

BEING THE SPOUSE OF A HEART PATIENT: A QUALITATIVE STUDY ON THE SPOUSE'S VIEWS AND EXPERIENCES

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ABSTRACT

Purpose: This study aims to reveal the views of the spouses of individuals with coronary artery disease regarding the adaptation process to daily life and the difficulties experienced during the process.

Material and Methods: This qualitative and descriptive study was conducted between October 2021 and February 2022. The research sample consisted of the spouses of 16 patients who were followed up with a diagnosis of coronary artery disease for at least one year in a university hospital located in the city center of Ankara and who were hospitalized for at least one day. An information form and a semi-structured interview form were used to collect data. The COREQ was used in the structuring and reporting phase of the qualitative research. The data were coded using the MAXQDA 20 Plus program.

Results: Findings related to the experiences of the participants were grouped under 5 themes and 8 sub-themes. Our findings indicate that the daily lives of spouses are affected physically, psychologically and socially; the stress and anxiety levels of the spouses changed with the diagnosis; and there have been changes in family-wife and husband roles.

Conclusion: As revealed in our study, it is of great importance that spouses and caregivers receive training and inform about emergencies in the management of coronary artery diseases, as in every chronic disease.

Keywords: Coronary artery diseases, spouse, nursing, qualitative research

INTRODUCTION

Coronary artery disease (CAD) is a cardiovascular problem stemming from the thickening of the intima layer in the coronary vessel wall, narrowing the diameter of the vessel and causing the vessel to lose its flexibility (1).

Many methods are used to prevent, manage, and treat CAD. These methods generally include non-invasive methods such as lifestyle changes, medical treatments, and dietary practices, and invasive interventions such as vascularization treatments. The main lifestyle changes recommended are the restriction of smoking and alcohol consumption,

maintaining an active life instead of a sedentary life, and following a healthy diet (2,3).

Patients who receive support from their spouses in every aspect of their lives also need support during the management of this disease. For this reason, it is important to provide the professional care and counseling that the nurse gives to the patient during the hospitalization process to the spouses who support the patient at home (4,5,6). Studies clearly reveal the importance of spouses and caregivers in the management of the disease and in the process of providing self-care (6,7). The presence of spouses is

very effective and important in the management of medical treatment and improving the quality of life of patients. However, the support spouses provide may place a burden on them, which should not be disregarded. Spouses may experience difficulties in coping with changes and stressful situations in their lives; maintaining individual care, transportation, housework, shopping, and communication; and providing resources and the necessary financial means (8).

Despite the fact that spouses of patients with coronary artery disease have a lot of experiences and difficulties in daily life due to their caregiver roles, there is no measurement tool for caregivers of coronary artery disease patients in the Turkish literature. Therefore, in this study, a qualitative research design was used. Thus, this study aims to reveal the factors related to the adaptation process of the spouses of individuals with coronary artery disease to daily life.

MATERIALS AND METHODS

Study Design

This research is interpretative phenomenological research in a qualitative design. We used Husserl's descriptive phenomenological method to reveal the views of the spouses of individuals with coronary artery disease regarding the adaptation process to daily life (9).

Setting and Sample

Chronic diseases are a group of diseases that require treatment for more than one year or cause limitations in the daily life of the patient for more than one year, and according to the literature, there are three basic stages of chronic diseases. These; crisis stage, chronic stage and final stage. The first stage is the crisis stage; disease symptoms, diagnosis of the disease, appropriate treatment plan, adherence to treatment and efforts to cope with the disease. The chronic period in the second part is; It refers to the period from the diagnosis of chronic disease to the terminal period (10) For this reason, the sample of the study consists of the spouses of 16 patients who were followed up with the diagnosis of coronary artery disease for at least one year in a university hospital located in the city center of Ankara and were hospitalized at least once. Spouses of patients who had surgery for coronary artery disease or stayed in the intensive care unit were not included in the study

due to differences in their stress levels and postoperative adaptation processes. Qualitative research is a research design with a flexible structure, where there is no set rule for sample size. The sample size is determined according to the research question and the purpose of the study (11). Data were collected between October 2021 and February 2022.

