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İKÇÜSBFD

ARAŞTIRMA /RESEARCH

Life Experiences of Patients Using Oral Anticoagulant

Oral Antikoagülan Kullanan Hastaların Yaşam Deneyimleri

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Abstract

Objective: The aim of the study is to examine the life experiences of individuals receiving oral anticoagulant therapy.

Material and Methods: The research was carried out with face-to-face semi-structured interviews (n = 16) using the qualitative research method from the qualitative research design. All interviews were recorded by the mobile phone audio record programme and the interviews were transcribed into the text and evaluated in the Nvivo 8.0 packet program.

Results: The average age of the participants in the study was 58 ± 10.56 years. In the research, themes related to drug use knowledge and awareness, drug benefit perception, drug harm perception, treatment satisfaction, and its effect on daily life were determined.

Conclusion: Awareness/knowledge, benefit and harm perception, impact on daily life and treatment satisfaction were defined within the scope of five main themes. It is recommended that healthcare professionals consider these themes determined in the training programs they will plan for patients.

Keywords: Oral anticoagulant, heart disease, qualitative research, life experience.

Öz

Amaç: Araştırmanın amacı oral antikoagülan tedavi alan bireylerin yaşam deneyimlerinin incelenmesidir.

Gereç ve Yöntem: Araştırma verileri nitel araştırma deseninden olgu bilim yöntemi kullanılarak yüz yüze yarı yapılandırılmış görüşme tekniği kullanılarak (n=16) toplandı. Tüm görüşmeler cep telefonu ses kayıt programı kullanılarak kayıt altına alındı. Veriler metne dönüştürülerek, Nvivo 8.0 paket programında değerlendirildi.

Bulgular: Araştırmaya katılanların yaş ortalaması 58±10,56 idi. Araştırmada ilaç kullanım bilgisi ve farkındalık, ilaç yarar algısı, ilaç zarar algısı, tedavi memnuniyeti, günlük yaşama etkisi ile ilgili temalar belirlendi.

Sonuç: Belirlenen beş ana tema; bilgi/farkındalık, yarar ve zarar algısı, günlük yaşama etki ve tedavi memnuniyetidir. Sağlık çalışanlarının hastalar için planlayacakları eğitim programlarında belirlenen bu temaları göz önünde bulundurmaları önerilmektedir.

Anahtar Kelimeler: Oral antikoagülan, kalp hastalığı, nitel araştırma, yaşam deneyimi.

1. Introduction

Oral anticoagulants (OACs) are commonly used to prevent and treat heart disease, heart valve surgery, atrial fibrillation (AF), cardiac arrhythmia, deep vein thrombosis (DVT) and pulmonary embolism (PE) (1-5). At the same time, according to National Institute for Health and Care Excellence (NICE) and European Society of Cardiology (ESC), which are indicative guidelines in heart diseases, usage of anticoagulant is recommended for non-valvular AF patients with one or more stroke risk factors (3). OACs has been widely utilized since the 1950s. Today, 5% of the population uses OACs on a regular basis. In addition, usage of anticoagulant increases with age (3,5). According to the data of the National Trauma Databank; while the use of warfarin was 2.3% in 2002 in patients of all age groups, it was 4.0% in 2006; while it was 7.3% in 2002 and 12.8% in the patient group aged 65 and over, it was determined to be 12.8% in 2006 (6,7). Due to the medications used by the patients, INR (International Normalized Ratio) follow-up is important and ineffective anticoagulant management may increase the thromboembolic and hemorrhagic risks, which are

among the larger complications (8). A Türkiye-based large-scale study conducted by Kilic et al. (7) revealed that the rate of usage of inappropriate anticoagulant (Warfarin and Aspirin) use was 20%. Since complications such as thromboembolic events or bleeding are common during OACs treatment, managing oral anticoagulants is difficult, causing patients dissatisfaction and negatively affecting their quality of life. Therefore, it is critical to adjust the correct medication dose (6,9,10,11). It was reported in the study of Kılıç et al. (7) that the problem of bleeding is common in monotherapy patients after treatment, and that the major bleeding problem is 13% within one year of starting treatment, while it is emphasized that this rate is 29.5% higher in combined treatments.

