



## Research Article

## Living with Atrial Fibrillation: An Analysis of Patients' Perspectives

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## SUMMARY

**Purpose:** The aim of this study was to determine the perceptions of patients with atrial fibrillation regarding the disease, to reveal their feelings, thoughts and wishes, and to investigate their perspectives and coping behaviors towards their condition.

**Methods:** Phenomenological methodology was used. The study population consisted of a total of 225 patients treated by the cardiology department of a university hospital, while the study sample consisted of 32 patients who met the inclusion criteria. A semistructured interview addressed perceptions of patients with atrial fibrillation regarding the disease. Data were collected by asking the participants the three questions on the In-depth Individual Interview Form. Data were analyzed using the continuous comparative method of Colaizzi.

**Results:** In the study sample, 50.0% of participants were female, 69.0% were married, and the mean age was 66.90 years ( $\pm$  7.90 years). As a result of the content analysis, four main themes and 15 subthemes were identified: patient's mental status regarding the disease, patient's social status regarding the disease, patient's physical condition regarding the disease, and disease management and coping with the disease. The study found that individuals with atrial fibrillation faced major limitations in their daily living activities and social lives due to the disease symptoms and warfarin use.

**Conclusions:** Patients need to be provided with relevant individual training and counselling so that they lead more satisfactory lives. In addition, appropriate health appointment and monitoring systems should be developed for patients to reduce the problems associated with frequent follow-up appointments.

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## Introduction

Atrial fibrillation (AF) is a supraventricular tachyarrhythmia encountered most commonly in routine clinical examinations. The incidence of AF increases with age. Thromboembolic events constitute a significant proportion of the morbidity and mortality associated with AF. The main objectives in the treatment of AF include anticoagulation (warfarin use) to reduce the risk of stroke, control of the ventricular rate, conversion of the rhythm into sinus rhythm and the maintenance of the sinus rhythm [1,2].

The quality of life of patients with AF is significantly affected because of the condition's symptoms, including shortness of breath, palpitations, chest discomfort, and immediate fatigue [3,4]. In particular, individuals with permanent AF may avoid activities requiring exertion, such as work/housework, climbing stairs,

exercise, and sexual activity, fearing their palpitations will be triggered. These limitations experienced due to AF symptoms may cause the individual to move away from having a social life, preventing him or her from receiving satisfaction in life. By blocking the individual's purposes in life, this disease may cause the individual to fall into despair, have decreased self-esteem, experience breakdowns in relationships, and have an increased dependency on family members and health professionals due to the loss of health. Research has shown that individuals with AF avoid activities requiring exertion due to continuous palpitations. In addition, research has demonstrated that individuals with AF have a high rate of anxiety and depression [3–5]. Likewise, these patients may suffer from anxiety because they have to have frequent blood tests due to warfarin use, follow a strict diet and face a risk of bleeding or embolism as part of the medication's side effects. They may also face financial losses and disruptions in their professional lives due to frequent follow-up appointments [3,6,7].

There are some quantitative studies investigating the information level and adherence of patients using warfarin regarding

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compliance with medication and healthcare recommendations [3,8,9]. However, there is a limited number of studies investigating the individuals' opinions on what living with AF means for patients and their families, as well as what their coping strategies are [7].

## Methods

### Design

This qualitative research employed the phenomenological method. A semistructured interview addressed perceptions of patients with AF regarding the disease. Data were collected by asking the participants the three questions on the In-depth Individual Interview Form. Data were analyzed using the continuous comparative method of Colaizzi [10].

Qualitative research is different from conventional/quantitative research methods in terms of research questions, objectives, sampling processes, and data collection and analysis methods. Unlike quantitative research, data in qualitative form usually is not represented in numerical form. The primary aim of qualitative research is to provide the reader with a descriptive and realistic situation about the topic in question. Therefore, the data collected in qualitative research should be elaborate and in-depth, and the opinions and experiences of the individuals involved should be presented in as direct a way as possible. Qualitative methodology allows a much richer description of the fears and problems encountered by patients than is possible with quantitative methods. The qualitative research technique provides useful methods to understand and appreciate the complexity of patients' medical, emotional, and social needs, as well as their health beliefs and attitudes. Patient care or research protocols for individuals or groups of individuals can be informed by the results. Finally, qualitative research can be used to generate hypotheses for subsequent quantitative research [10–12].

