



UNDERSTANDING THE MEANINGS OF HEART DISEASE FOR WOMEN EXPERIENCING CLIMACTERIC

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ARTICLE INFO

Article History:

Received 20th August, 2018
Received in revised form
23rd September, 2018
Accepted 25th October, 2018
Published online 30th November, 2018

Key Words:

Heart Disease,
Women's health,
Nursing.

ABSTRACT

Objective: To know the meanings of heart disease for women experiencing climacteric. **Methods:** Qualitative study with 25 cardiovascular women, conducted from June to August 2013. The interactionist perspective (symbolic interactionism) was used as a theoretical-methodological reference and, as a modality, the analysis by focus group technique. **Results:** four categories were identified namely "Incapacity for activities of daily living"; "Feelings of frustration"; "Family" and "Spirituality." Women emphasized the transformations and repercussions in their daily lives. Feelings of dependence and uselessness are caused by both the aging process and heart disease. The awareness that heartdisease leads to feelings of frailty and impotence causes women to seek emotional comfort through family, friends, and spirituality. **Conclusion:** Heartdisease has evident repercussions in women's daily lives, being responsible for changes in their lives, which become more valued and endowed with more meanings. The perception of the severity of the disease drives them to modify their behavioral habits and their interpersonal and transcendental relationships.

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Citation: Líscia Divana Carvalho Silva and Marli Villela Mamede, 2018. "Understanding the meanings of heart disease for women experiencing climacteric", *International Journal of Development Research*, 8, (11), 24326-24330.

INTRODUCTION

Heart disease is the leading cause of death in the world, causing 7.4 million annual deaths, corresponding to 13.2% of all deaths. This disease accounts for 20.0% of all deaths in individuals over the age of 30, surpassing, in this age group, neoplasms, respiratory tract diseases and external causes, such as urban violence and traffic (HUEB and JATENE, 2016). It reaches 48.0% of mortality in women aged 50-65 years and 79.0% in those over 75 years of age, thus revealing a higher risk when compared to breast cancer (REZENDE and SILVA, 2016; ROMANO *et al.*, 2016). Evidence shows that cardiovascular women have a worse prognosis when compared to men, which may be due to the onset of the disease at a later age and for presenting more comorbidities (KANNAN *et al.*, 2013). Thus, the incidence increases dramatically in the climacteric due to the reduction of estrogenic protection present in premenopausal women.

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Women's knowledge about this disease is very limited, which leads to a low level of risk perception in society in general, and in women in particular (MONTERROSA *et al.*, 2013). Recent data from the American Heart Association showed that only 46.0% of women are aware of this fact (ROMANO *et al.*, 2016). The literature shows that, in general, studies conducted with populations of different ethnic groups address the health of climacteric women in the presence of various diseases, such as breast cancer, diabetes, obesity or cardiovascular risk itself. However, there is a paucity of studies that interrelates the perception of women about heart disease (MONTERROSA, 2013; POLICIANO, 2016). The meanings built around heart disease in the climacteric woman seem to be strongly associated with worsening of health status and physical dependence, accepted as normal and unavoidable characteristics of the process of human growth and development. In this perspective, the understanding about the meaning of health and disease can expand the knowledge and explain the meanings of this complex phenomenon (heart disease). The research question was defines as: How does a woman experience heart disease, and how does she symbolize

and share the meanings of this experience? Addressing women's perspective regarding the manifestations of heart disease in the climacteric provides a perspective for planning health promotion strategies, as well as the opportunity to know one's own behavior in the way of being, feeling, perceiving and acting in the face of a disease, especially when the processes experienced are not perceived so explicitly. Therefore, the present study aimed to know the meanings of heart disease in climacteric women.