It is important to determine the factors affecting medication compliance in patients using OACs (8). Studies show that patients do not have sufficient knowledge and awareness about why they receive OACs treatment (12). It was also reported in the same study that this group, who reported low knowledge and awareness, had a low quality of life and high anxiety levels (12). In the management of OACs treatment, during the hospitalization of the patients and in the post-discharge period; it has been determined that they do not know medication interactions and possible bleeding symptoms; their knowledge about diet is insufficient; they lack confidence in the process of expressing themselves, the language they can understand is not used in the trainings; and they have problems regarding costs (such as application fees to the clinic and travel expenses) (1,10,13,14,16-19). In another study, it was stated that patients did not have basic knowledge about OACs management, and that qualitative evidence was lacking in patient education materials for the treatment they received (8). The disease may cause some physical and psychosocial problems. For example, patients' may dislike going to the hospital and may not comply with hospital appointments. In addition, they may feel insecure due to the inconsistency of laboratory results measured in different hospitals (20). Another study reported that as people get older, they cannot manage their OACs treatments and experience problems due to multiple drug use (polypharmacy) (16). It was also stated that stroke was seen more frequently, that 43% of the patients forgot the medicine dose to be taken and they did not go for blood follow-ups (11). In this context, socio-demographic variables (such as age, gender, income status, education), variables related to the disease process (such as use of different medications, duration of disease, the presence of other chronic diseases) and individual variables (such as disease knowledge and self-management of the patient have been categorized among the problems that patients have experienced (11,16,21,23). Studies examining anticoagulant applications in primary care were mostly carried out with quantitative methods.

It has been noticed that there is a lack of information on this subject in Türkiye, that the problems experienced by patients are not emphasized enough by physicians and nurses, and that evidence-based studies are scarce. It is noteworthy that there are few studies worldwide on this subject (1,16,19,21,22,24). Despite the establishment of a room/unit where patients using anticoagulants are monitored in some cardiology clinics in hospitals; it is observed that these patients are not systematically educated, the training materials are insufficient, the patients are not followed at home, and their records are not kept regularly. Hospital-based home care services for these patients have not been carried out yet. In this context, it is necessary to carry out studies to determine the problems of patients using anticoagulants in cooperation with the hospital and, to strengthen the self-management of individuals with home monitoring and support programs. Considering the problems experienced by the patients during the treatment process and the specific gains in disease management, the following questions were addressed in this study;

- How is the disease management of individuals receiving OACs treatment?

- What are the qualitative aspects of the behaviors associated with the problems experienced by individuals receiving OACs treatment?

answers to their questions were sought.

2. Materials and Methods

2.1. Purpose and Type of Research

This research was carried out using the phenomenological approach, planned as a qualitative type, in order to examine the life experiences of individuals receiving oral anticoagulant therapy.

2.2. Population and Sample of the Research

The study was conducted from September 1 to December 31, 2019, involving individuals who sought care at the Cardiovascular Surgery and Cardiology outpatient clinics of a university hospital in Izmir. Among these patients (278 people), those who received OACs treatment for whatever reason (such as valve surgery, stroke, AF/Arrhythmia, DVT) were selected using the criterion sampling method. The sample included 16 patients. The selection of the patients to be included in the study was determined by considering the criteria of being individuals who received OACs treatment for any reason (such as valve surgery, stroke, AF/Arrhythmia, DVT). The study comprised patients who could read and write, had good mental health and understood Turkish. Individuals who could not speak Turkish, were illiterate, under the age of 18, or over the age of 80 were excluded.

2.3. Data Collection Method and Tools

The data consisted of six questions including sociodemographic characteristics (gender, education status, marital status, employment status, social security, occupation), presence of a supportive family member, health perception status, health perception and disease diagnoses, reason for anticoagulant treatment and number of medicines. The data were collected using a 12-question patient information form, six of which included information, and a semi-structured interview form consisting of questions (6 questions) about benefits, side effects and symptoms, effects on daily life, and satisfaction for individuals receiving OACs treatment. Interviews with the participants were conducted in the form of in-depth face-to-face and semi-structured interviews using the phenomenological approach. It was recorded using voice recording programs on mobile phones and also notes were also taken.