### Participants

The study population consisted of all of the patients treated for AF at the Department of Cardiology of Mersin University Faculty of Medicine Hospital ( $n = 225$ ). The study sample consisted of patients who came to the department of cardiology of the same hospital for follow-up appointments due to their AF diagnosis. The sample participants were 18 years old or older, had been diagnosed with AF at least 6 months prior, used an oral anticoagulant (warfarin), and agreed to participate in the study. The study used a sampling approach that required continuous data collection until the concepts and processes that help to answer the research question (saturation point) begin to repeat. In light of this, the researchers would decide that they reached a sufficient number of data sources when the emerging concepts and processes began to repeat one other. Therefore, the study sample consisted of 32 patients [11].

### Data collection

Data were collected by conducting individual in-depth interviews with each of the patients in the study sample in order to explore what living with AF meant for the patient. We also wanted to reveal the patient's feelings, thoughts and desires [11]. There were three questions on the Individual In-depth Interview Form: (a) What does it mean for you to live with AF (arrhythmia) disease? (b) What are your thoughts/experiences about using anticoagulant drugs? (c) What do you recommend in order to live with this disease in a more harmonious way? A total of five patients were given a pre-application in order to assess the usability of the Individual

In-depth Interview Form. The form was then revised in light of the pre-application.

Both the Ethical Committee and the Office of the Chief Physician of the hospital where the study was conducted approved this study (Ethical no.: B.30.2.MEÜ.0.70.03.00-605.01-971/9375). When the patients came to the hospital's department of cardiology, the researchers informed the patients about the study and the patients gave their verbal consent for participation. The individual in-depth interviews were conducted in the meeting room of the cardiology department. During the interviews, the patients and researchers sat next to each other or face-to-face. All of the conversations in the interviews were recorded using a voice recorder, with the exception of one participant who did not agree to be recorded. In that case, the researcher wrote the participant's answers. The researchers also took notes on the patients' body language and changes in their face expression and gestures. All of the data obtained during the interviews were kept confidential so that they could be used for scientific research. The interviews lasted 60–75 minutes on average.

### Data analysis

As a part of the data analysis, the voice recordings were transcribed first. After that, the raw data were obtained by combining the transcripts with the observations. The transcripts were then entered into Microsoft Word, resulting in a total of 66 pages. Colaizzi's [11] continuous comparative method was used in the qualitative analysis of the research data. The raw data were read multiple times before being grouped. Because it was impossible to interpret the vast majority of this data in numbers, the researchers noted that the results could not be generalized and they were limited to the participants of this study. For a qualitative analysis of the data, a content analysis was performed considering not only the words themselves, but also how common the comments expressed by the participants' responses were, the number of the participants making the same comments and using the same words, the actual meaning underlying the statements and the authenticity of the participants' responses. The patients' responses were evaluated separately for each topic discussed. The responses of the patients were combined by considering the differences and similarities between them. After the raw data generated were read separately and carefully by each of the researchers, the data were processed (i.e., coding of meaningful concepts and themes). Themes were identified by combining the coded data. For the analysis of the data obtained, two experts with experience on qualitative research were asked for their expert opinions on the given raw data. As a result of the data analysis, four main themes and 15 subthemes were identified [10–12].

The interview sessions were held in Turkish, native language of the patients. The paper was translated from Turkish to English.

### Trustworthiness

Some additional methods (e.g., participant verification, peer verification) are used to help verify the results for the sake of validity and reliability in qualitative research. Receiving confirmation from the participants to confirm the findings is significant for establishing the validity and reliability in qualitative research. It is also essential to provide direct quotations from the individuals interviewed and to explain the results based on these [13]. The above-mentioned criteria are met in this study.

## Results

As a result of the content analysis carried out on the data obtained through the qualitative study regarding the meaning of living with AF, four main themes and 15 subthemes were identified

(Table 1). Out of the patients in the study, 50.0% were female, 69.0% were married, and the mean age was 66.90 years (7.90).