METHODS

This is a qualitative study carried out at the Cardiology Outpatient Clinic of the University Hospital of Maranhão, Brazil, in the period of June and August of 2013, with women aged between 45 and 65 years who had identified some climacteric symptom and who were carriers of heart disease. The women were individually questioned while they waited for the medical consultation in a room in the University Hospital clinic, respecting their privacy; they were invited to identify the climacteric symptoms through the Menopause Rating Scale (HEINEMANN *et al.*, 2004). The menopausal status was also investigated by the information given by the women regarding the menstrual characteristics of the last three months (frequency, spacing, regularity and menstrual flow), when present, or the time of amenorrhea, according to the woman's clinical history. Those who had some climacteric symptom were contacted by telephone and invited to participate in the focus groups. Considering their acceptance and availability, the participation on the focus groups was scheduled. The focus group meetings were held in a room on the fourth floor of the University Hospital. Confirmation of heart disease was made by coronary arteriography. The exclusion criteria were those submitted to oophorectomy and hysterectomy; users of hormone replacement therapy in the last five years; speech difficulties and mental disorders. Twenty-five women participated in six focus group sessions, with a variable number of participants: the first session, with five participants, lasted 1h39; the second session, with four participants, lasted 1h23; the third session, with six participants, lasted 1h34; the fourth session, with three participants, lasted 50 minutes; the fifth session, with three participants, lasted 1h05; and the sixth session, with four participants, lasted 1h20. An audio recorder was used. The focus groups were held in a private room that provided participants with privacy. The work team was composed of one researcher, who acted as moderator and observer, and two nursing academics, as research assistants. In the first focus group, there was the participation of a psychologist, as an observer, who reported her impressions and considerations; these observations guided the conduct of other groups. The central theme of the sessions was aimed at understanding what women know about heart disease, seeking to understand the meanings they built in relation to heart disease and their own life: *What do you think it may be related to heart disease? What does it mean for you to live with a heart disease? Are there changes in your lives that you attribute to the heart problem? Can you describe, in a word, a feeling that represents the heart problem? What do you think about the future and what do you want to do and do?*

For the analysis and interpretation of the data, we used the Symbolic Interactionism (BLUMER, 1969) based in the content analysis method (BARDIN, 2011). The use of the interactionist perspective allows understanding behaviors,

feelings and expectations in the perception of the dynamic interactive processes of women in the experience of the heart disease with the environment, other people and the social context, since they are endowed with value and meanings, thus enabling to unveil the meanings that women attribute to the situation experienced. To maintain participants' anonymity, the women will be presented through the letter "P" (for participant) accompanied by the number that identifies them in the research. The study respected the formal ethical precepts contained in national and international norms regulating research involving human beings and received a favorable opinion from the Research Ethics Committee of the Ribeirão Preto College of Nursing, University of São Paulo, on June 5, 2013 under the number 293,900.

RESULTS

Four categories were identified, namely "Incapacity for activities of daily living"; "Feelings of frustration"; "Family" and "Spirituality".

Category 1: Incapacity for activities of daily living

When a symptom manifests in the body, it can draw attention, interrupting to a greater or lesser degree the activities of daily living, sometimes slowly, sometimes abruptly, producing a feeling of incapacity, dependence, and uselessness. The major changes perceived by women are mainly related to the physical inability to perform household chores and work activities. Many domestic tasks used to be part of women's responsibility, which gave them autonomy to solve them. They reported behavioral changes that interfere with their lives: *It has changed my agility. I used to work a lot in the morning and afternoon, now I cannot do this anymore. Carrying weight, I cannot anymore; I cannot clean the house. I used to work until late, now I cannot do it (P15). It is different. I do some little things, but not at the pace as in the past. I do it; if I feel something, dizziness, I sit, and then it has passed, so I do it again. There is no one to do it; I have to put up with it, to put up with my husband. It has to be, for our husbands, because there is no other way, or we lose our husbands; it is worse. So, we lead our lives as God wants to (P8). It has changed because I feel tired, I do not feel good, oh, I say, oh, I cannot anymore, no. It has changed in this field of activity, because I used to do farming a lot. Today, I cannot do anything; I do not do anything anymore: carrying water, sweeping the house, washing clothes. I cannot do anything I used to do (P23).*

The women stated that not only the routine was modified, but also the activities they set out to accomplish. They revealed that the heart disease decreased the possibility of remaining useful, thus generating a degree of dependence, especially with regard to the work they used to do. Daily activities, both at home and at work, play a determining role in people's lives, as they are linked to the present reality and to the complexity of the relationships involved, often constituting a guiding factor in human life, with direct implications in the physiological, psychological, economic and social conditions. This reveals that the meanings attributed to heart disease by women are surely related to the limitation imposed by the disease and its chronicity, translated to them as a feeling of contempt and depreciation of themselves: *I use to be very agile, now I am stuck. Everything I do I get tired. I used to walk from Fialho [neighborhood] to the return of Calhau [neighborhood] every morning, now I walk a little. We cannot do certain things,*

cannot carry weight, cannot walk faster; if we do it, we feel it. I will not do it anymore because it can harm me (P13). It is a disease that let me very weakened. I do not have that willingness anymore. I used to cook snacks to sell, clean houses. Now I cannot work in anybody's house, I cannot do it anymore condition, even if I want to, I do not do it (P1). It is different. I do some little things, but not at the pace as in the past. I do it; if I feel something, dizziness, I sit, and then it has passed, so I do it again. There is no one to do it; I have to put up with it, to put up with my husband. It has to be, for our husbands, because there is no other way, or we lose our husbands; it is worse. So, we lead our lives as God wants to (P8).

