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What experience the individual and family of patients with cardiovascular difficulties? Recognizing the main themes and internal states of heart disease experience

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***Abstract*---**This research identifies the main themes and internal states of heart disease experience in individuals and families of patients with cardiovascular difficulties. It is applied in terms of purpose and methodologically qualitative and phenomenological. Its population is patients admitted to Baqiyatallah Azam Hospital. It includes the patients who had a long and severe chronic illness in this area (or without long and severe chronic illness). We performed in-depth semi-structured interviews with 6 patients in the CCU ward of Baqiyatallah Al-Azam Hospital. With the introducing 4 family members of the participants, the number of people with whom we worked until the final stages reached 10 (two participants refused to introduce their family members). We analyzed data using the methods proposed by Van Manen and Colaizzi. According to the results, the main themes of experiencing heart disease are initial experience of cardiovascular (malfunction) difficulty, experience of internal conditions related to cardiovascular disease, family's initial experience of cardiovascular disease, atmosphere governing the participant's life

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before heart disease, the last slices of life before experiencing cardiovascular disease, perceived changes after experiencing cardiovascular disease, and experiencing cardiovascular disease. Regarding the initial experience of cardiovascular difficulty (dysfunction), sub-themes include reported symptoms, type of diagnosis, and duration of illness. As for the experience of internal states caused by cardiovascular disease, sub-themes include the initial reaction after experiencing cardiovascular disease, the initial unpleasant emotions of the person after experiencing cardiovascular disease, and the initial thoughts of the person after experiencing cardiovascular disease.

***Keywords*---**heart disease experience, families patients, coding method, phenomenological studies.

Introduction

With a wide range in types and relatively high and increasing prevalence in the global population, cardiovascular diseases have attracted in recent years the attention of many experts and researchers in this field (*Sinuraya, R. K., et. al., 2021; Alzahrani, S., et. al., 2019; Berezin, A. A., et. al., 2021*). According to the latest report from the World Health Organization (WHO), ischemic heart disease and stroke are the world's biggest killers, accounting for 15 million deaths in 2015. The next report from the World Health Organization (WHO) in 2016 put the number at 17.7 million, accounting for 31% of the world's deaths (World Health Organization, 2016). Stewart et al. found that moderate or severe psychological distress, consistently assessed over 4 years, was associated with a 2- to 4-fold increase in the risk of death in cardiovascular patients over the next 12 years (Stewart et al., 2017). According to the latest researches, anxiety constitutes a 41% higher risk of cardiovascular disease (Tali et al., 2015, Emdin et al., 2016). Life with heart disease is not easy, but it affects millions of people. People with heart disease not only need to deal with the physical limitations of the disease, but overly they need to manage emotional issues that can affect their lives and the lives of those close to them.

For example, in their study, Sheindy Pretter, Victoria H. Raveis, Monique Carrero & Mathew S. Maurer found that "the stress of living with heart disease can affect the marriage and change its nature. Continuous care for heart patients should include focusing on caring spouses and supporting both members, because they jointly face the challenges of the disease" (Pretter et al., 2014). In another research, Rodrigo López et al found that parents of children with congenital heart disease (CHD) showed more symptoms of depression, anxiety and hopelessness compared to parents of healthy children. Along with the described symptoms, parents may experience inability. These parents performed significantly worse than the parents of healthy children in the general health questionnaire and had less feeling of happiness compared to the parents of healthy children (Lopez et al., 2016).

Studies (Stewart, 2000, the National Institute of Mental Health, 2002 and Dusseldorp et al., 1999) show that the range of injuries caused by the disease goes beyond the physical problems, disadvantages, and costs that sufferers incur. In addition to individual identity, each sufferer is an influential member of the whole family, who brings with him/her a host of symptoms, deficiencies, limitations, and stress into the family and communication space. Due to the unique family system and the interaction of individuals, this set of inputs has a unique and different output in the entire family system and each of its members, including the affected person and other members. In fact, the family is in a social context and itself a social context.

In other words, accepting that a family member has heart disease and the stress of living with a heart patient can be so effective in the family that it changes its nature. In fact, contrary to the materialist view, heart disease occurs for a family, not an individual. Although biologically we can say that the disease occurred only in the body system (blood circulation), in reality it may have the greatest impact outside this biological system. However, there is not much study on the interactions between the spectrum of the disease and the family system. There is almost no organized research on this subject in Iran. Accordingly, this research embarks on identifying the main themes and internal states of heart disease experience in the individual and in the family of patients with cardiovascular difficulties.

