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Heart disease experience of adults undergoing coronary artery bypass grafting surgery

ABSTRACT

OBJECTIVE: To evaluate the meanings of heart disease experience in patients undergoing rehabilitation post-coronary artery bypass grafting surgery.

METHODS: Ethnographic study carried out between 2003 and 2005 in the city Goiânia, Central-West Brazil. Direct observation and in-depth interviews were conducted in 11 patients undergoing rehabilitation post-coronary artery bypass grafting surgery. Using an interpretative anthropology approach, data were gathered in narrative documents and analyzed through the identification of units of meanings and thematic groups.

RESULTS: Disease-related meanings included heart disease realization, triggered feelings, formulated explanations, surgery acceptance and post-surgery life. Heart disease experience was understood as a biographic rupture, a situation between life and death, disability, loss of autonomy, inability to work. The meanings, analytically constructed, followed a logic that articulated common sense, religion and fragments of medical discourse for the understanding of disease and surgery.

CONCLUSIONS: The study results showed that heart disease and surgery experience mark a rupture in the patient's lifestyle, work and their understanding of the health-disease process. The disease experience approach contributes to transcend the limits of a medical model based on disease, its symptoms and causes, and characterized by a biomedical understanding of the health-disease process focused on biological and/or psychological malfunctioning.

DESCRIPTORS: *Cardiomyopathies, rehabilitation. Self care. Psychosocial Impact. Anthropology, Cultural. Qualitative Research.*

INTRODUCTION

Given the many conceptual, cultural and scientific advances of modern society, investigators have increasingly focused their attention to the need of incorporating into their research new approaches and care models that include the social and cultural background of those receiving care. Concepts linking health and life conditions have been formulated taking into consideration the existing balance-imbalance relationship between people and their environment.¹⁸

This new perspective calls for studies that, as well as providing evidence on the efficacy of interventions and specialized diagnostic procedures, can also describe and contextualize the social reality of those people suffering from chronic conditions.²² Cardiovascular diseases are major conditions causing early morbidity and mortality in industrialized urban societies and they are anticipated as the main cause of death and disability by 2010.²⁵

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As a treatment of coronary artery disease, coronary artery bypass (CABG) surgery is intended to provide coronary insufficiency symptom relief, improve heart performance, prevent myocardial infarction and physically, psychically and socially recover patients with the overall goal of improving quality of life.^{1,4} Yet, even when successful, surgery has physical, psychological and social impacts on patients requiring lifestyle changes.²¹

Most studies have focused on biomedical characteristics of heart disease but few have addressed it from the perspective of patients and their family. In Brazil, researchers have taken an interpretative anthropology approach to study cardiovascular conditions such as Chagas' disease²⁴ and arterial hypertension in the elderly.^{2,5} In the literature, there are three remarkable studies: one on cognitive aspects of patients and their family about the experience of congestive heart failure;¹¹ the second on beliefs, knowledge and behaviors associated to heart disease and prevention;¹⁹ and the third on needs and concerns of patients and their family after CABG surgery.²³

But there is a lack of research to understand coronary artery disease and CABG surgery from the perspective of those experiencing it. Anthropological studies that focus on meanings specific social groups assign to illness can provide improve knowledge on behaviors, beliefs and values associated to disease and therapeutic processes.^{7,12} This understanding can open up opportunities of communication between health providers and patients and improve quality of care.

Influenced by Geertz anthropology, medical anthropology studies have sought to link health and disease to people's social and cultural backgrounds, which is regarded as a "web of meanings"⁶ woven by them.^{7,8,10} Kleinman^{9,10} claim researchers in this area have assimilated concepts of *illness* (psychosocial experience of disease) and *disease* (disease from a medical perspective), appreciation of disease experience conceived as a cultural construction and explanatory models of disease.

Thus, the objective of the present study was to evaluate the meanings of heart disease and treatment experience in patients undergoing CABG surgery.

METHODS

Ethnographic study that applies an interpretative anthropology approach to grasp meanings of people's experience in their cultural background. Linked to modern hermeneutics, in Geertz's interpretative anthropology, ethnography is a "dense description"⁶ in search of meanings from discourses and manifest behaviors, which are considered empirical data.

Focused on the concept of *illness* within a cultural dimension, the present study was based on narratives and behaviors of people experiencing coronary artery disease and CABG surgery. The study group comprised patients undergoing CABG surgery in a general hospital of the city of Goiânia, Central-West Brazil. The study hospital is a reference center for heart disease patients requiring surgery.

The study inclusion criteria were as follows: both male and female patients undergoing CABG surgery, living in the city of Goiânia, aged 18 years or more, post-operative period ranging between 6 months and 2 years and outpatient follow-up.