Category 2: Feelings of frustration

The feelings of frustration in relationships, justified by dependence and uselessness, are caused both by the aging process and menopause/climacteric and by the heart disease, contributing to the feeling of loss of the social role in face of the illness process, as described by the participants: *When you go somewhere, you have to go with someone to help, right? I cannot do anything else, it seems that the body weakens; it loses strength (P18). Sadness, I am very sad. I look at a person, a healthy person, I get sad because I wanted to be like that person. It is envy; I envy in this. The other things, I am not envious of anything (P22). If I speak from the heart, I have a lot of things. We feel, we stay, live at the expense of others; we cannot do what we used to. I used to work, wash, iron, do the chores in my house. When I used to work at so-and-so's house, I used to wash, iron, when I got home, my house was like this (messed up). We work, but we feel humiliated. I used to say, I am living at the expense of others, I am eating at the expense of others (P7). Suffering is what we are feeling. We suffer from this problem (heart). That is a suffering, feeling that, suffering from that problem (P24).*

Some women, while acknowledging their limitations, reported that they continue to perform some activities because there is no other person to do them: *We get limited in everything. In my case, I cannot do it, but I have to do it because there is no one to do it. At home, I go out all the time: to go to the fair, home, everywhere, to pay the bills. I have no one to ask for, to do it, and I have no bodyguard (smile). So, it is very difficult. I have to do it; I cannot be waiting for someone to do it for me. I have to put up a fight, don't I? (P8).*

Most interviewees consider the experience of having heart disease as a sad, painful and permanent process, both in the physical and emotional aspects, as it is, often, an unexpected disease that generates the fear of death. There seem to be concrete reasons to affirm that women do what is necessary to keep themselves alive; they seek strategies not only for survival, but for a better life despite the difficulties, and also for ways of finding they are able to face their own suffering in a more tolerable way. This may be noticeable not only for women, but for all family members.

Category 3: Family

The imagery that women have built in relation to heart disease comes from lived experiences and social support relationships, including the spouse, children and grandchildren, among others. According to the reports, the family relations can become closer, since the illness and the consequences

imposed, especially in relation to the change in the performance of roles, concern not only them but also their family members, favoring a more attentive and affectionate relationship, since for these women, family relationships are crucial for the adequate coping of the disease: *Thank God I live with my husband, live with my children. He fights with me against this disease, against these pains. He does everything. Sometimes, when I am bedridden, he makes food, he does everything. That is why I cannot complain to this day (P20). I was worried and it worried my family, too. I got more attention from my sisters. I got more concern from my family; I got more attention from them. It is something that has changed. Sometimes, when I feel something, I do not even call them, because I know they will stop doing what they are doing, to come where I am, to know how I am (P19). He also improved in that part, in that sense, right? He became more attentive, stays more at home, is less womanizer (smile). All this is bad for the heart, you know? Anger, I used to feel it. I think that this problem that I have, for example, if I did something wrong, if I did not solve it at that time... I had to get that out. I pity those close to me! And I pity him (husband) because he was close (P7). The family is very important at this time, the friends, and we take life in this way, knowing that the only certainty that we have is death. We do not know what awaits us. Today we are here, but just as we have this disease, other people do not have it, but at the same time, suddenly, they are not here anymore (P8).*