### Theme 1. Patient's mental status regarding the disease

#### Acceptance of the disease

Among the participants, one-fourth of them stated that they accepted the disease, they got used to the disease and disease-related medications, and they learned to be friends with the disease. Also, one of the patients stated that it was hard to accept the disease at a young age, while three of the patients stated that they were not able to accept the disease. One patient said the following:

I think accepting the disease is like getting along well with my husband in my marriage. I want to do the same with this disease because there is no other way. I want to be friends with my disease and I don't want it to be mad at me. (74 years old, female)

#### Feelings of burnout due to frequent visits to hospital for follow-up appointments

Half of the patients in the study stated that they regularly had blood tests done, but more than half of them stated that they had problems going to the hospital early and waiting for their follow-up appointments in long lines of patients to have their blood tests examined. Among the participants, four of the patients stated that they did not regularly have their blood tests done because of the feelings of burnout caused by frequent visits to the hospital for follow-up appointments. One patient said the following:

I cannot come to the hospital regularly for the blood tests. You know waiting in the line in front of that door is just killing me. That is why I haven't been here for the last 6 or 7 months. When I come here, I have to make it as early as 7 o'clock. Then I start the endless waiting. (74 years old, male)

#### Dependence

Nearly half of the patients stated that because of their disease, they could not come to the hospital on their own for follow-up appointments. They were also not able to go shopping or for a walk in the town on their own, they were not able to do anything alone, and they felt dependent on the hospital, their children and their spouses. One patient said the following:

I cannot come to the hospital on my own. My son takes me here because I get confused here, I even feel confused about how to get the hospital, and I cannot follow the process here. (55 years old, female)

#### Reaction

Among the participants, one-fourth of the patients stated that they reacted to the disease because of their obligation to use medications for the rest of their lives and because they have to follow a strict diet. Similarly, one-fourth of the patients stated that they had been quick-tempered, unkind and resentful since they were diagnosed with the disease. One patient said the following:

I react because I cannot understand why it is me and why I have this heart condition. (67 years old, female)

#### Fatalism

Half of the patients in the study stated they believed that the disease came from God, they persuaded themselves in this way, they were grateful for the situation and they prayed. One patient said the following:

Because of this illness, I cannot eat or move the way I used to, but I really am thankful. There is always someone worse off than you. May God grant them a favour and patience! I think this is God's will. May God prevent a worse situation and help us protect our mental health! Of course, having this disease is not a good thing, but it is a reality that came from God. (76 years old, female)

#### Anxiety

More than half of the patients stated that they were continuously anxious because they were worried about having palpitations at any moment or having stomach bleeding or a cerebral haemorrhage, depending on the medications they used. In addition, almost half of the patients stated that they suffered from sleeping disorders due to their palpitations. One patient said the following:

Sometimes I fear that I may have palpitations of course. For example, I am just worried like a pregnant woman who goes on a trip but still feels concerned about having labour pains. (63 years old, male)

#### Fear of being paralyzed

Among the participants, one-third of the patients stated that they did not fear death, death was some kind of liberation, and one day, life would end any way. On the other hand, half of the patients stated that they were afraid of being paralyzed as a result of clotting and bleeding due to the disease and they suffered a fear of being a burden to others and being dependent on others. One of the patients said the following:

**Table 1** Themes and Subthemes of Patients' Perspectives.

Themes	Subthemes	(n=32)
Theme 1: Patient's mental status regarding the disease	Acceptance of the disease	8
	Feelings of burnout due to frequent visits to hospital for follow-up appointments	20
	Dependence	15
	Reaction	8
	Fatalism	16
	Anxiety	18
	Fear of being paralyzed	16
Theme 2: Patient's social status regarding the disease	The disease has adverse effects on social life	16
	The disease has adverse effects on financial situation	16
	Protective-caring behavior of family members	6
Theme 3: Patient's physical condition regarding the disease	Inability to carry out daily living activities related to the disease	24
	Sexual problems related to the disease	11
Theme 4: Disease management and coping with the disease	Feelings of insecurity due to the frequent change of healthcare providers	16
	Negative coping with having the disease due to lack of information	21
	Positive coping with living with atrial fibrillation	1

What I fear most is the possibility that I get paralyzed and become a burden to others. May God protect us! Who would take care of me if I am paralyzed? (57 years old, female)