Before starting the interviews, informed consent was obtained from the patients who agreed to participate in the study and allowed voice recording.

Before the interviews, the patients were given codes (such as Interviewer-I1-I16). The purpose of the research was explained to the participants. Patient interviews were continued until the data reached saturation. The interviews were terminated when the qualitative data were repeated.

2.4. Evaluation of Data

All recorded interviews were transcribed by the same researcher after an average of 15 days of one hour study, in order to avoid any data loss. The content analysis method was used in the data analysis. The data obtained in this review were evaluated in the Nvivo 8.0 package program. To ensure the reliability of the study, each transcript was read and evaluated independently by each researcher. The obtained data were read, classified, logically brought together and themes were created. After pre-reading, a code list was developed and categories were created. Then, the qualitative data were coded, the thematic framework was created, the findings were placed within the theme, interpreted, and the data were reported within the framework of categories (26,27). Data analysis was carried out by the researchers and analysed using the Nvivo 8.0 package program. Data analysis was carried out in collaboration with two experts in the field. Similar codes were combined, reduced to a certain number of categories and reported to create the basic idea in the data. It was aimed at contributing to the validity of data analysis by comparing the codes and categories with the literature.

2.5. Ethical Aspect of Research

Before starting the study, written consent was obtained from the University's Non-Invasive Clinical Research Ethics Committee (Decision No: 05.07.2017-2017/131) and from the institution where the study would be conducted, in accordance with the principles of the Declaration of Helsinki. In addition, written and verbal informed consent was obtained from the patients participating in the study after explaining the purpose and the method of the study.

3. Results

The mean age of 10 men and 6 women participating in the study was 58±10.56 years. Thirteen of the participants were married and 3 were single. Eight of the participants were primary school graduates, 3 were secondary school graduates, 3 were high school graduates, and 2 were university graduates (Table 1).

The median number of person living in the house is 4±1.08, and in any case, 7 reported that they received support from their spouses, 3 from their children, 2 from other relatives, one from their spouse and children.

- History of medication usage

When the reason for the use of blood thinners was questioned in the interview with the participants; data on knowledge of medication use and awareness on this issue were obtained.

Table 1. Socio-demographic Characteristics

Socio-demographics	**N**
Age	
43	2 (I4, I12)
47	1 (I5)
50	1 (I16)
51	1 (I15)
52	2 (I13, I14)
53	1 (I10)
57	1 (I11)
62	1 (I2)
65	1 (I1)
67	1 (I3)
69	1 (I7)
70	1 (I9)
73	1 (I6)
74	1 (I8)
Gender	
Male	10
Female	6
Education	
Primary School	8
Middle School	3
High School	3
University	2
Marital Status	
Married	13
Single	3
Social Security Status	
Yes	13
No	3
Work Experience	
Self-employment	1
Retired	9
Housewife	3
Unemployed	3

N=Number; I= Interviewer

Theme: Knowledge and awareness of medication usage

Thirteen of them answered "Because I have a heart disease". Two of them said they did not know why they were using the medicine. Another said; "There was a lot of pain because of varicose veins." I15

"I have heart disease, I had a heart attack, I need to drink." I1

"I have a heart problem. There is vasodilation in the aorta." I3

"Because I have a heart condition." I16

• Disease Management

Theme: Perception of medication benefit

The results revealed a medication-related benefit perception theme. The patients expressed their perception of benefit as follows: Ten of the interviewees stated that the medicines they used "provide benefits".

"So far, I have not seen any harm, what the doctor wrote and recommended… When I went to private doctors from time to time, I also went to public hospitals, they did not change it. It has continued since that day." I1

"It provides, there is no problem at the moment, all my checks are going normally." I2

"I swear, if we didn't use it anyway, I think the heart valve would end and the clot would break out. I swear, without this job, our job will be crippled." I13

Six of the interviewees state that they are "not sure" about the benefit of the medicine.