Ethical Considerations

Prior to the study, permission was obtained from the Non-Interventional Clinical Research Ethics Board of a state university ethics committee (Decision no:2021/055; Code no:2021053). Before the interview process, the participants read and signed the Informed Consent Form prepared by the researchers to inform the participants about the study. The spouses of the patients who did not want to participate in the study were not included in the interview process. The participants were informed that a voice recorder would be used during the interviews, and they were assured that their identities and the recordings would be kept confidential. Each participant was interviewed once and no repeated interviews or audio recordings were performed. The spouses were coded as "P" (participant) and each participant was ordered as P1, P2, P3 etc. according to the order of the interviews. The study was conducted taking into account the Declaration of Helsinki.

Data Collection

The data were collected by semi-structured, in-depth, face-to-face individual interview technique as suggested in the literature (11,12). An information form developed by the researchers in line with the literature and a semi-structured interview form consisting of six questions were used to collect data (12,13). Two experts on qualitative research were consulted for the semi-structured interview form. Before the study, data collection tools and questions were piloted on two spouses who were not included in the original study. (Table 1)

The interviews were conducted in a quiet environment with no one but the interviewees and when the participants felt ready. Each interview lasted approximately 42-64 minutes and was recorded on a voice recorder. In this process, the texts were read repeatedly and during the interview, trying to prevent data loss. Audio recordings of all interviews were

Table 1. Semi-Structured Individual Interview Questions

1. What is coronary artery disease? Do you think coronary artery disease can be prevented?
2. How was your spouse diagnosed with coronary artery disease? How has your life changed after diagnosis?
3. How did you feel after the diagnosis of your spouse? Has your perspective on the disease changed with this disease?
4. Has a special diet, exercise and daily activity program been developed for your spouse? How did this affect your daily life?
5. Have you been informed about your coronary artery disease by your doctor and nurse? Has your life become easier with being informed?

Table 2. General Characteristics of Participants

Participant	Gender	Age	Level of education	Coronary artery diseases	Other chronic diseases
P1	Woman	43	Bachelor's degree	No	No
P2	Woman	46	Bachelor's degree	No	No
P3	Man	45	High school	No	No
P4	Woman	43	Bachelor's degree	No	No
P5	Man	54	Bachelor's degree	No	No
P6	Woman	50	High school	No	No
P7	Woman	51	Bachelor's degree	Yes	Yes
P8	Woman	66	Associate degree	Yes	Yes
P9	Woman	58	High school	No	No
P10	Woman	57	High school	No	No
P11	Woman	59	Middle school	No	Yes
P12	Man	69	Bachelor's degree	Yes	Yes
P13	Man	65	Bachelor's degree	Yes	Yes
P14	Woman	67	Primary school	Yes	Yes
P15	Woman	52	Bachelor's degree	No	Yes
P16	Man	62	Primary school	No	Yes

deciphered manually, and COREQ-Consolidated Criteria for Reporting Qualitative Studies was used to construct and report the qualitative data (14).

Data Analysis

The data were coded using qualitative data analysis software MAXQDA 20 Plus (VERBI Software GmbH, Berlin, Germany). After the coded texts were created individually by the researchers, they were grouped under themes and sub-themes. Content analysis by Graneheim and Lundman was also used in the thematic data analysis (15).

Rigor

Criteria such as reliability, consistency, confirmability and transferability were taken into account in the data obtained (14,15,16). Credibility depends on the reality of the findings obtained by the researcher and being objective. Transmissibility research results by readers require similar meanings. For this reason, direct quotations were used and detailed comments were included. Consistency refers to the consistent handling of the variables of the research process. In order to ensure consistency in the research, the same procedures were carried out in data collection and

analysis, and the opinions of the same experts were taken while taking the expert opinion. Verifiability is the continuous updating of the results obtained in the studies and supporting each other with the data (15,16). The results of this research are presented based on data. After the development of the theme and sub-themes, same two experts were consulted on qualitative research. At the stage of reporting, participants' statements were translated into English by a native speaker.