### *Theme 2. Patient's Social Status Regarding the Disease*

#### *Disease has adverse effects on social life*

Half of the patients in the study stated that their lives were limited because of the disease, they were not able to go on vacation, they did not want to visit their friends because they had to refuse the food offered during their visits due to their strict diet, they could not have friends at home as they had to go to the hospital frequently for follow-up appointments or they have palpitations and feel exhausted all the time. All of these had adverse effects on their social lives. On the other hand, it is interesting to note that one of the patients said that she had the opportunity to socialize by coming to the hospital for follow-up appointments. Regarding the adverse effects of the disease on the patients' social life, one patient said the following:

This disease is affecting my social life. I cannot go anywhere. I cannot move anything. I cannot prepare food for my friends and it is not appropriate to have guests without offering them food. I used to visit my friends at their places and I would have them in my house. We had regular home meetings. What a hardworking woman I was! But, for the last two years now, I haven't been able to do any of it because of this disease. My heart beats really fast when I have palpitations or when I dream, so I try having a rest. I love shopping, hanging around in shopping malls or markets, or spending money, but I cannot go to these places myself. I have to have somebody with me all the time. (67 years old, female)

#### *Disease has adverse effects on financial situation*

Half of the patients stated that they had financial problems because they had to pay for transportation as they had to go to the hospital weekly or fortnightly for blood tests due to the disease, and a certain amount of money was deducted from their salaries for examination/treatment and medication costs. Similarly, they stated that they got hungry while waiting in line for examinations and follow-up appointments and they spent money on snacks, like pretzels and water, but even these little expenditures were costly for them as people receiving a pension. Thus, for these patients, their financial situation was adversely affected. One of the patients said the following:

We have to pay a certain amount of money, all of the cost sometimes, for treatment and medication. This naturally affects my financial situation. Using public transportation to go to the hospital for a blood test costs five Liras. What is more, I have to get to the hospital in the morning and I get the test results in the afternoon, which increases the cost even more. Today I will ask for a favour. They are always giving the results in the afternoon. I cannot wait here all day, so I have to go home and come back again in the afternoon to get the results, show them to a doctor and go back home again. Sometimes I have to take two rides a day. Depending on the results of the blood test, I am supposed to come to the hospital once in a week or twice or three times in a month. Can you imagine how much that costs for a pensioner? (65 years old, male)

#### *Protective-caring behavior of family members*

Among the participants, six patients stated that their family members adopted a protective and caring attitude towards them, and especially their children, would not leave them alone fearing

that they might have sudden palpitations. Similarly, six of the patients stated that they felt like a burden to their families. One of the patients said: "My children are always asking me, 'Mom, have you taken your drugs?' or 'Mom, do you need anything?'" (67 years old, female)

### *Theme 3. Patient's physical condition regarding the disease*

#### *Inability to carry out daily living activities related to the disease*

The vast majority of patients in the study stated that due to the symptoms of the disease, they could not perform activities that they were able to perform before the disease (e.g., walking, cooking, housework, shopping). One of the patients said the following:

Now I am not able to take this key from here and put it in another place. It is my daughter now that does the chores at home. I cannot do exercise anymore. My heart starts to beat fast even if I move my arm. I just stop as soon as I walk for 50 meters. I now calculate even my footsteps and I'm moving in slow motion without straining myself. (67 years old, female)

#### *Sexual problems related to the disease*

Among the participants, one-third of the patients reported that they were worried about having palpitations due to a possible excitement during sexual activity or having sexual problems caused by the disease. One of the patients said the following:

Of course my illness is affecting my sexual life. It affects erections, for example. Sexual activity causes a feeling of excitement in my body and, immediately, I have palpitations and it (the feeling of excitement) naturally fades away. (65 years old, male)

### *Theme 4. Disease management and coping with the disease*

#### *Feelings of insecurity due to the frequent change of healthcare providers*

Half of the patients in the study stated that their doctors frequently changed when they came to the department for follow-up appointments, but they wanted their follow-up to be performed by the same doctor as much as possible. One of the patients said the following:

A single doctor should always follow patients like us. I always see a different doctor every time I come to the department for follow-up appointments. The doctor does not know the patient. The patient does not know the doctor, either. It is difficult for both parties. It would be better if we could go on with the same doctor. I think this is very important. (71 years old, female)

Nearly half of the patients in the study stated that they had to come to the hospital throughout their lives for the international normalized ratio (INR) test, and they frequently had to wait in long lines for examinations. This situation was very exhausting and tedious for them. Therefore, they felt as though they should have been given priority for examination. Also, seven of the patients stated that they there should be a separate unit for patients like themselves, while one of the patients stated that there should be a way to conduct this test at home. One of the patients said the following:

