

The Challenges of Living With an Implantable Cardioverter Defibrillator: A Qualitative Study

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Abstract

Background: Dysrhythmia is one of the most common causes of sudden cardiac death worldwide. An implantable cardioverter defibrillator is the most effective method of treatment for dysrhythmias causing cardiac arrest. However, living with an implantable cardioverter defibrillator is associated with challenges such as fear, anxiety, and depression.

Objectives: The purpose of this study was to identify the challenges of living with an implantable cardioverter defibrillator.

Patients and Methods: In this qualitative study, an interpretive phenomenological approach was used, with thirteen participants (seven men and six women) between the ages of 21 and 70 years old (mean = 58.15, SD = 14.4). The duration of having an implantable cardioverter defibrillator was 1-120 months (mean = 23.15, SD = 33.31). Maximum variation sampling was used to purposefully select the participants from the governmental Imam Khomeini hospital in Tehran, Iran, between May and October of 2013. Semi-structured interviews were conducted for 30 to 45 minutes, and Van Manen's six-step method was used in this study.

Results: The challenges of living with an implantable cardioverter defibrillator include: living with fear, concerns about the future, concerns about device malfunction, fearing death during the shock, pain due to the shock, loss of control, the cost of the device, and the lifestyle limitations.

Conclusions: Patients who live with implantable cardioverter defibrillators face many concerns and challenges. Therefore, the role of nurses in teaching patients before and after implementation is very important.

Keywords: Implantable Cardioverter Defibrillator, Phenomenology, Challenge

1. Background

Cardiovascular diseases are the most common causes of death and disability in all countries, and are the leading causes of sudden cardiac death (1). From 65% to 80% of sudden cardiac deaths occur due to ventricular dysrhythmias (2), and implantable cardioverter defibrillators (ICDs) are the most effective treatment for cardiac arrest (3) and ventricular dysrhythmia (4). The ICD detects tachycardia and terminates it automatically (5).

Overall, patients have accepted ICDs as life sustaining technology, and they are widely used worldwide (6). The first ICD was used in 1980 (7), and in Iran, the history of this device goes back to 1995 (8). Although an ICD is much more effective than other treatments in controlling dysrhythmias and heart diseases (9), living with an ICD is accompanied with challenges for both the patients and their families (3). For example, social and family relationships, physical activity, psychological status, and quality of life are affected after ICD implantation (5, 9).

The results of several studies have shown that ICD patients experience fear (9), anxiety, depression (10), depen-

dency, fear of death during shock (11), psychological challenges (12), financial problems (13), changes in social relationships, changes in social roles, sleep disorders (14), post-traumatic stress disorders (15), and reduced physical activity (9). However, the healthcare team, especially nurses, can increase the success of treatment by understanding the challenges of living with an ICD (16). Although studies have been done on the quantitative and qualitative aspects of living with an ICD, the challenges of living with an ICD can be very different.

To the best of our knowledge, the challenge of living with an ICD has not been investigated in Iranian patients, and information is lacking in this regard. Without a full understanding of the problems and challenges of patients with ICD, providing comprehensive care to meet all of the needs of the patient and his family is not possible.

2. Objectives

This study was conducted to explore the challenges of patients living with ICD.

3. Patients and Methods

This study was performed using a qualitative approach and hermeneutic phenomenology. Phenomenology is the most appropriate method for understanding the phenomena and meaning of lived experience, and Van Manen's method of phenomenological research was used in this study. Van Manen believed that knowledge and understanding come through analyzing the reflective descriptions of people with relevant experience, and he introduced six methodological steps as a practical approach to the hermeneutic phenomenology (17). The first step refers to the researcher's interest in the phenomenon, and in this case, the researcher was interested in understanding the challenges of patients living with an ICD when he was working as a clinical nurse. The second step was the selection of study participants who exhibited the challenges of living with an ICD. The participants were purposefully selected with maximum variation sampling from those patients referred to the cardiac clinic of the governmental Imam Khomeini hospital in Tehran, Iran in 2013. Seven men and six women participated in this study, and the inclusion criteria were the willingness of the patients to participate in the research and talk about their experiences. Those patients with psychological problems and severe illnesses affecting their experiences were not selected.