Research method

The present research is an applied one in terms of purpose and methodologically a qualitative and phenomenological research. Its population is patients admitted to Baqiyatallah Azam Hospital, the patients who have had this disease suddenly or without a background (or without a long and severe chronic illness in this area). The sample consists of patients with acute heart disease who referred to the CCU of Baqiyatallah Hospital for their treatment, along with a member of their family for performing an interview by the patients themselves. The sampling framework and selection of participants were based on standard sampling method.

In the present research, we started interviews with 8 patients in the CCU ward of the hospital. We excluded two participants from the samples during the interview due to death and failure to continue the interviews. With introducing 4 family members of the participants, the number of people reached 10 (two participants refused to introduce their family members). The main method of data collection in this research was semi-structured interviews. First, based on the study of the research background, we identified the subjects of the interview questions. In the next step, we drew the outline and mind map based on the subjects and made the components of the subjects more specific. Then, for each subject, with the guidance of professors and consultation, we modified and reviewed the initial questions, and finally obtained the main form. In addition to the interviews, the participants' schematic drawings (in cases where the participants were in trouble by myself (the interviewer) and with the help and guidance of the participant) were the source of access to their mental information. Other methods, such as

using medical records, observation, field notes during interviews, and drawing participants' genograms, have been usable to reinforce the findings.

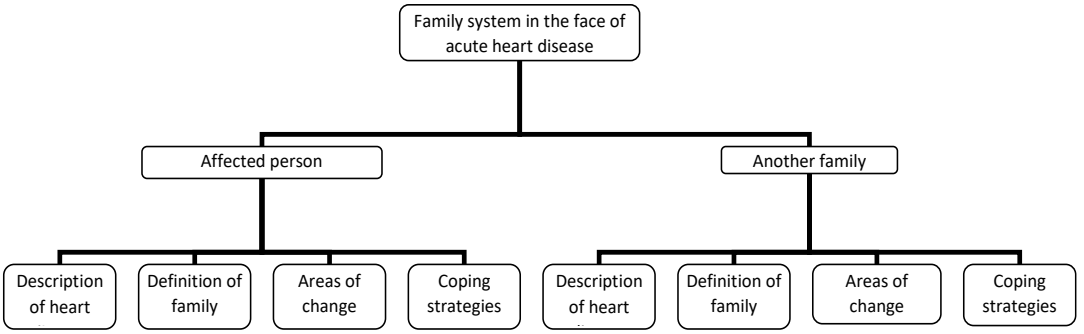

Diagram 1: Mind map of questions and interviews

Family system in facing severe cardiovascular disease, afflicted individual, other member of family, describing cardiovascular disease, defining family, change areas, coping working procedures, describing cardiovascular disease, defining family, change areas, coping working procedures

Through the process of coding and summarizing the codes and finally presenting the data in the form of figures, tables or written discussions, we analyzed and reduced the data in the form of several themes. First, we should state the interviewer's personal experience of the phenomenon. This is an attempt to set aside the researcher's personal experiences so that he can focus well and directly on the participants. A list of important statements is prepared. The next step is considering important statements and categorizing them into larger information units called semantic units or themes. It is possible to describe what participants experienced in studying the phenomenon. This is an "underlying description" of the experience.

A description is presented the process of experience itself called a structural description, during which the researcher provides information about the environment and experienced context. Finally, the researcher presents a descriptive combination of the phenomenon or a combination of both underlying and structural descriptions. It is in fact the essence of experience; the high peak a phenomenological study must reach. The same thing that tells the reader what the participant did and how he or she experienced it (Creswell, 2007).

According to the method specified by Creswell, after the suspension of personal experience, the stage of coding and extracting the themes was as follows. Entering the first interview in the software MAXQDA 20 and the initial coding of the first interview in the software. At this stage, in order to get a general concept of the interview text, we read it several times from the beginning and reviewed its codes many times. Then we entered the second interview into the software and coded. We also recorded and coded the initial interviews (interviews conducted in the CCU ward) in the software. We changed and revised the main and secondary themes over and over again. To evaluate the reliability of our research, we

recorded and wrote interviews along with field notes. As for the repeatability of the research, we provided full details of all the steps to guide the similar researches.