Through medical record review, there were selected 44 patients who met the inclusion criteria, of which five had died and 39 continued being followed up. Of these, there were contacted 17 potential participants and 11 agreed to participate in the study.

Data was collected between November 2003 and April 2005 using a socioeconomic classification questionnaire, direct observation and semi-structured interviews.²⁰ Subjects were interviewed at home to assure contact in the setting that is most relevant for understanding the meanings investigated in the study.⁷ All contacts were previously scheduled.

Observation was restricted to patients' family life in settings of their choice, at different times and days, characterized by sporadic contact between the investigator and subjects.²⁰ A description of behaviors was recorded in a field log at the end of each contact. Information on home environment conditions, subject's interaction at home, and eating and body habits were collected.

Semi-structured interviews following a guide including selected topics were conducted as a part of the dialogical process¹⁶ and recorded with subjects' consent. The number of interviews per subject ranged between two and four according to a content saturation criterion.²⁰

The leading questions in the first interview were as follows: "Tell me about your heart problem. What happened to you? How did all start?" Then they were asked questions drawn out from their reports and study guide. In subsequent interviews there were revisited questions that required further discussion and allowed to identifying contradictions and inconsistencies. The interviews were literally transcribed at their termination and analyzed during the entire field work.

Data arrangement required first structuring of each subject's "narrative document", including personal information, field notes, fully transcribed interviews, observation notes and medical record information.

For the interpretative analysis, a thorough reading of all narrative documents was carried out to assure "data impregnation by the investigator".²⁰ Data were systematically arranged according to similarities and

differences of meanings to form units of meaning.¹⁴ Similar units of meaning were gathered to form thematic groups that reveal underlying values originated from the cultural logic.³ Empirical data interpretation was based on theoretical references of interpretative anthropology⁶ and medical anthropology.¹⁰

The study was approved by the Research Ethics Committee of Santa Casa de Misericórdia de Goiânia. Subjects' anonymity was assured and they all signed a free informed consent.

RESULTS

Of 11 subjects studied, seven were men and four were women aged between 53 and 74 years. Most had elementary schooling, except for three (incomplete or complete high school education). The majority had low monthly incomes, ranging from no income (three subjects), half a monthly minimum wage (MMW) (1), one (4), two (1), four (1) and more than 20 MMWs (1). Before surgery, all subjects had informal occupations; seven were retired (six of them before surgery), four have never had formal jobs and one retired due to surgery-related disability.

Feelings associated to heart disease experience were surprise to know one had a heart problem; fear of dying; putting one's life in god's hands; and acceptance of surgery. Subject's narratives showed a link between disease experience and three main components: subjects' discovery, accompanying feelings and reasoning. Discourses are identified by subject's ID number, gender and age.

According to subjects, they could not imagine by trying to find out the origin of their uneasiness, they will discover their chest discomfort and agony, arm pain, stomachache and back and neck pain were due to heart problems, an organ they believed had a sense of life, and "if it stops, it is all over!". They associated their symptoms to problems related to other organs, habits, age, stress, depression and existential suffering:

"I thought the problem was in my stomach and lungs because I was a smoker for a long time." (Subject 5, M, 65)

Disease perception was associated to feeling (physically and morally) weak, which affected their willingness to work, a state perceived as disability and biographical disruption.

"My world fell apart, especially when I got to know I had to go through this bypass operation! At that moment, it was all over for me!" (S4, F, 54)

Disease was translated as loss of health and signaled by their inability to work and find pleasuring activities. This loss was associated to depression and dissatisfac-

tion, physical (due to pain, new dietary needs and work limitation) and psychological impairments with loss of autonomy and self-confidence (they expressed feeling sadness, anxiety, distress, helplessness, unproductiveness, isolation, and frustration), concerns with their family and about dying. Becoming ill meant a disruption in their life: they had to stop working or could not work and did not feel like doing anything. Inability to work was a major sign of disease.

Having to face the loss of instrumental body functions for working and an imminent risk of dying, they looked for a meaning to their disease through religious beliefs. Out of the image of an all-powerful, punishing god, there arises a sense of guilt over the disease, which is perceived as punishment, and a conflicting notion exempting them from any responsibility.

