



## Iranian Patients' Experiences of the Internal Cardioverter Defibrillator Device Shocks: a Qualitative Study

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### ABSTRACT

**Introduction:** Implantable Cardioverter Defibrillator (ICD) is a valuable treatment for the patients at risk of sudden cardiac death. In this method, after diagnosis of pathological cardiac rhythms, shock is automatically applied to normalize the rhythms. Shock is discharged when the patients are conscious, but the patients' experiences of shock have remained unknown. Thus, this study aimed to identify and describe the patients' experiences of shocks received from ICD.

**Methods:** The present qualitative study was conducted through thematic analysis and semi-structured interviews on 9 patients mean age 41.55 (1.57) with ICD from November 2013 to July 2014. Data analysis was also performed simultaneously using constant comparative analysis.

**Results:** In this study, two main themes, namely "with a parachute for life" and "Faced with nuisance", were obtained representing the patients' experiences regarding ICD shock. With a parachute for life included subthemes, such as "Rebirth", "Comforter and healing", and "Life assurance". In addition, "Faced with nuisance" consisted of 2 subthemes of "Discomfort in moments of shock" and "Displeasure after shock".

**Conclusion:** This study provided a basis for evaluation of patients nursing after discharge. By identification of the patients' experiences regarding shock, the present study can help the professional health staff to efficiently play their roles and provide patients with holistic care. It can also be effective in designing behavioral and cognitive interventional programs to change the patients' attitude and promote their adaptation with their conditions.

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### Introduction

Cardiovascular diseases are among the major reasons of mortality and morbidity worldwide.<sup>1</sup> In spite of advances in diagnosis and treatment, sudden cardiac death is still considered as a global problem, accounting for more than half of all cardiac

deaths.<sup>2</sup> Implantable Cardioverter-Defibrillator (ICD) is one of the rhythm management devices utilized for prevention of death in the patients survived after cardiac arrest or life-threatening ventricular arrhythmias.<sup>3</sup> Implantation of ICD has shown considerable improvements through

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the recent years.<sup>4</sup>

According to some studies, pacemaker implantation is the first phase of lifetime treatment in these patients,<sup>5</sup> because insertion of a device into the heart is accompanied by some alterations which involve all but some unique characteristics of the patients.<sup>6</sup>

Determining the potentially dangerous cardiac rhythms and discharging shock, ICD normalizes cardiac rhythm.<sup>7</sup> Nevertheless, this treatment causes some psychological distresses in this patients and non-adaptation with ICD can affect the patients' quality of life.<sup>8</sup> According to research, almost half of the patients experience shock within the first year after implantation. Therefore, these patients restrict their physical daily activities, become depressed, and do not believe in their adaptability.<sup>9</sup>

To date, the major part of our knowledge is related to the technical function of the device and the patients' biophysical life. Yet, the negative psychosocial effects of shock on the patients turn shock-related experiences into a valuable source for research.<sup>10</sup> Up to now, only a limited number of studies have been conducted on the patients' experiences of encounter with ICD shock and its effects on their adaptability,<sup>11</sup> while more information is required in this regard. Most previous studies have investigated experiences of living with ICD<sup>9,12-20</sup> in female recipients,<sup>21</sup> male recipients,<sup>22</sup> old men,<sup>7,23</sup> spouses of patients with ICD,<sup>24,25</sup> and these patients' families.<sup>26</sup> However, only few studies have specifically focused on shock,<sup>27,28</sup> mental adaptability with shock,<sup>29</sup> patients' attitude towards shock,<sup>30</sup> and patients' and their families' experiences regarding shock.<sup>31,32</sup>

Besides, most of these studies have been carried out in other countries and no reliable documents were found concerning the experiences of patients with ICD in Iran.

Knowing the lived experiences of patients is important and should be

included in designing healthcare services. This can increase nurses' ability to understand and interpret patients' views, improve the quality of patient care, create positive outcomes, and enhance patients' satisfaction.

Overall, we felt the need to raise awareness about shock experiences of patients with ICD. Despite some consistent studies in other countries, multiple and subjective interpretations of reality necessitate performance of this research. Thus, considering the effect of cultural and religious contexts, the present qualitative study was conducted on Iranian patients with ICD in order to identify and describe their experiences of the shocks they received from the device.

