# Cardiovascular patients' experiences of living with pacemaker: Qualitative study

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# **Original Article**

#### **Abstract**

BACKGROUND: A pacemaker implantation is considered major life event for cardiovascular patients, so they will probably have very interesting experiences of living with this device. The aim of this study was to explore the experiences of cardiovascular patients living with the pacemaker.

METHODS: In this qualitative study, 27 patients were chosen through purposive sampling to achieve data saturation, and their experiences were examined using semi-structured interviews. The patients' statements were recorded with their consent and analyzed using content analysis method.

**RESULTS:** Participants' experiences included three main themes: "Problems and limitations," "feeling and dealing with pacemaker", and "sources of comfort" and 10 sub-themes including: physical problems, financial problems, social problems, the first encounter, the feeling of living with the pacemaker, how to cope with pacemaker, satisfaction with pacemaker, good family support, hospital and hospital staff performance, and role of religious beliefs.

**CONCLUSION:** Planning to solve social problems, identifying and changing feelings of patients using pacemakers, reinforcing the resources of comfort especially family support seem to be necessary steps for improving quality of life and impact of using pacemaker.

**Keywords:** Cardio-Vascular Disease, Pacemaker, Experiences

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## Introduction

Cardiovascular diseases are among the most common causes of disease-associated mortality.1-4 Due to rapid increase in urbanization, industrialized lifestyle, lack of sufficient physical activity, and socio-economic conditions, the morbidity and mortality caused by these diseases is still rising so that today,5 about 30% of all deaths are because of cardiovascular diseases.6,7 In the United States, about 12 million people suffer from coronary artery disease, and annually about 1.5 million people suffer from heart attack and nearly 600 thousand people die due to coronary artery disease.8,9 In Iran also, cardiovascular diseases are considered to be the most common cause of mortality. 10,11

One of the most important advances in providing care and service to cardiovascular patients is using pacemaker in patients suffering from acute cardiac problems.<sup>12</sup> Pacemaker is a device that continuously monitors the status of the body and regulates heartbeats based on the body need.13 About 3 million people worldwide have a pacemaker and about 600 thousand pacemakers are implanted annually.14 Implantation of pacemaker may lead to changes in one's mental expectations of this device, and can result in problems relating to psycho-social compatibility and quality of life, and can trigger emotional disorders.<sup>15</sup> So, these people will probably have very diverse and interesting experiences of living with this device. Since quantitative studies have certain limitations in exploring such issues, 16 the present study has been designed and conducted as a qualitative study with the aim of examining and determining the experiences of people living with a pacemaker.

#### Materials and Methods

This qualitative study was conducted in 2014 at Tabriz University of Medical Sciences, Iran, (TUMS). The rationale for choosing the method of qualitative

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studies was because of the capability of these studies in accessing the experiences and the unknown knowledge within the participants and their ability to pull them out.16,17 Among different approaches of qualitative studies, the phenomenological approach was chosen due to its ability of reviewing human experiences and believing that in the life experiences and phenomena, there are essences that can be fathomed and studied.<sup>18,19</sup> The participants were selected from among cardiovascular patients, who had the history of using pacemaker, and had referred to subspecialty Heart clinics in TUMS for care and follow-up. Some patients did not participate in the study because of some physical problems and lack of time. These people were selected due to having great experiences of living with pacemaker. Inclusion criteria included: At least 6 months experience of using pacemaker and having the desire and ability to participate in the study. Purposive sampling was used for selection of participants (In this method, people who have the greatest and richest information and could appropriately provide the researchers with their information are selected as the participants<sup>17,20</sup> and was continued until data saturation, i.e., to the point that the researchers feel that they cannot get new information by continuing the sampling.<sup>21</sup> This stage was fulfilled with 21 participants in the present study but for obtaining more confidence, the researchers continued the sampling up to 27 patients. Semistructure interviews were used for data collection. During the interviews, guided questions designed using the literature review and the opinions of experts in this field were used (Appendix 1). Duration of each interview ranged from 30 to 60 minutes. The interviews were recorded with the participants' consent, and also the interviewers took notes for recording information. Soon after each interview, the record was assessed several times by the researchers and implemented. Content-analysis, which is a method for identifying, analyzing and reporting themes within a text and applicable in the analysis of qualitative data, was used for data analysis.<sup>22,23</sup> Responded validity was used for data rigor so that at the end of the meeting, the participants' statements were summarized and retold to give the chance to the participants to confirm the accuracy of the notes and perceptions of researchers. Peer check and immersed in data which are methods for creating rigor were used as well. Considering the ethics, informed consent was obtained from participants, and they could withdraw and leave the study at any time they would like to. Besides, the objectives of the study were

explained to the participants at the beginning. To conduct the present study, ethical approval was obtained from the Regional Committee of ethics in research at TUMS.