RESULTS

The age of the participants varied between 43 and 69 years. Eleven spouses were women and five were man. While five of the spouses also had CAD, eight spouses had other chronic diseases (hypertension, hyperlipidemia, diabetes mellitus- type 2, hyperthyroid and rheumatoid arthritis) (Table 2).

The spouses of 16 patients who were followed-up due to coronary artery disease for at least one year and who were hospitalized for at least one day in a university hospital were interviewed to reveal their views on the adaptation process to daily life. The data on the experiences of the participants were gathered under five themes and eight sub-themes (Table 3).

Table 3. Spouse's Views and Experiences

Example/verbatim quote	Subthemes	Themes
<i>'As far as I have seen and watched on the news, it is an age-related disease, especially seen in men. However, after my husband was diagnosed with this disease, I realized that it is a progressive familial disease related to nutrition. The risk can be reduced, but it just appears suddenly.'</i> (P2)	Suddenly	Coincidence
<i>'When you retire and reach a certain age, you start to visit doctors. My sister is a nurse. She is leading us in this respect. Luckily, we had a check-up. Routine control is a must for this disease.'</i> (P7)	Routine control	
<i>'Since my wife does all the chores at home, I try to help her. But when it comes to food, salt-free and fat-free meals are pushing me hard. My wife cooks the meals. She gets up every morning and walks, but I haven't been able to accompany her yet. So, it was just a dietary change for me.'</i> (P16).	Change	Lifestyle
<i>'With the change in our diet, we try to stay away from sugar, salt and fat and eat more vegetables. Also, we do not buy packaged fruit juice anymore.'</i> (P5)	Order	
<i>'My wife had a heart attack right in front of my eyes and I was scared for the first time in my life, realizing that I couldn't do anything. It was such a moment that I just remember my knees shaking and I just didn't know what to do. I hope nobody experiences this feeling... After that day, I feel that I am constantly stressed out. Maybe I should receive psychological treatment.'</i> (P12)	Fear	Shock
<i>Actually, from the beginning of this disease, I have started to empathize with my husband. I'm going through the same thing after all. We have children; they have a life; they are attending school... Everyone has been affected. We supported each other. We constantly encouraged each other to be cautious and organized, and at the same time we always tried to stay away from stress. Even our fights are calmer now...'</i> (P6)	Sharing	We are one
<i>'We were informed about the disease by both our doctor and our nurse. There are risk factors for this disease. It is especially important that children whose parents have coronary artery disease should pay attention to their nutrition starting from young age. It is not known whether my husband's parents had this disease. But we had the disease in my husband, which also means that we can have it in my children. That's why, I have both of my children examined regularly.'</i> (P15)	The role of genetics	Always in my mind
<i>I can't do anything without my husband. His disease affected the whole family. No one cares for me but my husband. Look, he's lying here, but I didn't leave him alone for even a second. The only thing I want is to see him healthy again. I'm always on the alert. The angiography was successful, but I'm still waiting for him here. He will be discharged tomorrow and I will wait by his bed at home.'</i> (P8)	What would I do?	

Theme 1: Coincidence

While the participants were expressing their views on coronary artery disease, they defined the disease and explained what this disease meant to them. Although the spouses of the patients actually knew the name of the disease, they stated that they were diagnosed as a result of sudden or accidental situations because they had insufficient follow-up regarding the disease. There are two sub-themes under this theme: suddenly and routine control.