"I swear, we don't know that they shoot, is there or not? Well, they shoot, they do something." I12

"I'm not sure if it does." I3

Theme: Perception of medication harm

At the end of the interviews, the theme of the perceived medication harm was identified. Ten of the interviewees stated that they experienced no "side effects" from the medication they used.

"No not. It does not have any side effects." I16

Six of the interviewees emphasized that they felt" side effects" from the medicines.

"It's like a heaviness, like a lump, the pain is very slight, but it feels, I feel there is something there, but then it goes away" I4

"Of course, I feel a burning sensation in my stomach, I have reflux and gastritis. Combustion and violent gas, gas…"I1

"I have palpitations, but I don't have any bleeding." I11

Theme: Treatment satisfaction

The theme of treatment satisfaction was identified. Eight of the interviewees stated that they were "satisfied" with the blood-thinning medication they used.

"I'm glad; otherwise it would have been different. How should I explain before using it… My movements were slower. I'm a housewife, so I'm more mobile. I have grandchildren, I have mother-in-law…" I15

"We are very pleased, it is risky if we do not take the medicine, it will be used for life. The situation I am in now is related to that pill." I13

It is observed that 8 of the interviewees stated "indecision and dissatisfaction" in their satisfaction with the blood thinning medicine treatment they used.

"I will understand my satisfaction in control, what will control show now." I9

"Because Coumadin is a heavy pill, its use… So something difficult to use would be better than a suitable blood thinner. Because when you use this, you can't use any medicine or anything. Sorry when you even used painkillers… (Painkiller name mentioned) I was using these, nothing else. When I go to another doctor, I say that I use Coumadin, according to him, they give me the same medicine. Because it's a heavy medicine, it's the opposite..." I10

Theme: Impact on Daily Living

The theme of the daily-life effect was identified. Seven of the interviewees emphasized that they "did not know" how the medicine they used had an effect on their daily lives, and whether the pain or discomfort they experienced was medication-related.

"I don't know at all, I just started taking the medicines last year, but the complaints still continue for 1 year." I5

"What are the effects, how will the effect be? We lie here, they shoot, we can't do anything." I12

Seven of the interviewees stated that the medicine they used did not have a negative effect on their daily lives.

"I didn't notice." I14

"I saw the benefit, I saw it very useful, Thank God, that is, the medicines that saved my life." I8

Two of the interviewees emphasized that the medicine they used made some changes in their daily lives.

"So my heart palpitations. To tell the truth, I don't think the medicine has any effect, but I still have heart palpitations, tightness of my heart, pain in my left arm, numbness... So these things go on all the time." I16

"I always have to be in control, I always have to limit my activities. My walks, and others… There are many times when I feel tired, I have work to do, even if it is urgent, I have to quit. I always have to control myself. I'm more careful, even if I don't have food, it stays, it's not done." I2

4. Discussion

Knowledge and awareness of medication usage

Even those who gave correct answers when questioned about the reason for medicine use in the study had limited knowledge and awareness on the matter (10,15,17,18). The disease management was deemed to be inadequate in studies (15,16,19) where it was claimed that patients did not receive sufficient information about the use of anticoagulants while they were hospitalized and after discharge (10,13,15,16,18,19). In the Clarkesmith et al. (6) study, the evaluation of the patients' opinions of the medication was made under the theme "Patient perceptions of treatment". It was emphasized that the treatment of OACs is not well understood and that patients have a poor perception of the effects of their treatment. For example, one patient thought that OACs treatment improved his irregular heartbeat. Another patient assumed that his blood was much thicker than

normal before starting treatment. They found that the patients who were discharged from the hospital did not have sufficient knowledge about warfarin one week later; the terms that patients could understand were not used, they did not know about possible bleeding symptoms and medicine interactions, and they could not maintain the level of vitamin K in the diet. Yıldırım and Bayık Temel (17) found through their randomized controlled trial that the nurse's home education and support program was effective in outpatients. Significant progress has been observed in patients' self-management of their illness, treatments, diets, and medications. In this study, it was determined that there was a significant increase in treatment compliance in the experimental group, but no effective change was observed in the control group. The patients in the experimental group were able to self-administer their medications, were aware of the risks and benefits of medications, and could recognize medication interactions and side effects. In addition, patients were able to successfully self-administer warfarin and complications were significantly reduced in the experimental group.

