



## Patients' Experiences of Living with Implantable Cardioverter Defibrillators

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### ABSTRACT

**Background:** Implantable Cardioverter Defibrillator (ICD) is an acceptable treatment method in patients suffering from life-threatening ventricular dysrhythmias. In spite of many advantages, ICD can lead to many challenges in living for these patients. Therefore, understanding these experiences can lead to improvement of holistic care and treatment of these patients.

**Objectives:** This study aimed to identify and describe the patients' experiences of living with ICD.

**Materials and Methods:** This qualitative study was conducted using interpretative phenomenological approach. The participants who were selected through purposive sampling included 4 women and 6 men (mean age:  $43.1 \pm 1.6$  years). The data were gathered through semi-structured interviews and field notes from November 2013 to December 2014. The data were also analyzed simultaneously using Van Manen's proposed stages.

**Results:** Analysis of the data resulted in emergence of 4 themes and 11 subthemes representing the dimensions of the patients' lived experiences with ICD. These themes included "compromised self-identity", "crossing the border of the unknown", "fluctuation in the adjustment path", and "surrounded by changes". Compromised self-identity was manifested through "loss of prestige", "changes in body image", and "being hurt by the battery label". "Unpredictable situation", "rise and fall", and "internal turmoil" were the main axes of crossing the border of the unknown. In addition, fluctuation in the adjustment path included "wandering to cope with ICD" and "institutionalization of ICD in life". Considering the patients' descriptions of surrounded by changes, "family changes", "social role changes", and "change in manifestation of routines" were of great importance.

**Conclusions:** This study allowed in-depth identification of aspects of living with ICD. The results also promoted the ability of nurses to understand and interpret the views of patients about living with ICD. In this way, the quality of patient care becomes more favorable, resulting in improvement of the patients' satisfaction. It can also provide a basis to conduct further researches on different aspects of prevention, care, treatment, and rehabilitation of these patients, leading to strengthening of the nursing research body.

### 1. Background

During the last twenty years, by making improvements in

diagnostic technology in medical and surgical treatment, changes have been created in the field of health care. Implantable Cardioverter Defibrillator (ICD) is among the improvements undertaken in the field of medical technology (1). During the past two decades, this device has been accepted as a treatment in high-risk patients with life-

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threatening dysrhythmia (2, 3). Studies have also revealed its impact on prevention of sudden cardiac death in high-risk patients after heart attack (4, 5).

Despite the benefits of medical technology approach including promotion of physical health, it can be accompanied by new problems and challenges, including dependence on technology, and a feeling of uncertainty associated with dependence on technology (1). ICD can also be associated with mental disorders, such as anxiety, depression, panic, and loss of quality of life in patients (6). These concerns can exist even without considering the possibility of imposing shocks (7). Other problems for such patients include biophysical problems, such as difficulty in working life and sexual life, sleep disturbances, emotional life, and increased levels of anxiety, fear, and depression over time after implantation (8), impact on the lives of mental patients (9), impact on cognitive activities (9, 10), impact on social and cultural life such as loss of independence and overprotection by the family (11), avoidance of activities, irritability to family and friends, aggressive attitude towards the loved ones, and problems in spiritual life (9, 10, 12).

Evaluation of the patients' experience of ICD implantation is important during recovery. A comprehensive understanding of the experiences of patients during illness and treatment is preferred over detailed, broken focus on physical and physiological aspects of the patients' treatment (13). Therefore, qualitative research is mainly used to detect the human emotions (14). Using qualitative methods increases the depth and richness of the results so that it is not comparable to quantitative research methods. Moreover, depth and richness of the results peaks in phenomenology (15). Phenomenology, as a research method, is defined as a systematic, critical, and precise method that is done on a phenomenon (16).

Awareness of the lived experiences of patients is so important that it should be included in the design of healthcare services (17). Knowledge about concepts and lived experiences of patients with ICD can also be valuable in improving the patient care, such as improving life expectancy and quality of life (11, 18). Despite numerous studies on the experience of living with ICD in non-Asian countries (1, 7, 12, 13, 19-21) and performance of a research project in the form of paper in Tehran (22), this phenomenon is still poorly understood in Iranian society. Therefore, the present study was done in Iranian culture to describe the experiences of patients living with ICD. In this way, a deeper insight can be gained about the lives of these patients, and nursing community will be able to identify the ways to help understand the patients' needs and improve their care.