Category 4: Spirituality

The awareness that heart disease brings to their sufferers the sensation of frailty and impotence causes women to seek emotional comfort through spirituality. Spirituality was present in the lives of all participants and all showed a bond with some religion, attending a church and seeking help and comfort in religion. Thus, one can perceive not only the awareness of their physical frailties and their sense of powerlessness in the face of illness, but also a search for certainty in relation to death, which made them seek spiritual comfort in an attempt to alleviate their fears and anguishes: *I got attached to religion, for example, I go to the church, so I think it contributed a lot to a better life at this stage of my life, right? In that field. We are going to get strength, to find strength. In my case, I found it in religion, right? In God. Religion does not save anyone, we know that. It's God. So, God is the source that takes me and I see that He is leading me and I'm getting attached to Him (P8). This disease just came to kill me. I am an evangelical person, my thoughts are on God, for him to make my heart get better and not stop (P11). We get very nervous, when I came to get hospitalized and then I left, the people from the church, I'm Catholic, went home to pray, they said some very beautiful words, which I remembered when I was in bed (P7). I'll pay my own promises. There are people who do not believe, but I believe and I have faith. I will pray to São José do Ribamar, Nossa Senhora de Fátima, Nossa Senhora da Conceição, and Nossa Senhora da Graça. When I do the angioplasty and everything is fine, I will pay all these promises, as I have already paid for catheterization. I'll, God willing, and Jesus, much faith, I'm very Catholic, my house is full of saints (P3).*

For women experiencing this new condition, in a very unique way, religiosity can be configured as a significant point of support in the face of illness and possibility of death. In their speeches, thanks were often expressed to God: *I'm 63 years old, so from now on, my future is very little because age is*

already, but God willing, because only He knows. Today we are here talking to everyone, but tomorrow, later, nobody knows if we will still be here, right? And if he still allows me to have many years to live, I want him to allow my health, wisdom to the doctors who take care of me, beneath Him, and a better future for my family, for my family to continue well, thank God. Because the important thing in life is not to be rich, it is to have peace, to have happiness and I want God to keep my health and my doctors taking care of me, right? (P2). I am Catholic. I used to go to church only on Sundays, now it's already been six years since I go to the church all the time. It calmed me down. Thank God I'm at this age and thank God I'll be 80 soon (P9).

DISCUSSION

The speeches revealed that the experience with heart disease can trigger significant changes in a person's life, which transforms their social identity from a healthy and working person to an identity of a patient, incapacitated for labor activities. Women are culturally and historically assigned to the household chores, to care, to maternity, among others. In this sense, when women cannot give effective responses in the sense of providing the basic needs of the family, the changes that the disease causes are translated into personal dissatisfaction. In this respect, it is possible to verify a strong influence of the culture. Work becomes an element to be considered since in our society it is placed as a central axis, offering status and granting various forms of belonging. In this way, having the capacity to work is placed as something that promotes, includes and translates into improved quality of life and personal satisfaction (ROMANO *et al.*, 2016). The physical problems, the psychological and social issues involved, the medical restrictions, among others, make the woman with heart disease feel at least limited because, according to the prescribed recommendations, these women can no longer perform most of the activities that they used to do before they were affected by the disease, and therefore feel constantly dependent on others. In general, women are responsible for household chores and are often demanding on home environment and everything that refers to it, such as the quality of food, clothing, and cleanliness. With the disease, the limitations related to the "frailty of the heart" make them change (DUNCAN *et al.*, 2013). However, now these skills are no longer part of their daily lives, and this bothers them deeply. Therefore, building personal autonomy in their personal lives means rebuilding deeply the feminine and collective identity, and for that, it will be necessary to rebuilt their visions on their relations and their social practices. It is essential to build supportive environments for these women, who need to be supported in their care giving actions and other roles, such as the provision of health care specifically designed to manage the health problems women face as they grow older with a chronic illness. A long and healthier life is a social goal that will give women opportunities that they and their communities will value and which, at the same time, will lead to major social changes in the organization of work, family and social support (World Health Organization, 2008). The multiple tasks and social demands fall on most middle-aged women because they remain active, whether at home or at work, but some symptoms related to climacteric or to a pre-existing illness can interfere in their work process (REIS *et al.*, 2011). The main strategy is to evaluate people's daily lives and to plan ways to ease the symptoms or deficits (ZORTEA, 2015). The way an individual defines who he/she is can vary

widely in different cultures, even if these different self-concepts serve the same functions: regulating, organizing, and emotional functions (ARONSON *et al.*, 2013). When it comes to a society whose values are established by purchasing power, the issue of income coming from work can also become absolutely present. Thus, there may be a rigor of self-analysis since the socially understood concepts do not correspond to the personal ideal. The woman's own cultural condition still does not allow her to verbalize her frustrations, feelings and desires, and the responses obtained may contain "indicatives" of alienation, a result not of a choice built by her, but of social representation. The meanings that permeate this health condition implies in being (un)satisfied with themselves, implies a more accurate reflection, constituted in a cultural manner, since, in order to make such an analysis, there is need of a constant evaluation, and it must transcend immediacy (ROMANO *et al.*, 2016).