The researcher introduced himself to the patients, explained the purpose of the study, and obtained informed consent to participate in the study and record the conversations. The interviews were conducted in a private room in the clinic, and they were performed using semi-structured methods. Individual and face to face interviews were conducted with each participant, who was informed of their right to stop the interview at any time and continue when they were ready. At first, the demographic characteristics of the participants were recorded on a separate sheet, and then, the researcher proceeded by asking questions, such as "Please briefly explain your heart disease history and medical therapies." The interview continued with more specific questions like, "What does living with this device mean to you?" or "What is it like living with this device?" and to clarify the exploration of the concepts, "What did you mean when you said...?" or "Can you explain in more detail?" The duration of each interview was between 30 and 45 minutes, and the interviews continued until data saturation was achieved, and no new information emerged. In this study, after 10 interviews, data saturation was achieved.

The third step was to contemplate the intrinsic themes to describe the phenomenon. At this stage, the researcher used a thematic analysis to determine the main theme of the challenges of living with an ICD. Van Manen has

suggested selective, fractionation, and holistic approaches to analyzing themes. In the holistic approach, the researchers considered the text of each interview as a whole, wrote their perceptions of the life challenges, and the text was read frequently with a selective approach. Those sentences, phrases, and words which seemed relevant to the challenges of living with an ICD were selected; then, the same phrases and sentences were transformed to become the meaningful units. The units obtained from each interview were written on a separate sheet, and the semantic similarities and differences were placed in a separate column. The researcher achieved more general terms with the integration of semantic units.

The fourth step of Van Manen was the art of writing and rewriting. At this stage, the researcher extracted the essential themes of the interviews and wrote them several times to determine a strong description of the desired phenomenon. Moreover, the fifth step was to maintain a strong relationship with the desired phenomenon regarding the main research question.

The sixth step was balancing the research context by considering the parts and the whole. Therefore, the researcher, with regard to the main question, used holistic and selective approaches to maintain the relationship between the whole and its parts. According to Lincoln and Guba, the researcher verified the accuracy of the data with the four criteria of validity, reliability, credibility, and transferability (18). In order to increase the reliability of the data and create a deeper understanding of the phenomenon, the investigator used prolonged exposure to the subject and obtained data, reviewing the data and matching them with the experiences of the participants and the observers' comments. To confirm the data, the extracted themes were given to the participants and their feedback was considered.

Stepwise replication and an inquiry audit were used to evaluate the reliability of the data. In addition, for the achievement of conformability, all stages of the research were recorded accurately. It should be noted that the data analysis phase was guided by activities three through six from the interplay activities introduced by Van Manen (17).

3.1. Ethical Consideration

This article was based on the design of the research center of the school of nursing and midwifery of the Tehran University of Medical Sciences (No: 14655-99-03-90), which has been confirmed by the ethics committee of the Tehran University of Medical Sciences. At the beginning of the interviews, the participants were informed about the research aims, the confidentiality of the interviews and data, the elimination of all of the recorded information after the end of the study, and their freedom in the expression of

their experiences and feelings. They were informed that they could end their participation at their will, and their consent was obtained.

4. Results

Thirteen married participants (seven men and six women) between the ages of 21 and 70 years old (mean = 58.15, SD = 14.4) participated in this study. Their durations of living with ICD were between 1 and 120 months (mean = 23.15, SD = 33.31). [Table 1](#) represents the characteristics of the participants in the study.

4.1. Living with Fear

All of the patients with ICDs experienced fear, especially in the first months after the placement of the device. For example, participant 1 said, "This device helps me so far, I'm just worried about its battery discharge. If you had told me before, all the time I was not afraid unduly. I saw a woman with a depleted battery, she was too much bother."

4.2. Concerns About the Future

The participants were worried about their lives due to the lack of knowledge about ICD performance with regard to heart problems and timely action. As stated by one participant, "I have to ask what this device is and when it must be activated. If it did not work, I do not know what could I do" (participant 8).