### Results

In this study, the experiences of 27 cardiovascular patients with a history of using pacemakers were extracted. 14 patients (52%) were female. 11 patients (40%) were illiterate. The mean duration of pacemaker use was about 43 months.

Some demographic characteristics of participants are shown in table 1.

The results of the analysis and coding of the participants' experiences were three main themes and 10 subthemes shown in figure 1.

#### **Problems and restrictions**

### Physical problems

Many participants complained about health problems after pacemaker implantation. The most common of these were neurological problems; the participants noted that they were bored and bad tempered after pacemaker implant. Participant number 6 stated that, "... I have become impatient; I get angry quickly ...." Another common problem that patients complained about were pain.

Participant number 15 mentioned that, "... When I'm walking, it aches (the heart) ... when I want to work, it aches (the heart) ..." Other health problems that participants were suffering from included dyspnea, fatigue, and sleeping problems.

#### Financial problems

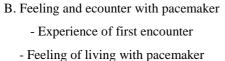
Some participants complained about high costs of the pacemaker and said that financial problem was their main concern about the pacemaker implant surgery. Participant number 2 stated that, "... It costed too much..." and participant number 6 said that, "... I was upset both in terms of operation and its costs (pacemaker implant) ..." Some other participants were also upset about the high cost of surgery and pacemaker implant.

#### Socialization problems

Most of the participants mentioned the limitation of their social relationships and activities after pacemaker implant. Participant number 4 said that, "... my heart has become like a broken dish since I had the battery in (the pacemaker), just like a broken dish if it is hit, it'll break. I go out with fear." Or participant number 7 said that, "... I cannot go out a lot anymore ..." And participant number 20 said that, "having tour and going out cannot be the way it used to be (before pacemaker implant)."

Table 1. Some demographic characteristics of participants

Number	Sex/age	Job	Education	History of pacemaker implant (month)
1	M 71	Carpenter	Illiterate	4
2	M 66	Farmer	Elementary	11
3	F 73	Housewife	Illiterate	21
4	F 68	Housewife	Illiterate	20
5	F 81	Housewife	Illiterate	60
6	F 77	Housewife	Illiterate	72
7	M 82	Army officer	Elementary	18
8	F 61	Housewife	Elementary	96
9	F 46	Housewife	Elementary	72
10	F 53	Housewife	Elementary	36
11	F 60	Housewife	Elementary	48
12	M 73	Carpet maker	Illiterate	72
13	M 87	Medicine man	Elementary	60
14	M 67	Clerk	Illiterate	30
15	F 58	Housewife	Illiterate	6
16	F 35	Housewife	Elementary	60
17	F 76	Housewife	Illiterate	120
18	M 52	Unemployed	Illiterate	84
19	F 75	Housewife	Elementary	72
20	M 79	Clerk	Illiterate	8
21	M 53	Tailor	Elementary	3
22	M 69	Clerk	Elementary	12
23	F 51	Housewife	Diploma	108
24	M 65	Repairman	Diploma	14
25	M 82	Army officer	Elementary	18
26	M 77	Teacher	Bachelor's degree	8
27	F 56	Faculty member	Bachelor's degree	24



- How to get used to pacemaker
- Satisfaction with pacemaker

- A. Problems and restrictions
  - Physical problems
  - Financial problems
  - Socialization problems

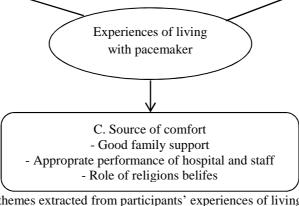


Figure 1. Main themes and subthemes extracted from participants' experiences of living with pacemaker

### Feeling and dealing with pacemaker

#### The experience of first encounter

Feelings of fear, sickness and getting shocked were the most common feelings and experiences among the participants when they had first heard that they needed the pacemaker. Participant number 3 said that, "The first time I heard, I was a little scared ...." Participant number 7 said: "... I felt I was ill...I got a little upset ..." and participant number 16 also said that, "... It was a shock to me, I cried all night ..."