We come to the hospital every week. If we do not wait in the line, other patients naturally think this is just not fair. Well, maybe there could be a separate unit where the blood test can be done and we could get the results. Or perhaps there could be a doctor who is just assigned to carry out the INR because

doctors are always busy, as you know. The doctor does not have enough time to ask the patient questions. The patient does not have this time, either. They do not even have 5 minutes. (62 years old, female)

#### *Negative coping with having the disease due to lack of information*

The vast majority of the patients in this study stated that they regularly used warfarin, while more than half of them stated that they did not have sufficient information about warfarin; they did not know much about the drug; they were not informed of the drug's benefits or adverse effects. Only one of the patients in the study stated that she constantly carried a card indicating use of the blood thinner in case of an emergency. One of the patients said the following:

I take my medication regularly and adhere to what the doctor suggests. I do not know its effects exactly, I do not know much about the side effects, but I comply with the doctor's prescription. (70 years old, female)

The vast majority of patients in the study stated that their information about nutrition was insufficient. Their doctors told them not to eat green leafy vegetables, but they did not know the reason for that and they had difficulty following this diet:

They told me not to eat green leafy vegetables, so I do not eat them but I do not know why. People ask me why I do not eat them and I say I do not know. They offer me salad saying it is good for losing weight, but I never eat. The doctor did not explain why I shouldn't eat them. (64 years old, female)

Among the participants, nine patients stated that when they came to the department, the doctors just adjusted the medication dose according to the INR results, but the doctors did not give any information about the effects of the drug or a diet to follow. One of the patients said the following:

My experience with doctors is like this: A doctor looks at the test results and says my blood values are normal or sometimes beyond the limits. But the doctor does not explain if they are beyond the coagulation or liquefaction limits. I just want doctors to talk to us more clearly and inform us. (55 years old, male)

#### *Positive coping with living with AF*

Among the participants, only one patient stated that he took up gardening and planting flowers as a positive coping strategy. Although one-fourth of the patients in this study reported that they accepted their disease, the study found that they did not employ coping strategies that would make them happy, that were unique to each individual and that were help them be active at the same time, such as making time for themselves, going to the cinema or theatre, reading, and planning and implementing leisure activities. Considering the fact that using positive coping strategies to live with a chronic illness is extremely important in terms of the patients' quality of life, the finding that the patients in this study did not use positive coping strategies is the most remarkable. The patient who used a coping strategy said the following:

My wife and I keep ourselves busy by planting flowers. (63 years old, male)

## **Discussion**

The aim of this study was to determine what living with AF meant for patients with AF, as well as to reveal the patients'

feelings, thoughts and wishes, and to investigate their perspectives and coping strategies regarding the disease.

While one-fourth of the patients reported that they accepted the disease and they became like friends or husbands and wives to the disease, more than half of them stated that they had feelings of burnout due to related situations, such as frequent blood tests and waiting in long lines for examinations at the department. Burström et al [14] found that some of the patients got used to living with the disease, learned how to get their symptoms under appointment and had self-esteem, while some of the patients felt guilty because they had the disease. Similarly, McCabe et al [7] found that the patients had feelings of exhaustion and burnout due to the symptoms of the disease. While individuals with chronic diseases have feelings of burnout and despair in the presence of the disease symptoms, they may also develop disease-acceptance and self-confidence when they learn to manage symptoms and develop coping strategies in time. Providing patients with training and counselling about the disease and symptom management could increase individuals' ability to cope with the disease.

In this study, one-fourth of the patients stated that they reacted due to the lifetime obligation to use medication and abide by a strict diet, whereas the same proportion of patients stated that they needed to accept the disease, thinking it was God's will. Similarly, Corbi et al [6] found that patients with AF permanently using anticoagulation suffered anxiety due to frequent follow-up appointments for blood tests and needing to shift their diet. Also, Burström et al [14] found that individuals with heart failure experienced anger and frustration when they had physical function failure or coping failure. Warren-Findlow and Issel [15] showed that some individuals with chronic diseases tended to use emotion-oriented coping strategies by either ignoring the situation when the symptoms got worse or seeking refuge in God, while other patients used cognitive coping strategies, such as the belief that disease symptoms can be controlled by demonstrating positive health behaviors or compliance with medication and diet recommendations. Research found that patients' religious beliefs, such as seeking refuge in God, having faith in God, or praying play a key role in coping with disease symptoms [9,16]. In a study the patients stated that they regarded the disease as fate and they were thankful believing that everything was an act of God [17].