The certainty of no longer returning to the past life, the perception of the present state - being sick - makes women feel like they have lost their previous identity. The suffering caused by the disease leads to awareness of their limitations, in search of new and healthier ways of living. The deprivation of work and withdrawal from job keep women longer in their homes and obviously provides greater coexistence with the family, which favors family relationships and often promotes closer approximation. The woman, as a carrier of heart disease, is most often surrounded by her family members, because her health status concerns not only her, but everyone with whom she relates, especially her husband (GARCIA *et al.*, 2016). The vulnerability imposed by the chronic condition, the emotional suffering, causes the person to choose to solve difficulties, modify attitudes, so that they can be able to deal with usual pressures, reducing or even eliminating stressful situations. Family members are the ones who most support patients from a physical and emotional point of view. They are, therefore, the largest source of emotional and social support. Chronic illness affects all aspects of family life. Family patterns are changed forever, and family roles and tasks are routinely changed. Some families may become so close that they become agglutinated, other families may, on the contrary, become apart because of the stress the illness causes, leading to separation or even divorce. The quality of family life has a huge impact on how patients adapt to the disease and how they recover (CARVALHO *et al.*, 2016). When discovering the disease, the family needs to provide support. In the initial phase of treatment, despair, anguish and revolt are responsible for changes in the family situation. The act of caring for a family member is often idealized by trying to support and increase the quality of life of the sick person. Such a will leads the relative to play new roles, never before performed and for which he/she has no qualifications. During the treatment, there is the family's attempt to stay 'normal' in the face of everyday situations. When the decision is based on the affective relationship with the patient, these feelings become gestures of respect and solidarity, alleviating the suffering of both. Spirituality emerges as a support point for this situation considered extreme (ENCARNAÇÃO; FARINASSO, 2014). People conceive that religion plays the role of offering explanations to the human being about their limitations, thus revealing the need to know themselves and approach the religious phenomenon as an integral part of the human being, as well as a potential resource for pain management, expressed by pain in the face of issues associated with death, finitude and hopelessness (SALTARELI *et al.*,

2015). The most significant levels of religiosity are associated with a more benign perception of the disease, which, in turn, is associated with better physical and emotional well-being. The relationship between religiosity and subjective health may thus reflect the ability of religiosity to alleviate the threatening feelings related to the disease. This seems to happen through the development of a sense of protection against the uncertainty and adversity, there being an increased sense of control over it and the acceptance of life despite the illness (KARADEMAS, 2010). It is recognized that people with a heart disease are exposed to risks, discomforts and burdens, which may lead to changes in their personal life, family dynamics, work due to the need for greater care attributed to the situation of greater vulnerability and the limitations imposed by the disease. Therefore, health professionals should know the meanings that permeate this health condition and identify effective ways to maintain and promote the development of positive attitudes in the population to improve the coping capacity and prepare this population for the unpredictable task of living with a chronic illness (ENCARNAÇÃO and FARINASSO, 2014).

Conclusion

The symptoms related to heart disease has evident repercussions in one's daily life, which become, in some cases, more perceived and valued and, therefore, endowed with more meanings. Cardiac symptoms are responsible for major changes in their lives, such as the physical inability to perform household chores and work activities, which makes them dependent on others and physically and emotionally disabled. For them, the experience of this situation goes beyond physical suffering, but also involves psychological, emotional, economic and social suffering. They become physically weakened and psychologically vulnerable. This sense of instability and imbalance imposes limits, restraints, anguishes and frustrations, making women fragile and insecure. It reveals a conflict between the desirable world and the real world, a concrete reality of limitations and loss of autonomy, a threat to life and physical and emotional integrity. Suffering pushes them to reach the limits of their perception of the severity of the disease and the importance of changing their behaviors, their interpersonal relationships, especially with family and friends, and the spirituality, the Church, which provides comfort and acceptance and a motivation for facing difficult situations and conforming to the facts, which cannot be modified. As limitations of this study, we can mention the specific peculiarities of the qualitative research, as the knowledge of a reality of a specific group, the women in the experience of complex phenomena, such as the climacteric and the heart disease, the fragmentation and specific and pre-defined moments by which the women were going through, the geographic region where the study was developed, in addition to the space where the data collection took place, i.e., in a hospital and a specialized service. This research could be expanded, since it is an initial mark for other social works, services or markers, such as family members or health professionals, and especially an invitation to search for new meanings that contribute to the advancement of knowledge.

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