## 2. Objectives

This study aimed to identify and describe the patients' experiences of living with ICD.

## 3. Materials and Methods

Considering the nature of the research question, this study followed a qualitative phenomenological method. The participants were selected from the patients referred to

the cardiology clinics of two hospitals affiliated to Shiraz University of Medical Sciences using purposive sampling. The inclusion criteria of the study were being over 18 years old, having lived with ICD for at least 7 months, having the ability to take part in interview for at least 20 minutes, not having cognitive impairment, and having the ability to recall and express living experiences with ICD.

After all, considering age, gender differences, and cultural and socioeconomic conditions, 10 patients (6 men and 4 women) announced their agreement to participate in the study. Afterwards, the participants received the essential information about the study objectives and signed written informed consents for taking part in the research.

The study data were collected through semi-structured in-depth interviews and field notes. The interviews were performed in Iran from November 2013 to December 2014 and began with the following question: "How is life with an ICD". All interviews were performed once, except for one case who was interviewed twice. The interviews lasted for 35 - 80 minutes (averagely 60 min). It should be noted that all interviews were recorded using a voice recorder and the interviewees' consent was obtained before starting the interviews.

All interviews were performed in the researcher's office and cardiology clinics of the two study hospitals when the participants were comfortable. The participants were followed up to determine their viewpoints regarding the study objectives. Field notes were also written at the same time to better understand the patients' viewpoints regarding the study objectives. The sample size was determined with data saturation when the researchers ensured that no new data in relation to the research question would be added to the meaning units, sub-themes, and themes. In other words, sampling was discontinued when the research team acknowledged the richness and depth of the emerging themes.

The study data were analyzed using the proposed interpretative phenomenological approach by Van Manen (six dynamic and overlapping activities to conduct phenomenological hermeneutic research).

It should be noted that the data were collected and analyzed simultaneously. The analysis was performed as a reciprocating flow and there was an attempt to pay constant attention to the research question and avoid the involvement of the mind with the details. In this way, by reading numerous interviews (word by word), immersion in the data, rethinking about field notes, determination of the meaning units, integration of meaning units in primary themes, and continuous attention to internal cohesion and communication components, the phenomenon of living with an ICD was presented. In order to organize the data more efficiently in this study, MAXQDA software (version 2010) was used.

The methods proposed by Lincoln and Guba (1985), such as prolonged engagement and persistent involvement, were used to ensure the trustworthiness of the data (15). In doing so, enough time was spent for data collection and patient follow-up was carried out through visits and telephone calls. Besides, three experts in qualitative research carefully analyzed the data. Indeed, peer debriefing and member checking were performed to enhance the study's credibility.

Finally, in order to increase the data transferability to similar situations and groups, the participants were selected from two different hospitals in two regions of Shiraz.

This study was conducted according to the Helsinki Declaration after obtaining the approval of the Ethics Committee of Shiraz University of Medical Sciences (ethic code: CT-92-6757). Before the interviews, the researcher introduced herself and explained the study objectives to the participants. The participants were also provided with some information about the use of voice recorders and recording the conversations. Then, the participants were required to sign written informed consents for taking part in the study. They were also reassured about the confidentiality of their information, secrecy of their recordings, and the right to withdraw from the study in any phase of it.

#### 4. Results

This study was conducted on 10 patients (6 men and 4 women) with the mean age of  $43.1 \pm 1.6$  years, ranging from 24 to 74 years. (Table 1) Following responses to the research question, four main themes were emerged as follows: “compromised self-identity”, “crossing the border of the unknown”, “fluctuation in the adjustment path”, and “surrounded by changes”. (Table 2) These themes were the result of the participants’ rich, deep, and full descriptions in the interviews and 1044 meaning units of words, sentences, and paragraphs expressed in terms of the research question.

##### 4.1. Compromised Self-Identity

Continuous review of the interviews caused the researchers to pay attention to the participants’ self-identities, resulting in gradual emergence of this theme.

##### 4.1.1. Loss of Prestige

Some participants expressed a sense of loss after placement of the device. In this regard, participant No. 8 stated a feeling of shortcoming after battery insertion: “After insertion of ICD, it’s not the same! I always feel there is something in my body! I feel deficient! I feel like I have a problem! My heart works with the battery! There’s a piece of iron in my body”.