Findings

1. What are the main themes of experiencing heart disease for individuals?
After coding the interviews and following the steps of data phenomenological analysis, we obtained 7 main themes. These themes include the initial experience of cardiovascular difficulty (dysfunction), the experience of internal states caused by cardiovascular disease, the family's initial experience of cardiovascular disease, the atmosphere governing the participant's life before the experience of cardiovascular disease, the last slices of Life before experiencing cardiovascular disease, perceived changes after experiencing cardiovascular disease, and exposure to cardiovascular disease.

Table 1: Overview of research findings through the main and secondary themes of cardiovascular disease experience by the individual and his family

Findings of present research	Main themes	Secondary themes
"What" of the Experience of cardiovascular disease	Initial experience of the Cardiovascular (malfunction) difficulty	Reported Symptoms
		Type of diagnosis
		Duration of disease
	Experience of the inner states associated with cardiovascular disease	Initial unpleasant emotions of the person after experiencing cardiovascular disease
		Person's initial thoughts after experiencing cardiovascular disease
		Person's initial reaction after experiencing cardiovascular disease
	Family's initial experience Of the cardiovascular disease	Initial feelings of family members after experiencing cardiovascular disease
"Why" of the Experience of cardiovascular disease	Atmosphere governing the participant's life before cardiovascular disease	Family from the perspective of the participants
		Family schematic diagram
		Genogram
		Lifestyle of participants and family
	Last slices of life before experiencing cardiovascular disease	Final stressors before the cardiovascular experience
"How" of the Experience of cardiovascular disease	Perceived changes after experiencing cardiovascular disease	Emotions after the experience of cardiovascular disease
		Person's perspective after the experience of cardiovascular disease
		Participants' perspectives on the family after experiencing cardiovascular disease
		Changes in family and members

		after experiencing cardiovascular disease
	Experiencing cardiovascular disease	Participants' exposure to cardiovascular disease
		Families' exposure to cardiovascular disease
		Impact of family on the process of adaptation of person with cardiovascular disease

2. Initial experience of cardiovascular (malfunction) difficulty
The first theme refers to the changes that the interviewees reported in the process of understanding the experience of cardiovascular disease. Table (2) lists the sub-themes and the codes assigned to them.

Table 2: First main theme with sub-themes and assigned codes

Main theme	Secondary themes	Codes
Initial experience of cardiovascular (malfunction) difficulty	Reported Symptoms	Chest pain
		Asthma
		Chest burning
		Sweating
		Nausea
	Type of diagnosis	Heart attack
		Clogged arteries
		Clogged arteries and the need for open heart surgery
	Duration of disease	Received completely different codes

3. Experience of person's internal states in association with heart disease
One of the themes that helps to describe better the events that people have experienced is the descriptions that the interviewees reported of their inner states of the experience of cardiovascular disease. At the researcher's request, the interviewees addressed the subject in three different ways, explaining their initial feelings, thoughts, and reactions immediately after experiencing cardiovascular disease. For example, interviewee 5 says, "I remember all the pictures and sounds I saw and heard about the deaths of this disease. How many times have I heard that dying occurs more from a stroke or cardiac arrest. Sometimes "I also question why I was not careful and my action has dragged me here." Here the researcher has assigned the feeling of fear of death and the feeling of remorse and regret as the code.

Table 3: Second main theme and sub-themes with assigned codes

Main theme	Secondary themes	Codes
Experience of the inner states associated with	Initial reaction after experiencing	Shock
		Trying to deny the

cardiovascular disease	cardiovascular disease	disease
	Initial unpleasant emotions of the person after experiencing cardiovascular disease	Feeling scared
		Stress, anxiety and worry
		Feeling defection after surgery
		Feeling the pangs of conscience
		Despair
	Person's initial thoughts after experiencing cardiovascular disease	Predicting the outcome of diagnoses
		How long does the treatment take?
		Learning more about the disease
		Thinking about the causes of the disease

4. Family's initial experience in association with cardiovascular disease
The family, as the only institution that always shares with the main participants in the experience of cardiovascular disease, has its own feelings and perceptions of this experience. In this these, as in the previous one, we described the initial states of experiencing cardiovascular disease. From the family perspective, we also described the perceived findings of the person experiencing heart disease by his family and from the perspective of a family member.