Suddenly

When the participants were posed the question of "What is coronary artery disease? Can it be

prevented?", two participants expressed their ideas as follows:

'I know that coronary artery disease is a disease related to cardiovascular health. I had previous knowledge about it. However, after my husband had this disease, I learned more about it. It's a cardiovascular disease. It can be prevented with some changes in lifestyle.' (P1, 43A, F)

'As far as I have seen and watched on the news, it is an age-related disease, especially seen in men. However, after my husband was diagnosed with this disease, I realized that it is a progressive familial disease related to nutrition. The risk can be reduced, but it just appears suddenly.' (P2, 46A, F)

Routine Control

The participants were posed the question of “How was your spouse diagnosed with coronary artery disease? How has your life changed after diagnosis?”. The participants had various responses to this question:

‘My husband was diagnosed during a routine check-up. He was stressed about it because his father died due to a heart attack.’ (P4, 43A, F)

‘When you retire and reach a certain age, you start to visit doctors. My sister is a nurse. She is leading us in this respect. Luckily, we had a check-up. Routine control is a must for this disease.’ (P7,51A, F)

Theme 2: Lifestyle

The participants were posed the following questions: “What has changed in your life after your spouse was diagnosed with coronary artery disease? Has a special diet, exercise and daily activity program been developed for your spouse? How has this affected your daily life?”. It was clear that the patient-spouse relationship was influenced by the many lifestyle changes required after the onset of CAD. Most couples realized that they needed to get used to a ‘new normal’, the loss of previous activities and the presence of new restrictions in various aspects of their lives. Some spouses stated that they were able to cope with the changes in their own lives, even though they had difficulty adapting. Two sub-themes emerged under this theme: change and order.

Change

One participant responded to the questions as follows.

‘We try to lead a more stress-free life. I encourage my husband to do short-term exercises. We both do not do things that require a lot of effort. We have already been following a balanced diet. I try to be careful as much as possible, as I know that this disease can come any day.’ (P10, 57A, F)

‘Since my wife does all the chores at home, I try to help her. But when it comes to food, salt-free and fat-free meals are pushing me hard. My wife cooks the meals. She gets up every morning and walks, but I haven’t been able to accompany her yet. So, it was just a dietary change for me.’ (P16, 62A, M).

Order

Some participants stated that now they have a more regular life:

‘I used to smoke. I quit and now I regularly hike with my husband to support him.’ (P14, 67A, F)

‘With the change in our diet, we try to stay away from sugar, salt and fat and eat more vegetables. Also, we do not buy packaged fruit juice anymore.’ (P5, 54A, M)

‘Sleep, nutrition and exercise are important ... We are trying to manage life stress. I talk less about the problems I have at work so that she is not stressed out. Also, as far as adherence to treatment is concerned, I can say that we suddenly had to use more than one drug at a time. We set up a reminder on my wife’s phone. This application is a nice one. She uses her medications in a more regular manner without delay.’ (P3,45A, M)

Theme 3: Shock

The participants were posed the question of “How did you feel after the diagnosis of your spouse? Has your perspective on the disease changed with this disease?”. Spouses spoke about the need to repeat this information as they tended to be ‘couldn’t understand’ after first learning of the cardiac event. Participants noted the need for intervention at various times, including while in hospital, at the time of hospital discharge, and in the months post discharge. As partners attempted to deal with the fear of potentially losing their loved one and an associated desire to keep them healthy to prevent another cardiac event, they became protective, often overprotective. The analysis of the responses revealed the subtheme of fear.

Fear

The participants expressed how they felt after their spouses were diagnosed with CAD as follows:

‘I started counting my husband’s breaths at night. Even when there is a decrease in his voice, I feel anxious and fearful. I had some mental health problems after his disease.’ (P9, 58A, F)

‘After my wife was diagnosed with CAD, our lives changed. Since his doctor said that men are more likely to experience this disease, I have started to fear for myself. I quit alcohol and smoking and started going for regular check-ups.’ (P13, 65A, M)

Another participant stated that for the first time in his life, he felt his hands were tied:

‘My wife had a heart attack right in front of my eyes and I was scared for the first time in my life, realizing that I couldn’t do anything. It was such a moment that

I just remember my knees shaking and I just didn't know what to do. I hope nobody experiences this feeling... After that day, I feel that I am constantly stressed out. Maybe I should receive psychological treatment.' (P12, 69A, M)

Theme 4: We are one

When we asked the participants how they felt about their spouse's illness, they stated the importance of being together and being a family, and reported that they especially tried to keep their morale high.