Loss of prestige was expressed by the participants as a sense of humiliation, feeling of worthlessness due to need for help, dependence on others, change in mutual relationships after ICD implantation, and comparison of the current situation to the past. In this regard, participant No. 9 stated: “My dignity has decreased a little among my children! It seems that they are humiliating me in their heart! I don’t know how they look at me! I need others’ help to work, I’m so lethargic! I am a little useless...Ah”!

##### 4.1.2. Changes in Body Image

Changes in the body image in different forms were expressed by the participants as follows: “Sometimes I feel that one side of my body doesn’t work! I’m embarrassed when my friends say come and let us see what the battery is like” (p7). Participant No. 3 also paid too much attention to her body and mentioned: “Well, I feel that I have a metal thing inside me”.

##### 4.1.3. Being Hurt by the Battery Label

The participants also had an unpleasant experience about others’ showing them secretly and talking about their battery. For example, participant No. 6 stated: “In meetings, some people say I’ve implanted a battery! This issue affects

**Table 1.** Demographic Characteristics of the Participants

	Condition	Number	Percentage
Gender	Male	6	60%
	Female	4	40%
Level of education	Academic	4	40%
	High school	3	30%
	Middle school	3	30%
Marital status	Single	2	20%
	Married	8	80%
Employment status	Employee	4	40%
	Homemaker	3	30%
	Retired	2	20%
	Disability leave	1	10%

**Table 2.** The Emerged Themes and the Related Subthemes in the Present Study

Main Themes	Subthemes
Compromised self-identity	Loss of prestige Changes in body image Being hurt by the battery label
Crossing the border of the unknown	Unpredictable situation Rise and fall Internal turmoil
Fluctuation in the adjustment path	Wandering to cope with ICD The institutionalization of ICD in life
Surrounded by changes	Family changes Social role changes Change in manifestation of routines

my mood". Participant No. 7 also pointed to the battery label with much anger: "I'm not different from a robot! My friends tell me I'm like a statue..."

#### 4.2. Crossing the Border of the Unknown

ICD, with its best performance (i.e. the shock) saves the patients' lives. This situation creates uncertainty, which is full of ups and downs accompanied by internal turmoil of the patients' experiences. These comprised the theme "crossing the border of the unknown".

##### 4.2.1. Unpredictable Situation

ICD creates an unknown condition, which is full of instability and uncertainty and brings the constant expectation of the risk of shock to the patients. This new situation leads to ambiguity and surprise for patients, resulting in an unknown condition and leaving patients alone in permanent doubt. "I had no experience of shock! I didn't think it could give me a shock... It was sudden... I wasn't prepared for" (tp5).

##### 4.2.2. Rise and Fall

This device, which crosses the patients from the border between life and death, presents them with both bitterness and sweetness. As to feelings, such as peace of mind, assurance, security, encouragement, sponsorship, help, and support, of the participants in this study, ICD is closer to the image of the second heart. Despite all these benefits, a large number of problems may occur for patients, causing them to experience a failure. For instance, physical discomfort is inevitable after ICD insertion. Besides, patients suffer much psychologically after the shock.

About ICD, participant No. 4 said: "I call ICD a health collaborator or co-worker. Life with ICD is like living with a contributor or helper. ICD can guarantee the human health. Life is provided again with ICD". Participant No. 10 also pointed: "Another name for ICD is bodyguard or a second heart".

Despite these blessings, participant No. 9 said: "ICD seems to be heavy, like a ten-pound weight hanging from my shoulder". Moreover, participant No. 6 described shock as: "Shock is a state of severe electrocution... It is terrible. "After shock, my spirit was lost. My life was bitter" (p2).

##### 4.2.3. Internal Turmoil

Overall, moving in this path leads to endless turbulence, mental involvement, anxiety, fear, apprehension, worry, and dual feelings in patients. Thus, patients experience a part of death as the cost of acquisition of life. Anxiety was experienced by many participants. Statements, expressions such as "now my only problem is severe stress", were abundantly expressed during the interviews. Fear and anxiety were expressed as follows: "There is a fear in me. I don't like to sleep. Will I wake up in the morning?" (p5).

#### 4.3. Fluctuation in the Adjustment Path

Since the introduction of the necessity of ICD implantation, patients move backward wandering in the adjustment path and forward towards institutionalization of ICD in life. In other words, patients are faced with a continuum, with

one side including difficulty, wait, regret, bargain, fear, sadness, anxiety, demoralization, and uncertainty; the other includes companionship, support, religious beliefs, spiritual strategies, affection, intimacy, optimism, satisfaction, appreciation, and normal life. In fact, patients fluctuate in this path.