The majority of the patients in this study reported that they had difficulty performing daily living activities, such as going for a walk, doing housework, or going shopping due to the symptoms of the disease. Likewise, nearly half of the patients stated that they were dependent on their spouses and children, and they saw themselves as a burden to their families because they could not go to the hospitals alone for follow-up appointments. Research found that individuals with chronic diseases suffered physical symptoms, so they were more likely to be limited in their housework or shopping, were psychologically distressed compared to their spouses, and had difficulties in their sexual, professional and social lives. They also tended to experience domestic problems because of the possibility that frequent follow-up appointments and symptoms could have a triggering effect [4,5,7,18]. Again, research found that the professional and social lives, as well as the psychosocial wellbeing of family members of chronic disease patients were also affected. Therefore, the disease affected the quality of life for both patients and their family members [19,20]. Zhu, Ho, and Sit [21] found that families became overly protective of patients due to the symptoms and they did not allow their family members with AF to carry out any physical or social activities on their own.

In this study, the patients saw themselves as a burden to their families, but, at the same time, they thought it was a problem when they were not cared for by their family members. In Turkish family culture, elder children or daughters-in-law are expected to be

responsible for the care and health of the elderly in the family. However, the transition to the nuclear family structure in the changing social structure and women taking part in professional life more often made it difficult for individuals to fulfil their traditional roles. Therefore, older individuals with health problems have to solve their problems on their own. However, the current healthcare system in Turkey is far from providing an adequate nationwide infrastructure to facilitate access to the system for the elderly, in particular (except for the Centralized Hospital Appointment System via the Internet or Call-182 service by phone). Inclusion of family members in counselling services related to disease management offered to individuals with chronic illnesses, and the development of services necessary to facilitate access to the healthcare system could reduce the negative effects of the disease on patients and their families.

Half of the patients in this study were found to suffer from palpitations, stomach bleeding, and the fear of being paralyzed due to the disease and warfarin use. Corbi et al [6] found that AF patients using oral anticoagulants were worried about having palpitations, bleeding or paralysis, and they felt that they had to change their way of living and habits because of this feeling. Similarly, McCabe et al [7] showed that patients with AF suffered constant anxiety due to unpredictable AF symptoms and, therefore, they were not able to make career, social or travel plans. Research also showed that individuals with chronic diseases faced symptoms of the disease, the uncertainty of the future, side effects from medication, the fear of being alone or dependent, and the fear of death [4,22]. Also, patients with high levels of social support and those experiencing fewer disease symptoms were found to be less anxious [23].

In addition, one-third of the patients in our study stated that they avoided sexual activity fearing that they would have palpitations during sexual activity. Dabrowski et al [5] found that they were more likely to experience problems in family roles and sexual life. Similarly, Træen and Olsen [24] showed that individuals with chronic diseases refrained from sexual activity because of the changes in their body images and the possibility of symptom recurrence. Studies from Turkey on individuals with chronic diseases found that their sexual lives were adversely affected by factors such as changing body image and the triggering of symptoms [25].

In our study, half of the patients reported that some of their social activities, such as meeting with friends and going on a holiday, were limited, and their financial situations were adversely affected by the symptoms of the disease, limitations caused by the use of oral anticoagulants (e.g., reducing the use of vitamin K-containing foods), constant INR appointment, and follow-up appointments. In parallel to our study, previous research showed that patients with AF suffered constant anxiety due to unpredictable AF symptoms, the obligation to go to the hospital for frequent blood tests and the risk for suffering from the side effects of the medications; therefore, they were not able to make career, social or travel plans [6,7,22]. On the other hand, hospitality and having guests is one of the essential elements of social life in Turkish culture. In Turkey, women especially can visit their neighbours or relatives without an appointment. They also like to make special preparations for their guests and spend time with their many friends in the home environment. House meetings are an important social activity for Turkish women. Since both dietary practices and frequent follow-up appointments restrict patients' participation in such activities, symptoms of AF may lead to social isolation for the patients. Because the disease is usually associated with advanced age, the majority of patients are either retired or they cannot continue their careers due to the symptoms of the disease. Therefore, the fact that these patients' income levels are low (in Turkey,

the average pension is 1,000–1,500 Liras, or \$454–684 USD), around the minimum wage [26], and expenses for disease management and frequent hospital appointments contributed to having a negative impact on patients' financial situation.