Some spouses expressed that the event brought them closer together and made their relationship even stronger, despite the changes that occurred in their lives as a result of the CAD. Overcoming the difficulties of adjusting to the illness, they found new ways to show empathy, love and attention to each other. On the other hand, CAD has caused each member to change on the basis of their roles in the relationship. The subtheme under this theme is sharing.

Sharing

The participants expressed their feelings about the disease as follows:

'Actually, from the beginning of this disease, I have started to empathize with my husband. I'm going through the same thing after all. We have children; they have a life; they are attending school... Everyone has been affected. We supported each other. We constantly encouraged each other to be cautious and organized, and at the same time we always tried to stay away from stress. Even our fights are calmer now...' (P6, 50A, F)

'The disease has taken a lot from our family. We are not as sociable as before. We used to take a trip out of town every weekend. Now my husband cannot drive for a long time. He is afraid and gets tired more quickly. I have just got my driving license to take my husband to hospital. He has always supported us until now. Now it's my turn. I do not want my children to be affected by this disease. That's why, I'm trying to keep my morale high. I have to. This year my kids will take some important exams.' (P15, 52A, F)

Theme 5: Always in my mind

The participants answered the question of whether they received information from their doctor and nurse about coronary artery disease. The majority of the participants were given training on the disease and the treatment methods by both their doctors and

nurses. The participants were posed the question of "After your spouse's diagnosis, have you made any changes in your life regarding your heart health?" Participants requested practical information to help them cope with CAD management such as workshops on stress management, medication management, healthy eating and generally what to expect when discharged from hospital. The result of the theme was the importance of providing information to patients and their spouses. The subthemes under this theme are the role of genetics and what would I do.

The Role of Genetics

The participants stated that they were informed about coronary artery disease and learned that it is a genetic disorder.

'We were informed about the disease by both our doctor and our nurse. There are risk factors for this disease. It is especially important that children whose parents have coronary artery disease should pay attention to their nutrition starting from young age. It is not known whether my husband's parents had this disease. But we had the disease in my husband, which also means that we can have it in my children. That's why, I have both of my children examined regularly.' (P15, 52A, F)

Another participant stated that she had all the information given in training in her mind:

'My husband has this disease. At least I have to protect my children. I pay attention to their diet. I almost constantly check them to make sure they don't consume ready-made food. My daughter was with us when the doctor was informing us about the disease and she heard that genetic transmission is a risk factor. After learning about her father's illness, she is constantly doing research on the Internet...' (P4, 43A, F)

What would I do?

The participants added the following responses to the same question:

'I was very stressed while receiving information about the disease. There were many points I did not understand. During the hospital discharge process, I got my head together and asked everything I should. The nurse said that my husband should use his medications regularly and have a well-balanced diet and exercise. My husband is also diabetic. The nurse said that we should pay attention to this issue and he

should not forget to take insulin. Diabetes clogs arteries. When diabetics have a heart disease, they have a higher risk of having a heart attack. The nurse warned me that we will never know when a heart attack will occur, so we should not skip doctor's visit. ' (P11, 59A, F)

Another participant gave the following response to the same question:

'I can't do anything without my husband. His disease affected the whole family. No one cares for me but my husband. Look, he's lying here, but I didn't leave him alone for even a second. The only thing I want is to see him healthy again. I'm always on the alert. The angiography was successful, but I'm still waiting for him here. He will be discharged tomorrow and I will wait by his bed at home.' (P8, 66A, F)

DISCUSSION

Although there are many studies in the literature conducted with coronary artery patients, studies investigating the effects of this disease on spouses are limited. The discussion part of our study proceeds in line with the themes and sub-themes.

The knowledge level of patients and their spouses is very important in the management of CAD. It is necessary to educate the patient and the spouse not only about the management of the disease, but also about recognizing the symptoms of the disease, regular hospital follow-up and the precautions to be taken. The studies in the literature mostly investigated the knowledge levels and experiences of the patients in the management of CAD (17,18). However, in the management of the disease, it is necessary to inform the spouses of the patients as well as the patients (19). The knowledge levels of spouses and caregivers and their perceptions about the disease are significant (20,21,22,23).