##### 4.3.1. Wandering to Cope with ICD

Wandering due to fear, doubt, and hesitation was clear in the participants' statements: "When they told me I had to implant ICD, My heart fell... I was so angry after that... I was nervous. I couldn't control myself, I was afraid very much! At the time of implantation, I had a dilemma" (p5).

##### 4.3.2. Institutionalization of ICD in Life

Nevertheless, some participants talked about moving toward becoming normal. For example, participant No. 10 stated: "I absolutely think I'm like a normal person... I have no problems with ICD, I don't feel it. It's like a part of body, very normal. I don't think that I'm different from others".

#### 4.4. Surrounded by Changes

After ICD implantation, a wave of changes can be seen in the patients' family, community, and everyday life. Considering the patients' descriptions of changes in their daily lives, family changes, social changes, and change in manifestation of routines were of great importance.

##### 4.4.1. Family Change

After insertion of ICD, new sentiment, advocacy, conflict, extreme care, and income changes influenced the family. For example, participant No. 1 mentioned: "I have been hurt so much. My mother disturbs my comfort. My mom is very careful...provides...excessive care...oh...My condition is turbulent".

##### 4.4.2. Social Role Changes

Education and marriage also caused problems for the patients. Implantation of the device also caused both efficient and inefficient changes in the interactions between the society and the patient. Moreover, changes in the lifestyle occurred due to the limitations caused by ICD or patients' disability, and the patients mainly focused on the family. Furthermore, seeking social support, practicing self-relaxation, making an attempt to increase information about the device, quitting smoking and drugs, trying to maintain balance, caring for ICD, and trying to adhere to medical advice appeared in the patients' lives, leading them towards self-care.

##### 4.4.3. Change in Manifestation of Routines

Following the placement of ICD, restrictions lead to changes in everyday habits. Many limitations occur in the patients' daily living, such as keeping away from magnetic fields, avoiding utilization of certain electrical appliances, driving restrictions, etc. In this regard, participant No. 4 said: "I have restrictions in personal tasks, such as driving in reverse gear, taking a bath...I can't lift my hand too high. I can't lift heavy objects".

Participant No. 2 also pointed: "Living with the ICD



means living with limitations. This restriction is related to business aspects. For example, use of electrical appliances, metal detector and that sort of things". "I go to the pool...but I don't swim. I'm afraid of immersion in the water. Perhaps ICD gives me a shock" (p7).

## 5. Discussion

This study aimed to explain the lived experience of the patients with ICD and revealed four themes as follows: "compromised self-identity", "crossing the border of the unknown", "fluctuation in the adjustment path", and "surrounded by changes".

Compromised self-identity, as the main theme of the lived experiences of patients, was a novel finding not mentioned in the previous studies. However, the majority of researchers have noted themes, such as loss of independence and autonomy, loss of confidence, loss of vitality, and..., in the experiences of the participants living with ICD. These confirmed the subtheme of "loss of prestige" in the present study.

Palacios et al. mentioned such issues as sense of loss of control over life, isolation, and loss of vitality, as the patients' general feelings. Additionally, they considered change in the patients' role as a potential factor affecting the sense of loss of independence and confidence (1). Changes in an individual's view about how one is seen by others led to emergence of the subtheme "changes in body image" in the present study. Similarly, Saito et al. stated that after ICD implantation, the patients were faced with an image of someone kept alive by machines (13). Palacios et al. also mentioned that women experienced issues about body image after placement of ICD (1). However, other authors mentioned the change in body image after ICD insertion, regardless of gender (18, 23-25).

By labeling the patients to live with ICD, annoying conditions, such as mental preoccupation, demoralization, discomfort, disappointment, anger, concerns, and their subsequent complaints are created. Despite reviewing the related studies and searching for the term "stigma" in the available articles, no studies were found in this regard, except for the one performed by Saito et al. Therefore, the concept of "being hurt by the battery label", as a novel subtheme, was introduced in the present study.