Theme: Perception of medication benefit

In the study, ten patients reported that they believed it was helpful when the theme of perception of benefit regarding the medication was evaluated. Participants reported that a normal level of health during doctor's check-ups means that they benefit depending on the effect of the medication (I2), and that they find the medication useful (I13) because there is the thought of clotting due to the heart valve. Six people in the study said they were not sure about its benefits. Patients adhere to their medication regimens regardless of perceived efficacy, often following their physicians' recommendations.

Theme: Perception of medication harm

The quality of life is adversely affected since serious (such as major bleeding, mortality, or embolism) and minor (such as minor bleeding, bruising, respiratory distress, hematuria, or menorrhagia) side effects are common problems during OACs treatment. Indeed, existing literature underscores patients' apprehensions regarding this matter (8). In the study, symptoms such as experiencing side effects, effects of the body's inability to tolerate the medicine (I4 and I11) (stomach problems, gas, burning, heart palpitations), perception of bleeding (I11) were shown as negative side effects. In a study based on whole Turkish data, it was seen that the rates of major bleeding due to warfarin are high (13% in monotherapy and 29.5% in combined treatment) (7). In addition to medication side effects, patients experience some restrictions in their daily lives. Sometimes they may need to pay extra fees to have laboratory tests done. Furthermore, accessing the healthcare system may require patients to travel to another city, incurring expenses for transportation and accommodation. Consequently, patients may opt to forgo necessary laboratory tests due to financial constraints, thereby impacting their overall quality of life. In another study by Bajorek et al. (19), nurses reported that the barriers to the use of warfarin in elderly individuals cause forgetfulness and memory problems (12). Regarding the attitudes towards the use of warfarin, it was determined that the patients had trouble adjusting to the daily dose changes and were dissatisfied with them. Some patients have reported taking warfarin twice a day and experiencing substantial adverse effects. According to a meta-analysis study, the patients experienced a hemorrhagic stroke, which may have been caused by the OACs treatment (12).

Theme: Treatment satisfaction

Regarding treatment satisfaction, almost none of the patients reported that they were not satisfied with using the medication. Even those who were satisfied emphasized their desperation with the phrase “I have to use it for life” (I15). While eight of the patients reported that they experienced indecision and dissatisfaction, one person (I10) stated that it was difficult to use another medicine while using warfarin. Nurses identified five main themes regarding the use of warfarin in elderly individuals in a study conducted by Bajorek et al. (19): “Patient's attitudes towards warfarin use, barriers, lack of confidence in the process of self-expression, the role of the nurse in warfarin use, and the strategies and to increase warfarin use. While determining these themes, they benefited from the nurse's responsibilities, experiences and strategies to manage the treatment. As a result of the randomized controlled experimental research conducted by Yıldırım and Bayık Temel (17), they found that the anticoagulant treatment satisfaction and thus the general health perception of the patients in the experimental group who benefited from the nurse's home education and support program and were able to perform self-management had increased.

Theme: Impact on Daily Living

In the study, seven patients reported whether they had knowledge or experience of the effect of OACs on daily life, one patient was hopeless with the statement "We do what they say", and seven patients reported their perception of the medicine's negative impact on their daily lives. One person reported that his life was saved, two reported that his complaints continued, and one person kept his activities under control and did not do his daily work when he was tired. Shah and Robinson (22) identified many problems such as non-compliance with appointments, cost problems, inconsistency of blood measurement results in different laboratories, dislike of going to the hospital, and psychological and social problems caused by the primary disease within the scope of problems related to INR testing in the hospital. However, considering the complexity of the situation, it is recognized that it is necessary to examine the opinions, experiences and effects of warfarin users on their quality of life.