4.3. Concerns About Device Malfunction

Most of the participants in this study were concerned about the malfunction of the ICD device and the displacement of the leads. As one woman stated, "When I came to have the device put in, I saw a woman who had been admitted because of system failure. I am also concerned about the device being damaged so it cannot work. I am always afraid" (participant 12).

4.4. Facing Death During the Shock

The participants who had the experience of receiving an electrical shock from the ICD expressed it as the very worst moment of living with an ICD. They stated their feelings differently; for example, one woman said, "This device has given me so much shock. When the shocks my own found out it. The situation got so bad that I saw death with my own eyes" (participant 8). Another participant stated, "With the shock it seems I can see death. Those are the moments that I remember, I'm afraid" (participant 5).

4.5. Pain Due to the Shock

Those participants who experienced receiving a shock from the ICD described it as a painful experience. In this regard, a participant stated, "much painful the shock. It seems it presses you from within" (participant 13).

4.6. Loss of Control

With regard to receiving electric shocks from the ICD, the participants stated that during the shock they lost control and become unconscious for a few seconds. This caused concerns about losing consciousness while driving or even walking down the street. One patient said, "So its shock is bad, such an electric shock, I did not notice the shock when I was unconscious" (participant 8). Another participant stated, "The first time it shocked I was at home. I thought it was an electric shock or the electric wires on the ground. I got dizzy and I saw nothing" (participant 11).

4.7. The Cost of the Device

Many of the participants faced challenges with the cost of the device, in both the preparation of the new device and the regular follow ups after implantation. As explained by one participant, "I was dispatched to Tehran city, I needed a few hundred million Rials, and it was too expensive. How should I get this money? I must come to get the control device and visit the doctor every six months" (participant 10).

4.8. Limitations of Living with an ICD

The participants exhibited concerns about the limitations of living with an ICD. They had problems such as limitations in movement, driving, sleeping, traveling, medical diagnostics (such as MRIs and dental procedures), passing through the checkpoint at the airport, living near high voltage pylons, and heavy work. One participant expressed, "This system has made me limit my work and activity. I always limit myself because of this device" (participant 11). Another participant said, "For example, if I have a small operation, I have to see my doctor to get permission. If I have a dental appointment, I must go to the heart doctor. If I have cold or any other infection, I must go to the doctor because I have this device. This limits my life" (participant 8). Another said, "Every day I expected a shock, even after two months I thought it. It was gone in my mind and I suddenly stopped when driving, I told myself if I was shocked I cannot control my car" (participant 13). One participant explained, "You must be careful not to sleep on the side of the battery. I have the habit to sleep in this position, so it disrupted my sleep" (participant 6).

Table 1. Characteristics of the Study Participants

Participant	Age	Sex	Marital Status	Occupation	Educational Level	Time with ICD, m
P1	63	Male	Married	Retired	Higher diploma	25
P2	70	Male	Married	Retired	Illiterate	14
P3	66	Male	Married	Employee	Illiterate	1
P4	62	Female	Married	Housewife	Illiterate	3
P5	69	Female	Married	Housewife	Illiterate	3
P6	64	Male	Married	Retired	Diploma	1
P7	70	Female	Married	Housewife	Illiterate	60
P8	39	Female	Married	Housewife	Higher diploma	120
P9	21	Female	Married	Student	Higher diploma	12
P10	70	Male	Married	Retired	Diploma	2
P11	54	Male	Married	Employee	Illiterate	24
P12	51	Female	Married	Housewife	Diploma	24
P13	57	Male	Married	Employee	Illiterate	12

5. Discussion

This article is part of a research project with the aim of describing and explaining the phenomenon of living with an ICD, and the challenges of living with an ICD were discussed and interpreted. Moreover, the findings are the participants' responses to the challenges of living with an ICD. In other words, the findings suggest that the patients were faced with these challenges for years. In this study, some of the participants described the moment of electric shock discharge as a painful and bad experience. In addition, fear and anxiety were reported in this study as an important challenge, and the participants described concerns about fear and anxiety which were interfering with their lives. Eckert and Jones have also noted the fear and anxiety of unpredictable events and an inability to control them (12).

