patient redirects his attention to new aspects or perceives the experience from a new point of view. The relieve of suffering, the survival or the cure would not mean the return to the state before the disease; this changed situation is felt as new experience - a second opportunity of life brought about by survival. To achieve this, the adhesion to a religion, in accordance with the cultural construct of the social group, is more verbal than formal or systematic, and the patient attends to several of the religious practices and organizations available with support of the social network.

One of the difficulties of the professionals who deliver healthcare for the rehabilitation and survival

of oncologic patients is to understand how the patient perceives his/her own life after the disease. It is possible that the relationship that the health personnel establish with the patients is ruled by the expectation of searching for a rational and efficient survival, which may be incompatible with a comprehensive approach to the disease as a social and cultural construct. Recently, the role of spirituality and religion in the experience of cancer has been increasingly recognized, because instead of the reductionist explanation of medicine, the religious systems offer an explanation for the disease that is integrated into the patient's social and cultural context.

For this reason, the health professionals are increasingly aware of the importance to take religiosity into consideration when planning and delivering care to cancer survivors, in order to maintain trust and respect in relation to the patients' beliefs.

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Recebido em: 16.9.2005
Aprovado em: 12.3.2006