Table 4: Third main theme with sub-themes and assigned codes

Main theme	Secondary themes	Codes
Family's initial experience of cardiovascular disease	Family's initial states after experiencing cardiovascular disease	Family's being shocked
		Crying and restlessness of family members
		Despair
		Discomfort for the affected person
		Feelings of fear and anxiety of family members

Conclusion

The aim of this research was to identify the main themes and internal states of the experience of cardiovascular disease in the individual and family of patients with cardiovascular problems. As for the initial experience of cardiovascular (dysfunction) difficulty, the results showed that this theme, along with the sub-themes and codes assigned to it, refers to the fact that those chronic and congenital cardiovascular diseases have almost certain signs and symptoms (we reported them during the interviews). From among 6 patients with cardiovascular disease participating in the research, we classified 4 people with myocardial infarction and 2 people with coronary artery disease. According to the World Health Organization, there are common symptoms of heart disease without a

history. A heart attack or stroke may be the first warning of an underlying disease or problem in the arteries. Symptoms of a heart attack include pain or discomfort in the center of the chest, pain or discomfort in the arms, left shoulder, elbow, jaw, or back. Moreover, the person may have difficulty breathing or shortness of breath. Feeling sick or vomiting, feeling light or weak, cold sweats and becoming pale are also common symptoms of this complication. Women are more likely to suffer from shortness of breath, nausea, vomiting and back or jaw pain. The most common symptom of a stroke is a sudden weakness of the face, arm or leg, which occurs often on one side of the body. Other symptoms include a sudden onset of numbness in the face, arms or legs, especially on one side of the body, dizziness, difficulty speaking or understanding speech, difficulty seeing with one or both eyes, difficulty walking, loss of balance or coordination, severe headache for no apparent reason, and fainting or anesthesia. People who experience these symptoms should seek medical attention immediately (World Health Organization, 2017).

As for experience of the inner states associated with cardiovascular disease, almost simultaneously with experiencing cardiovascular disease physically, the patient experiences also a set of experiences of inner states including feelings, thoughts, and reactions. There is not much research on emotional experiences during cardiovascular disease. However, an interesting case study of Andrew M. Lane and Richard Godfrey in 2010 entitled "Emotional and Cognitive Changes during a Fatal Heart Attack and Up to a Year Later" could help analyze the findings. In a part of the published article, the subject describes his inner feelings, thoughts and reactions during and shortly after the attack. Describing the expression he uses, "I feel a strong emotional change, "he describes, "I felt light and everything turned black. A black and white darkness, nothing ... at first when I became aware of soft lighting somewhere, I felt calm, but then I felt terrified, I felt the urgent need to "get there." The desire to survive was brutally rippling through me, and it was exhausting. I felt terribly falling apart. I was screaming from the bottom of my lungs while it was completely heterogeneous and silent. It sounded like I wanted to swim against the tide with an anchor tied to my ankle; but I wanted to go there at any cost." The codes received and the feelings and thoughts experienced by the individual are generally similar to the reports of the participants and the findings of this research. For example, the feeling of fear and panic, the feeling of despair, stress and anxiety, and the feeling of hopelessness that we can take them as codes received from the above text, were close to the codes received by the participants in this research.

As for the experience of family's initial states in association with cardiovascular disease, the results showed that during this vast and comprehensive experience, the family, as the institution that has the most relationship with the afflicted person is involved in feelings, emotions and reactions similar to some extent to the sufferer's experience. It may seem that the intensity of these feelings for other family members is not as great as that experienced by the main participant, but the gender of these feelings is somewhat similar. Moreover, we should note that when each member of the family hears the news of the disease, depending on the status of the infected person and of course the said member and the roles that each is responsible for, he/she experiences a unique severity of these emotions.

Another dimension of this theme is the diversity of emotions. It seems that the initial experience of emotions in people with the disease is deeper, more intense and, of course, more diverse, and despite these differences, it is more stable. The sufferer spends more time in the sea of feelings and thoughts resulting from the experience, and the family resolves the feelings sooner, perhaps because of the need to accompany and help the person.

The focus of the present research was on the experience of cardiovascular disease, with the difference that we focused only on the experience of acute cardiovascular disease, so we did not propose any distinction about gender, age and type of disease. Based on the findings of this research and similar ones, it is possible to design effective rehabilitation packages and clinical interventions to improve the quality of life of families involved in this experience. We expect that the relevant authorities design some cardiovascular counseling courses for families involved in the experience to help their future well-being.

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