Inconsistent with the study findings, Pedersen showed that the ICDs did not have effects on anxiety, depression, and the quality of life (19). Flemme and colleagues revealed that patients with ICDs sometimes use coping strategies, but these strategies have been less effective. However, after 6 to 24 months, it seemed that the patients had accepted the new situation successfully, and that their anxieties decreased. This researcher proposed that nurses play an important role in follow up screenings in outpatient clinics with supporting and counseling patients with regard to anxiety and stress management (20). Moreover, the results of Freedenberg showed that younger females and those who have received ICD shocks were more vulnerable to emotional stress, and that cognitive behavioral therapy and counseling programs can help to reduce the stress of

these patients (21). In this study, the ambiguities of the future were of concern to the participants, and they had little knowledge about the functioning and care of the device. They stated that in cases of system failure, they did not know what to do until reaching the hospital.

The participants in this study also described the sense of being uncomfortable and facing death during the discharge of an electric shock. They described an unpleasant sensation during the shock (11). In this study, some of the participants described a painful electric shock. In addition, Rahman suggested that the participants who received electrical shocks experienced severe pain (22). In Wojcicka's study, electrical discharge (67.4%), multiple shocks (47.2%), and phantom shocks were reported in 21.4% of the patients, while anxiety due to ICD discharge was seen in 84.4%. About half of the patients had reduced their activities to prevent shock (23). Morken showed that the loss of control related to a sudden electric shock discharge in patients with ICDs could play an important role in decreasing the activity level (24).

Another finding in this study was that some of participants faced challenges with the cost of the ICD and the follow up care; however, in Iran, the hospitals of the Ministry of Health and Medical Education pay a percentage of the costs for the device. Moreover, many of the participants had difficulties with their regular checkups. In McDonough's study, the concerns and experiences of life among patients (18 to 40 years old) with ICDs included the cost and financial security (25).

Despite living with an ICD, the device comes with some limitations for the patients; for instance, restrictions in

movement were observed in all of the participants. This limitation was due to the fear of pain in the incision site and the displacement of leads (26). Moreover, patients with ICDs should be supervised by a cardiologist with regard to any medical procedure. For example, an MRI is absolutely contraindicated in these patients, and medical centers should be informed of the situation. In addition, patients with ICDs should not live near high voltage power pylons, which are likely to impair the function of the device. Moreover, because of interferences with the performance of ICDs, the patients should not be close to electronic inspection devices.

One of the reported limitations of living with an ICD was related to driving. In this regard there are many discussions among physicians and patients about driving laws. Our findings are consistent with the research conducted by Eckert and Jones suggesting that ICD patients, especially those who have experienced electric shocks, do not like to drive (12). Zayac and Finch suggested that patients with ICDs have a fear of driving (27). One challenge in physical movement was reported in a study in which all of the participants experienced restrictions of movement because of discomfort in the incision area (27). With regard to the importance of the extracted themes in this study, Palacios-Cena stated the need for training, support, and follow up care after discharge from the hospital following ICD implantation. This can be achieved by more interactions of the patients and families with the healthcare associations (28). Given the concerns and challenges raised by patients with ICDs, patient education becomes more prominent in the quality of life. Nurses and clinicians will be able reduce the challenges of living with an ICD by providing appropriate education and instructions to these patients.

This study recruited a small sample size because of the nature of the qualitative approach, and the inability to generalize the findings was one of the basic limitations in this study. A strength of this study was that all of the interviews and transcriptions were performed by the same researcher (first author).

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Footnotes

Authors' Contribution: Mohammad Abbasi designed the study, performed the data collection and data analysis, and was responsible for drafting the manuscript. Reza Negarandeh supervised all stages of the study and was the corresponding author. Reza Norouzadeh made critical revisions to the paper and submitted the paper. Amir Reza Shojae Mogadam was the coordinator.

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