### What it is like to live with the pacemaker

Some participants despite satisfaction of the pacemaker did not feel comfortable living with it. Feelings of absurdity, worthlessness and weakness in life were the most common types of these unpleasant feelings. Participant number 7 said: "... At that time (prior to pacemaker implant) I was like a king but now I'm like a worthless paper ... I have home, I have money ... but I am not pleased with anything ..." Or participant number 12 said: "... I feel I am retarded, I feel like a chipped dish and people think that if they touch me, I will break."

### Coping with pacemaker

Most participants pointed to a spontaneous process and others to a compulsory one as the ways to get used to living with pacemaker. For example, when the interviewer asked the participants how they coped with the pacemaker, participant number 2 answered, "... spontaneously, little by little ..." or participant number 7 said, "Gradually I got used to it ..." and participants number 5 and 18 replied, "... I had no choice..."

#### Satisfaction with pacemaker

As mentioned in the discussion of the feeling of living with pacemakers, most participants were satisfied with the performance and implanting of pacemaker and were happy with it. Here are some views of the participants:

Number 3: "... I have been comfortable since the battery was implanted..."

Number 13: "... Battery is a good thing ... it is like a help ... reassures you..."

Number 9: "Battery is good, not bad."

As a general view, the participants were satisfied with the performance of pacemakers.

### Resources of comfort

# Good family support

Most participants were happy and satisfied with the good support and help of family and friends and considered it as an effective factor to tolerate and improve the life with pacemaker. Participant

number 3 said: "... they care a lot (i.e., spouse and children) ... they are very nice ...," or participant number 16 who was satisfied with help and affection of relatives said: "My husband is so nice to me ... my mom, my sister, my sister-in-law and my mother-in-law help me a lot ..." and participant number 26 stated that "I get along with my family and relatives really well and I have great relationships with them..."

# Good performance of hospital and its staff

Almost all participants were well-satisfied with the performance of the hospital and doctors. Participant number 11 said that, "I had a good time at the hospital ... I was not annoyed at all ..." and participant number 18 said: "... I did not know how it passed (having a good time in the hospital) ... I was satisfied with them (doctors and nurses)..."

### Constructive role of religious beliefs

High religious faith made some of the participants get along well with the pacemaker and not be afraid of its consequences particularly death. Some ideas of the participants were as follows:

Participant number 2: "Man is born once and dies once..."

Participant number 4: "I said to myself I will either die or live; ultimately everybody will meet death..."

Participant number 11: "... I didn't think of anything ... I just trusted in God...".

### Discussion

In this study, physical problem was one of the main problems and complaints of patients using pacemaker. In the study conducted by Afrasiabifar et al.24 on the experiences of the elderly having had heart attack and in the study of Sadat et al.25 on the experiences of the patients with multiple sclerosis, physical problems was one of the main problems and complaints of the participants. Furthermore, this was the case with the studies of Hildingh et al.<sup>26</sup> and Kerr and Fothergill-Bourbonnais.27 Thus, regarding the results of this study and other similar studies, physical problems are among the major problems of the cardiovascular patients specially those using pacemakers, who indicates the need for serious consideration of the patients' problems, that must be reduced and eliminated using medical techniques, rehabilitation, and other supportive programs.

Some patients complained about financial problems during and after pacemaker implant in the present study. In the study of Rybarczyk et al.<sup>28</sup> financial problems and unemployment are referred to as major problems of the participants unlike the

present study. This could be justified by two factors, the first could be high cost of pacemaker implant and lack of appropriate insurance coverage for these costs and the second might be due to the fact that the majority of participants in this study were from rural areas and did not have good financial status.

One of the major limitations and problems of patients using pacemaker was limitation in social interaction and relationships with others. In a way that most of the participants noted a limitation in their social relationships and interactions after pacemaker implantation. In most of similar studies conducted in other categories of cardiovascular patients, these problems and limitations were also regarded as the main problem. Among the most important of these studies are the study of Abedi et al.29 in which the psychological experiences of patients receiving heart transplants were examined, and the study of Jones et al.30 reviewing the experiences of fatigue in patients with congestive heart failure. Other studies have also demonstrated these limitations and problems. 12,31,32

Although the participants in this study stated that their social relationships and communication have been limited, they referred to the good support of family members, relatives, neighbors, and others along with them. Despite this encouraging culture, providing the conditions and supportive programs for the patients' collaboration and social activities seems to be inevitable.