## Materials and methods

Considering the research question, this qualitative study was conducted through thematic analysis. Thematic analysis is similar to content analysis, but requires more attention to the qualitative aspects.<sup>33</sup> This method is appropriate for identification, analysis, and reporting of the themes and reveals different dimensions of the issues accurately.<sup>34</sup>

The participants were selected through purposive sampling based on a variety of different characteristics, such as maximum age range, gender differences, and different cultural, economic, and social conditions. Considering patients' follow-up at the clinic for ICD analysis, the participants were selected among the patients referred to the cardiology clinics of two hospitals affiliated to Shiraz University of Medical Sciences. The inclusion criteria of the study were having lived with ICD for a year or more, experience of shock from ICD, age above 18 years, understanding and speaking Persian, being able to remember and express one's experiences related to the study objectives, ability to take part in interviews for at least 20 minutes, being aware of time, place, and person, and not suffering from cognitive

disorders. After all, 9 patients with ICD (7males and 2 females) were recruited into the study.

After selection of the participants based on the inclusion criteria, the study objectives were explained for all participants, and written informed consents were obtained. All interviews were performed in a private room in the cardiology clinics when the participants were comfortable.

Interview, as one of the most fundamental, certain, and flexible data collection methods,<sup>35</sup> allows entrance to individuals' lives and is consequently an excellent source of data collection in qualitative studies.<sup>36</sup> In this study, the data were gathered through semi-structured interviews each lasting for 30-90 minutes from November 2013 to July 2014. The interviews were started by an open question about the patients' experiences of shock while living with ICD, and the patients could take a rest in case they got tired during the interviews. Data collection was continued until data saturation. Then, the interviews were read word by word and data analysis was performed simultaneously. In doing so, first the participants' descriptions were reviewed, primary coding was performed, and themes were determined. Afterwards, the codes with specific meanings were located in the same category with respect to context and these subthemes were then placed in the main categories based on content similarity. After that, the main themes were reviewed again and appropriate abstract terms were selected.

Data collection was stopped after nine interviews and reaching the point of data saturation when no new themes could be found in the participants' statements. It should be noted that the two final interviews were performed so as to make sure about data saturation. At the end, final descriptions were selected based on the research objectives and a comprehensive

description of the concept of shock was presented by considering all the categories' meanings.

In order to accelerate organization and coding in this study, MAXQDA software (version 2010) was used to seek for similar themes and combine the categories. In addition, various approaches were used to ensure the trustworthiness of the data. The researcher's prolonged engagement and insistent observation as well as considering sufficient time for data collection and patients' follow-up at the clinic and at home determined the credibility of the data. Also, member checking was done by some patients to compare the findings to their expectations. This helped the researchers better understand the study setting. It should be noted that three relevant experts directed data analysis and analytical field note was used to accurately determine the patients' experiences of ICD shock.

All the research processes were performed according to Declaration of Helsinki. Besides, the study was approved by the Ethics Committee of Shiraz University of Medical Sciences. When a study is conducted on human subjects, their rights should be taken into account. Therefore, the study participants were provided with the necessary information about the study objectives and procedures and written informed consents for taking part in the study were obtained from them. In this way, the participants were ascertained that they could withdraw from the study at anytime. They were also assured about the confidentiality of their information and explained about voice recording and how the recordings were going to be used. Thus, the archives of recordings, notes, and participants' information were kept completely secret.

## Results

In the present study, 9 patients with the mean age of 41.55 (1.57) years (range: 24-72 years) were selected through purposive

sampling based on the inclusion criteria of the study. The participants' characteristics have been presented in Table 1.

Investigating the participants' descriptions in the interviews, 184 primary codes were extracted according the research objective. After review and summarization, the codes were categorized based on their similarity. Then, by further reviewing, analyzing, and comparing the categories, conceptual names were selected for their meanings. Finally two main themes were revealed as follows: "with a parachute for life" and "Faced with nuisance". These themes were about the study objectives; i.e., identification and description of the experiences of shock in the patients with ICD.

#### 1. *With a parachute for life*

Despite the discomforts of shock for the patients, it was considered as a guarantee for life, revealing the first theme; i.e., "with a parachute for life". Parachute for life highlights the life-saving nature of the device. "Rebirth", "Comforter and healing", and "Life assurance" were the main axes of this theme.

##### 1.1. *Rebirth*

According to some participants' view points, shock played the role of a survivor. These patients mainly focused on continue living with the assistance of shock. A 52-year-old man mentioned: "See, that moment is a bad moment, but it is between life and death. It means that if that moment is not there, death will certainly happen, cardiac arrest. Between life and death, all choose life normally".

One of the participants pointed to rebirth as follows: "I call it second life" (a 30-year-old man). A 29-year-old man also said: "When I experienced cardiac arrest and the device gave me a shock, my life started again". Besides, a 56-year old woman with grief stated: "Shock was a man of hope. If it wasn't there, I might have been dead. But I gained a new life".