After ICD implantation, an unpredictable situation was created in the patients' lives, caused by uncertainty, and the possibility of imposing a one-time shock. In this respect, various authors have referred to the experience of uncertainty (13, 26, 27), heartbreak and doubts about the future (9), uncertainty about the shock experience, tendency to remove the ICD in case of shocks, and vulnerability of the patients due to possible future shocks (28). Besides, since patients do not know what to expect (9), the role of the unknown and fear of the unknown are highly important in their lives.

The concept of "rise" in the current study included concepts, such as comfort, convenience, recovery, peace, healing, security, assurance, encouragement, and protection of life. Bolse et al. confirmed these findings and referred to certainty through comfort, support, and trust in future (18). Pasyar et al. also mentioned that concepts, such as convenience, healing, relief of disease symptoms,

and peace, were involved in the subtheme "comforter and healing" (29).

Despite the patients' achievement of these benefits, ICD placement results in physical illnesses. Unpleasant symptoms of shock and physical and psychological suffering caused by shock affect the patients with ICD. In this regard, Tagney et al. indicated that all patients experienced physical discomfort at the beginning of ICD insertion (21).

Similar to the findings of the present study, Palacios et al. expressed that ICD created physical challenges, changes in the perception of body, reduced daily activities, and a range of psychological changes, after ICD implantation (1).

Furthermore, many authors have described the experience of anxiety in patients. For instance, feelings of resentment, anger, and anxiety after the shock have been reported in some patients (7, 30). Anxiety can occur due to a number of reasons, including possibility of shocks alone, thinking about shock event outdoors, and the fear of shock (9). In addition, fear of arrhythmia due to the risk of death could be seen in the patients (13). Moreover, concern about the future (7), concern about reducing the level of sexual activity and not being allowed to drive (21), worrying about ICD displacement (18), and concerns about a possible arrhythmia (1) have been addressed in several studies; these are in line with the findings of the current research. Kamphuis et al. (2004) pointed to the ICD recipients' anger and grief while being faced with physical restrictions. On the other hand, some recipients positively accepted the restrictions (9). These findings partly corresponded to those of the present study. This implies that issues, such as emotional reactions, limitations, complications associated with the disease, and severity or progression of the disease were effective in slowing the patients down in moving toward adjustment. It should be noted that none of the participants in this study accepted the restrictions positively and were satisfied with the existing conditions.

In line with the theme "institutionalization of ICD in life", Bolse et al. emphasized that patients continued to live and manage their lives. They went back to their previous occupations and resumed their daily routines. Moreover, they will be able to plan for the future with confidence and a deep sense of security and feel comfortable with their experience of ICD (18). In fact, they will be deeply appreciative of continuation of their lives (7). These results are in line with those of the current study and supported the subtheme of "institutionalization of ICD in life".

Changes in the family, community, and everyday life were manifested in the lives of the patients and the subsequent concepts, such as advocacy, conflict, extreme care of family, efficient and inefficient interactions, and changes in habits have been considered in many studies conducted on the issue. Some researchers believe that restrictions related to driving had a significant impact on the aspects of daily life of patients (1, 21, 31).

In line with the findings of the current study, Bolse et al. suggested, as to the theme of "empowerment" that receiving support, particularly emotional support, and information from family and professionals were very important. In this way, patients receive support from family, friends, and

healthcare professionals to apply to the required changes in their lives (18). However, termination of some friendships has been observed during the first year after placement of defibrillators (9).

Subtheme of “change in manifestation of routines” in the present study involved some aspects, such as change in habits and tending towards self-care. Consistently, evidence has demonstrated that more than 50% of patients did not return to their previous work after placement of defibrillators (1). In this regard, some authors stated that more restrictions in doing leisure activities were detected among the patients who experienced shock (7, 32).

In conclusion, the findings of this study can contribute to insight into the meaning of life with an ICD as well as to design and planning of training, support, and care for these patients. Moreover, promoting knowledge about the obvious implications of this study can play a key role in improving the quality of patient care. Notably, one of the limitations of the present study was that all the participants were Muslims. Hence, further studies are required to review the experiences of other ICD recipients with different religious backgrounds.

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### Authors' Contribution

F. Sharief, N. Pasyar and M. Rakhshan designed the study, participated in all stages of this research. N. Payar and MH. Nikoo contributed to data gathering. F. Sharief, N. Pasyar, M. Rakhshan and E. Navab contributed to Analysis and interpretation of data. N. Pasyar, F. Sharief and M. Rakhshan contributed to the writing and production of the final manuscript.

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