In this study, the feelings of sickness, absurdity and depression were the most common emotions and experiences when the participants found out they needed pacemaker for the first time and were feelings of living with. In some other studies also similar feelings have been expressed by the participants.<sup>33,34</sup> So, considering the effect of the feelings and attitudes of patients in their recovery and treatment process,<sup>33</sup> providing supportive and consulting programs aiming at improving the feelings of these patients seems to be necessary.

Most participants in our study pointed out to a spontaneous and compulsory process of getting used to pacemaker. Yet in most studies conducted in other countries, the participants regarded the lifestyle changes and increasing awareness of their condition as strategies for coping with their disease situation.<sup>35,36</sup> The reason could be due to the illiteracy and low awareness of the participants in this study. This indicates the need for increasing the awareness and helping to change lifestyle in the patients using pacemakers.

Good family support, proper performance of

the hospital and the hospital staff and the constructive role of religious beliefs were relaxing factors for the patients using pacemaker. In the study conducted by Shafipour et al.,<sup>37</sup> patients with a history of cardiac surgery noted the proper relationship with nurses, being placed in a safe and suitable environment for patients and good family support as the resources of comfort. The results of many other studies confirm these results.<sup>38-40</sup> So, considering the constructive outcomes of the mentioned factors inpatients' recovery, endeavors must be done for increasing the good family and relative support, improving the quality of hospital care, and reinforcing the religious beliefs to help the patients recover and feel comfortable.

The fear of pacemaker implantation and its impacts on life was also very common among study participants; an issue that was observed in Campbell et al's.<sup>33</sup> study too. Regarding the effect of feelings and attitudes of patients toward their treatment process,<sup>33</sup> providing supportive and consulted programs to change and improve these patients' feelings seems to be an important and necessary action.

The illiteracy or low education of many participants could be a limitation of the present study which caused most of the participants not to be able to give better and richer information about their experiences to the researchers in spite of the purposive selection. To compensate this problem, researchers continued sampling after saturation (21 patients) up to 27 participants by participants who were more educated to get more detailed and richer information than the previous interviews. Another limitation that could be pointed out as well was the lack of similar studies on the pacemaker patients' experiences in literature review which caused us not to be capable of comparing the results of this study with the results of other studies. Therefore, it is suggested that similar studies on pacemaker and its various aspects be designed and carried out. The results of this study could not be generalized to various conditions and patients like other studies' results. However, the method of this study can be used in other studies.

#### Conclusion

The study results showed that patients show different feelings about living with pacemaker ranging from fear and being shocked to spontaneous or compulsive adaptation to living with the pacemaker. It also showed that patients face different problems such as financial, physical and social problems after pacemaker implantation and to reduce or eliminate

these problems they rely on care provided by relatives, appropriate medical care and religious beliefs. Due to the increasing rate of cardiovascular patients using pacemaker and the lack of studies conducted in this field, the need to study the effects, patients' experiences and other aspects can be felt more than ever. The present study examined the experiences of pacemaker patients using qualitative research methods whose results can be used in providing high quality care, finding the best way to interact with patients, identifying and solving problems arising from pacemaker implantation, identifying and taking advantage of the experiences and feelings of patients and finally helping the patients using pacemakers.

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### **Conflict of Interests**

Authors have no conflict of interests.

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# Appendix 1: Interviews guides

- 1. When for the first time you realized that you have to live the rest of your life with a cardiovascular device how did it feel like?
- 2. What feelings or experiences do you have about this situation (living with a device) regarding your familial relationships and the role you play in your family?
- 3. What feelings or experiences do you have about this situation (living with a device) regarding the society and your role in it?
  - 4. What feelings or experiences do you have

- about this situation (living with a device) regarding hospitals or other healthcare providing centers and the care they have brought to you since?
- 5. How have you adapted to this situation (living with a device) and come along with it?
- 6. What are the most important barriers and obstacles for you regarding this situation (living with a device) and how do you feel about them?
- 7. Eventually what general experiences or feelings do you have regarding this situation (living with the pacemaker)?