Half of the patients in this study stated that doctors did not get to know them as different doctors examined them during the follow-up appointments each time. During medical visits, the doctors just adjusted the INR dose, but they did not provide information to the patients. Lowthian et al [27] found that patients using warfarin suffered cognitive dysfunction, anxiety, depression, and drug side effects, but the doctors were not aware of the difficulties experienced by the patients. Burström et al [14] found that these patients felt better and their communication was maintained when they were able to receive the healthcare they needed, were regularly visited by healthcare personnel, were treated by the same doctor at each health appointment and they were interviewed by a specialist heart failure nurse. Nearly half of the patients in the study stated that they had to come to the hospital throughout their lives for the INR test; they frequently had to wait in long lines for their examination. Therefore, there should be a separate unit for their follow-up appointments.

Research showed that telemonitoring and home-based approaches were more effective methods in maintaining the therapeutic INR range for patients using warfarin. In addition, the research found that individuals actively participated in disease management because the method gave individuals the autonomy to manage, monitor and assess their own disease [28,29]. Quin et al [30] found that in patients taking oral anticoagulant medications, the rate of provision and maintenance of the medication – diet requirements and the therapeutic INR range of those followed in the special anticoagulation unit was higher than that of the patients followed in other units. Stafford et al [29] found that education and home-based approaches were more effective in the management of warfarin. In Turkey, the prothrombin time and INR appointments of patients using oral anticoagulants are performed in outpatient departments where individuals with other types of heart disease are examined. In these departments, 130 patients are examined daily, on average. Therefore, these patients have to wait in lines for examination at each follow-up appointment. In addition, the time allocated for a patient is quite short, so there is not enough time for training and consultations. Additionally, training and consulting services are inadequate because there are no disease-specific specialist nurses (e.g., heart failure nurses, training nurses) available. Therefore, new systems that increase access to healthcare services are needed in order to improve adaptation of AF patients using warfarin, as well as their compliance with the health recommendations, to prevent possible complications and to improve quality of life. Evidence-based approaches must be integrated in chronic care process to improve the patient's quality of life [31].

In this study, while two-thirds of the patients stated that they did not know why they took warfarin, the vast majority of them stated that they did not know why eating some foods was limited. In addition, they were not appropriately informed about this subject, although they tried to adhere to the recommendations of health professionals. Studies from Turkey and other countries studies found that patients using warfarin had an above-average knowledge regarding the reason for using the drug, but they had insufficient information about drug–drug and drug–diet interactions [8,32,33]. On the other hand, research found that healthcare personnel were not aware of the problems/requirements of patients [7], but training offered by doctors/nurses/pharmacists increased the level of both information and compliance [34,35]. In this regard, using visual materials, such as videos and photos, along with written materials, in training this group of individuals with AF and including the social support system in this

training could increase the individuals' level of knowledge about and compliance with the disease and, therefore, their positive coping levels.

### Conclusion

The study found that daily living activities and the social lives of individuals with AF are significantly limited because of disease symptoms and warfarin use. In addition, patients suffered from constant anxiety due to the fear of being paralyzed and being dependent on others. Also, the patients had feelings of dependence and burnout, and they had financial problems due to several reasons, including frequent hospital appointments, the need for their family members' support for follow-up appointments, waiting in long lines in the hospital, and continuously being examined by different doctors.

Patients need to be provided with relevant individual training and counselling so that they lead more satisfactory lives. In addition, appropriate health appointment and monitoring systems should be developed for patients to reduce the problems associated with frequent follow-up appointments. In addition, consultation–liaison psychiatry nurses could take on an active role of helping individuals with chronic diseases cope with psychosocial problems. Finally, because patients using oral anticoagulants have to have frequent blood tests and use healthcare services regularly, setting up specific units to exclusively monitor these patients and providing them with an expert nurse in charge of their training could significantly contribute to these individuals' quality of life.

### Conflicts of interest

The authors declare no conflict of interest.

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