"Disease is a test we have to stand strong! I'm really afraid of meeting god without doing right here. I keep thinking it's because I deserve it." (S1, F, 74)

Some subjects referred to their past to find an explanation for their heart disease. They reported stressful circumstances (loss of significant others, work, "frenetic" life and family distress), other health problems (diabetes, hypertension, depression, renal problems) and eating and body habits (fatty foods, smoking, and inactivity) as illustrated in the narratives below:

"First I had diabetes. I thought it was no big deal, I didn't care much; I used to eat a lot of pasta, pork, everything that increases diabetes! They prescribed a medication but I didn't take it! The diabetes also made my kidney dry and it was certainly by that time it began to attack the heart." (S2, M, 64)

Eating habits, such as intake of fatty foods – perceived as "fatty," "tasty," "succulent," "strong" foods –, were identified as major causes of disease. At the same time, healthy eating meant eating fatty meat, toasted cassava flour (*farofa*), green vegetables, rice and beans. They also reported frequently using pork lard and large amounts of oils, identified as seasonings that make food more appetizing and the act of eating more pleasing.

Some subjects said they were not aware that eating habits could be potentially harmful to health. Others said that, though they were aware of that, they never believed it.

"I enjoyed eating fatty foods, meat. I used to smoke a lot! Then, because of all that, your health becomes weaker! I thought there was no harm in it." (S2, M, 64)

Subjects first tried to remediate their condition with common healing practices and, even after surgery, many of them reported following their friends' and relatives' advice and taking homemade remedies (teas, oils, coffee, and fruits).

As for disease appearance, subjects reported that coronary artery disease and occlusive symptoms had an insidious development and were identified through physical limitations, especially work-related. They all sought therapeutic support from their family before seeking medical care and perceived the eruption of disease as a biographical disruption.

CABG surgery experience was associated to three major components: feelings towards the impending intervention; surgery as a situation between life and death; and its consequences.

Feelings towards the impending surgery were limited to fear of death and rebellion against god's designs, accompanied by resignation to the need of surgery.

Recognition of their disease severity and risk of dying came after their doctors revealed them the need for immediate surgical intervention.

"When they told me I had to go through surgery I was in shock, completely stunned! I would die without the surgery." (S10, M, 58)

As the diagnosis itself, surgery was perceived as a landmark between life and death involving loss of self-control and putting one's life in the hands of god or somebody else (health providers). After they were discharged from the hospital, they realized the disease had caused a major disruption in their life that could not be repaired with surgery: they could not return to their working activities, which led to loss of autonomy, financial dependency and changes in life such as in their lifestyle and roles.

The time subjects perceived as the most difficult was when they were laying on a stretcher on the way to the operating room: they felt helpless, feared dying and leaving their family behind, and felt "put in the hands of god and the providers". They all referred to god who "took control over my destiny and blessed the providers' hands". They expressed feeling vulnerable, and stressed the loss of control over their life and the need to find comfort and assurance from the team of providers at a moment of pain and suffering throughout the entire hospital stay.

Subjects favorably assessed surgery as a way of assuring their survival and health:

"My health improved a lot! The way I was feeling, if I hadn't gone through the surgery, I think I would have died. God forbid!" (S5, M, 61)

After surgery, "life is more peaceful," the "pressure relieved," and currently they do "what (they) feel like". They are more afraid of dying now, and they take better care of their body. They see their post-surgery life as better, "more peaceful, not as frenetic and stressful".

Although they acknowledged improved quality of life after surgery, they stressed a growing fear of death and an acute feeling of vulnerability. Also, although they took better care of their health after surgery, subjects' narratives of current habits and observed behaviors illustrated difficulties in changing lifestyles. Some persisted with the same unhealthy eating and body habits and did not take the prescribed medications. The reasons for not taking their medications included: high drug costs; large distances to travel to reach the hospital (making them spend their money and time) and get free medications; and occasional lack of medications in health services.

Most reported increased expenses as a result of their disease and surgery (associated to medication costs), which aggravated their financial difficulties. Shame, sadness and frustration were feelings associated to these difficulties, which were aggravated after surgery since most subjects had lower income due to their inability to work. Men expressed their concern with their inability to work and financial difficulties, which was associated to reports of family dependence and burden.

DISCUSSION

To attribute to god the crucial determinations of disease and surgery shows that they are integrated into a global perspective of existence where life, death, disease and suffering are phenomena humans have no control of. This belief that affirms god as a power able to produce disease and save reveals the strength of a different logic, other than the scientific one, but that works together for assigning meanings to experiences. The support from what is sacred arises from the link between responsibility/guilt and punishment and the expression of a conflicting notion that exempt them from the responsibility for disease and ensuing sufferings.

Similar findings were described by Mahoney.¹¹ This author investigated the experience of congestive heart failure in North Americans and reported that the disease diagnosis elicits a perplexity reaction among patients and their family making them seek a religious meaning to understand the reasons for disease development and the disruption caused by it.