In this study, Shah and Robinson (22) determined the perceptions of patients who were followed up and registered at home in the treatment of OACs, and they summarized the situation in eight main themes using content analysis on the patients’ experiences. These themes are as follows: benefits to the patient, device-related issues, practice, performing INR measurement in the hospital, managing INR values, health insurance

issues, communication with the doctor and others (medical conditions, psycho-social variables). Within the scope of the benefits it provides to the patient, self-testing of INR; saving time for the individual, not restricting travel, personal control, providing choice, cheaper testing, fewer hospital visits and freedom. Within the scope of device-related problems, high prices, sustainability, validity, calibration, insecurity regarding the accuracy of the device, application mistakes in purchasing the device, and application errors in the use of the device were reported. When it was determined in the study that the patients did not want to read the user manual about how to use the INR device, it was also emphasized that giving the manual to the patients in the form of a video film or showing it to the patients would provide convenience in the application. Patients' comments underscore various obstacles associated with the process of having INR measured in the hospital laboratory, including time constraints, financial burdens, the need for frequent monitoring, and challenges in dosage adjustment. Addressing these concerns is crucial for optimizing patient care and treatment outcomes. Within the scope of INR management, the difficulties they encountered in communicating about test frequency, levels and outcomes were evaluated. It was determined that female participants would have a test once a week at home and once every three weeks at the hospital. One patient stated that she performs an INR test every 1-2 weeks. A female patient also stated that "Doctors and nurses informed me that the frequency of INR measurement should be between 2-4 weeks". Patients reported that their INR values should be between 2.0-3.0 or 2.5-3.5. When the research results and studies are considered, it is apparent that patients find it difficult to adhere to OACs treatment. Considering that OACs treatment is used more in the advanced age group, it is clear that it is not possible for these patients not to have compliance problems. The dissatisfaction of the patients with the treatment actually develops in parallel with the lack of compliance with the treatment or the lack of knowledge about the treatment. Adequate information and appropriate training can remove the uncertainty for these patients. In this context, the themes determined in the research are important.

4.1. Limitations of the Research

This research is a descriptive study that is specific to the institution where the study was conducted, regarding the environment in which it was conducted and the socio-demographic characteristics of the patients who applied. Due to the nature of the study, it is not possible to generalize the results obtained.

5. Conclusion and Recommendations

Within the scope of this research, five main themes were identified: knowledge/awareness, perception of medication benefit, perception of medication harm, affect on daily living and treatment satisfaction. In accordance with the findings of the research, it is recommended that the nurse and other health professionals, particularly the physician, who guide the patient consider these themes while developing the education program on OACs for patients.

6. Contribution to the Field

Considering the long duration of OAC treatment, its effectiveness depending on many factors, and the seriousness of complications that may develop in patients using OAC, this issue should be particularly emphasized in nursing services. Patients should be well informed about regular monitoring and dose adjustment, anecessary lifestyle, dietary changes and restrictions. In this study, problems were identified in line with the individual experiences of patients receiving OAC treatment. This study provides evidence for future research that aims to produce solutions to the research problem and strengthen the self-management of these patients.

Ethical Aspect of the Research

Before starting the study, written consent was obtained from the University's Non-Invasive Clinical Research Ethics Committee (Decision No: 05.07.2017-2017/131) and from the institution where the study would be conducted, in accordance with the principles of the Declaration of Helsinki. In addition, written and verbal informed consent was obtained from the patients participating in the study by explaining the purpose and method of the study.

Conflict of interest

There is no conflict of interest regarding any person and/or institution.

Authorship Contribution

Concept: JGY, GOÇ, SE; **Design:** JGY, GOÇ, SE; **Supervision:** JGY, GOÇ; **Funding:** -; **Materials:** -; **Data Collection/Processing:** GOÇ, SE; **Analysis/Interpretation:** JGY; **Literature Review:** JGY, GOÇ, SE; **Manuscript Writing:** JGY, GOÇ, SE; **Critical Review:** JGY, GOÇ.

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