In CAD, the disease-related process affects not only the patient but also the patient's spouse. The spouse experiences the role change experienced by the patient. Various physical, social or psychological needs of the patient are met by the caregiver, and the caregiver's personal health status, health beliefs and the patient's attitude shape the care process. Especially due to the traditions in our society, it is quite common and expected that the other spouse undertakes the care process of the sick spouse. Thompson et al, reported that caregivers are generally the spouses of the patients, they are more concerned with the health status of the sick individuals rather than their own health, and their

quality of life is affected almost as much as the quality of life of patients. The same study revealed that the physical and mental health conditions of caregivers worsen as the medical condition of the individual they care for deteriorates (22). The findings of Tulloch et al, revealed that the caregiver as well as the patient is negatively affected in CAD, supporting the findings of our study. The study further reported that there were serious communication breakdowns between the patient and the caregiver, the patient was overprotected by the family and caregiver, and serious lifestyle and role changes were experienced (23). This situation was also reported by the spouses of the patients who participated in our study.

Vilchinsky stated that partners are almost never taken into account in CAD care. The study reported that approximately 25% of the caregivers of CAD patients experienced post-traumatic stress symptoms (24). Noonan, Wingham, and Taylor identified six themes in their study. The themes identified in the study point to the fact that the mental health of the caregivers is negatively affected during the CAD care process, they experience a role change and assume the role of caregiver, they experience a lifestyle change due to the disease, and their relationships with their spouses affect the course of the illness and the care process (25). This situation was also determined as a result of our study. Verweij et al, reported that not only patients but also caregivers experience lifestyle changes (26). The spouses of the patients who participated in our study also reported that their daily lives and roles have changed, and that lifestyle changes have occurred with the patient. Halm stated that caregivers do not know what to do after the diagnosis of CAD, which has serious negative effects on them. The main focus is on the patient; however, caregivers also have various needs (27). The spouses of the patients in our study stated that they were more adapted to the disease, with the information of the doctors and nurses about the disease.

Dalteg et al, identified five main themes for patients and caregivers in their qualitative study. The identified themes are overprotective behavior towards patients, lack of communication between spouses, sexual concerns, changes in family roles, and difficulty in adapting to the disease (28). The overprotective attitude of the spouses participating in our study drew attention. In another study, Tillmann et al, emphasized genetic predisposition to CAD; however,

they also underlined the fact that smoking, poor dietary habits, high body mass index, and high cholesterol levels may trigger CAD (29). The spouses of the patients who participated in our study also mentioned genetic predisposition for CAD and also commented on the need to protect the patient by regulating nutritional status and daily activities. As a result of these studies, our study is very similar to the literature.

LIMITATIONS

This study is not without limitations. Data were collected at a university hospital in Ankara. This situation will strengthen our findings by investigating the needs and wishes of the population in other centers. Because the interviews were conducted only at one point and over a period of time, the findings cannot reveal how close relationships and the needs of the participants may change over time. Although our inclusion of CAD patients from any diagnostic group builds on previous research with selected CAD populations and provides a starting point for a general understanding of spouses' needs, it precludes assessment of the unique needs specific to a diagnostic group. Despite these limitations, this is the first study to explore desirable components of intervention to help patients and their partners better manage CAD.

CONCLUSION

This qualitative study aimed to reveal the adaptation process of the spouses of individuals diagnosed with CAD to daily life. Our findings indicate that the daily lives of the spouses were affected physically, psychologically and socially; the stress and anxiety levels of the spouses changed with the diagnosis; and there were changes in family-spouse roles. In addition, it has been clearly demonstrated that the spouses take an active role in the management of the disease and thus they should be informed about the disease and treatment protocols. As revealed in our study, it is of great importance that spouses and caregivers receive training and be informed about emergencies in the management of CAD, as in every chronic disease.

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