The literature shows that patients undergoing high-risk surgeries have feelings to those experienced by the subjects in the present study: fear of surgery and death, suffering due to family distance, withdrawal from one's own environment, helplessness and loss of control over one's life. Together with anguish and loneliness, these feelings become more intense during hospitalization.^{8,13,15}

Religion and belief in god make these meaningless and unbearable personal experiences of disease and treatment meaningful and bearable. Religion and belief, symbolically manipulated as elements for rearranging the chaos caused by the eruption of disease – characterized by

loss of self-confidence, fears and risk of death – ensure an understanding of the paradoxes of human existence by integrating the logic into the sacred. By attributing the origin of disease to a superior power, beliefs reveal a determinist demand and the persistence of a cosmology where the natural, the social, the individual and the supernatural are combined into the same order.

As for eating habits, also known as explanatory disease factors, in addition to reasons rooted in the sacred, similar findings were reported in a study on hypertension.⁵ As in other studies,¹⁵ in the present study, the plurality of meanings assigned to food gives up to the primordial representation of food as a conditioning factor for health and disease only after subjects are exposed to health provider's discourse.

The reluctance in giving up eating habits that associate good and abundant food to meat and fat shows that the appreciation of certain foods relies not only on what is tasteful or healthy, but also on the connotation of some of these foods as being first-rate in a scale of values. Food possesses moral attributes and symbolizes deprivation or abundance, weakness or strength.

Seeking support from interpersonal networks for health care before and after surgery points out to the importance of these networks in the group of people studied and evidences that their body care practices are guided by realizations acquired from experience making connection with common sense as a knowledge system. Seeking this kind of support also reflects the patients' lack of self-confidence and dissatisfaction with formal health care services that cannot always meet their needs. To make use of common therapeutic practices represents a sense of belonging and acceptance.

In the perception of illness as a biographical disruption, the link with work ability is the central rule that defines health and disease.⁷ The importance of leading an economically productive life, as opposed to disability, allied to the connotation of worthlessness of those who lost their social and personal value, results in the apprehension of body and health through the inclusion in the working world. Therefore, a body that lost its major function is a dead body: "it's all over".

There can be identified a concept of the body as an instrument of work and of physical and mental normalcy subordinated to work ability frequently seen in urban, industrialized capitalist societies that permeate common sense and medicine.^{17,23} Such concept, based on an economic rationality, merges with other notions that denote dishonor for heads of the family to be unable to work and produces feelings of embarrassment for being dependent and causing financial difficulties to their family.

The knowledge acquired from experience and the interpretations rooted on moral and religious beliefs explain

the attribution of meanings to physical disarray as well as its rearrangement. Seeking formal health care promotes the strengthening or inclusion of new meanings for understanding disease. Subjects incorporate fragments of medical discourses, especially those involved with the importance of biological aspects of disease, and the search for causes of disease in life habits.

Kleinman⁹ has framed the concept of explanatory models of disease and systematized the models used by different groups to face disease manifestations that are also ways of thinking and acting with respect to disease.^{8,10} This author makes a distinction between professional explanatory models (developed in science to guide health interventions) and non-professional, cultural models. The professional model focuses on disease from a biological perspective (*disease*), describing it by its symptoms and investigating causal relationships in habits, genetics, and behaviors among others. Cultural or popular models are based on disease experience (*illness*) and converge beliefs, values and behaviors of social groups.

Explanatory models expressed by subjects illustrate how they understand the disease experience, choose and evaluate treatments. These models refer to subjects' experience in a certain social and cultural setting, reflecting an overlapping of several life dimensions: affective, social, natural, supernatural, and economic.^{8,9,11}

The feeling of guilt/responsibility for the disease, determined by the sacred dimension of the Jewish-Christian religious tradition, is reinforced during contact with the professional model expressed by health providers who look for risk factors for diseases in the patient's biography, genetics and behaviors.

The meanings of disease experience reflect different individual course of actions taken within a certain array of social and cultural choices. However, the convergence of beliefs and behaviors in the event of disease, described by several other authors as well,^{5,11,13} support the inclusion of popular explanatory models into the planning of public health actions.

In conclusion, for the understanding of health problems experienced, subjects follow a logic that combines daily experience, moral values, tradition, economic rationality, supernatural dimension and sciences. Based on these references, patients assign to the body, health, disease and surgery meanings that associate religious beliefs, knowledge and traditional standards with fragments of medical discourse. The meanings linked to health-disease representations show how in the event of disease people manipulate knowledge, standards, values and beliefs to guide their practices.

Since every disease constitutes a phenomenon to which several meanings are assigned, there is a need for health interventions to incorporate a comprehensive

dimension so to include the views and practices of those people cared, and the meanings they associate to the disease experience. Therefore, there will be the required dialogue between the professional and the cultural explanatory model. The approach to disease

experience and cultural manifestations of disease helps crossing the strict boundaries set by the professional model characterized by a biomedical understanding of health-disease process focusing on disease defined by its symptoms and causes.

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