#### 1.2. *Comforter and healing*

Concepts, such as convenience, healing, relief of disease symptoms, and peace were involved in emergence of this theme. Some of the participants referred to the comforting and healing nature of the device as follows: "After the device's shock, my heart was quiet. I mean I didn't have palpitation. My heart rate was regulated. Now I'm comfortable...somewhat comfortable" (a 29-year-old man). A 47-year-old man also mentioned: "A few minutes later, you're fit again; you're on your way and your heart rate will be regular". With regard to healing and peace, a 45-year-old man stated: "Living with shock is like living with a health contributor. After the shock, the situation is calming and healing...at least physically".

##### 1.3. *Life assurance*

In the patients' descriptions of shock, life assurance was of great importance. Accordingly, the device played the role of a supporter for the patients. After ICD implantation and shock delivery, the patients experienced assuredness: "ICD is like my second heart and shock is a body protector. Well, I'm glad I had the device implanted and I saved myself from worry about cardiac arrest" (a 56-year-old man). One other patient also said: "I'm feeling peace of mind that the device is implanted. I'm reassured, I have hope" (a 26-year-old man). A 47-year-old man also stated: "Finally, ICD has benefits...think...if you fall somewhere, it gives you shock and you can stand up again. I feel being supported". Besides, a 56-year-old man explained: "After receiving shock, I thought to myself...don't worry... you don't have any problems...if a problem arises, you won't need a doctor".

#### 2. *Faced with nuisance*

The other dimension of the patients' experiences of shock was "faced with nuisance". Nuisance was experienced as a whole and more detailed statements were

expressed by the patients, which will be discussed more extensively in this section. According to the study findings, nuisance involved "discomfort in moments of shock" and "displeasure after shock".

#### 2.1. Discomfort in moments of shock

In some patients, unpleasant alarming signs of shock were expressed as an aura or a relative awareness of the probability of shock before shock discharge: "Shock is a bad feeling. It is like you know something bad is going to happen and you are aware of it. One knows it is going to discharge shock. It gives one a bad feeling" (a 52-year-old man). In this regard, the patients stated that they had a relative awareness of the probability of shock before its discharge, which was accompanied by apprehension as well as physical signs, such as flushing and dizziness.

Shock was accompanied by a spiritual experience in some patients. A 52-year-old man said with worry: "At the moment of shock, one recurses to God and holy prophets until that moment is gone. One still has the same feeling afterwards".

At the time of discharge, the patients experienced physical problems, such as pain, burning, being thrown, and reduction of physical power, and then needed to follow battery analysis. In spite of believing in the life-saving role of shock, most patients considered it a bitter and disappointing experience in life. A 45-year-old man said: "When the device discharges shock, it is a very bitter and disappointing experience, a bitter experience". Some participants stated that shock was accompanied by a pressure or strike on the chest. A 47-year-old man mentioned: "At the moment of shock, you have just fallen on the ground and something like a bomb is exploding in your chest".

Also, some other participants considered shock to be similar to electric shock and stated that "It is like you have caught an electric wire", "Shock is itself an electric flow", and "I didn't get whether it was

shock or I experienced an electric shock" (a 26-year-old man). Moreover, shock was sometimes considered to be equal to death. In this regard, a 24-year-old woman said: "Shock produces a sound inside you and you think you are leaving here. You feel you are leaving here and that's too bad. Shock is a part of death".

#### 2.2. Displeasure after shock

By creating excitement in the patients, shock led to dissatisfaction, inability to tolerate shock, fear from shock, relating physical problems to shock, anxiety after shock, and worry about discharge of shock which resulted from confusion, novelty of the experience, permanent probability of shock at any time and place, discharge of shock at consciousness, and previous experience of shock.

The study participants stated that the effects of shock were highly undesirable: "It's terrible; I'd rather die but not experience shock again". Fear from shock was also experienced by most of the patients and was expressed by "I was really scared", "I've become timid since then", and "I'm afraid of it". In addition, some patients indicated that confusion was effective in their fear. For instance, a 49-year-old woman said: "Confusion adds to the effect of anything. It was difficult that I was confused". On the other hand, they experienced force to accept shock, preoccupation, mental evasion, irritation, acceptance of the nature of shock, seeking a way to remove shock from the device's program, and regret from implantation of ICD. In this regard, a 72-year-old man said: "I always have shock in mind, I never forget it. I may forget eating, but I don't forget the shock. I always remember it". Considering acceptance of the nature of shock, a 45-year-old man stated with sadness: "Well, this is what the device is good for, it is a part of it, it discharges shock whenever needed". However, some patients were desperately seeking for a way to stop the shock. A 72-year-old man mentioned: "I don't know

what to do. Please kindly do something that it doesn't give shock. I'm innocent". Furthermore, some patients regretted ICD implantation and expressed that "I don't want it anymore, I regret" (a 47-year-old man).

Shock led to some aggressive behaviors, including fighting with children and unwilling to watch other patients experiencing shock. Shock also had various effects on the patients' social conditions. For instance, restriction in daily activities and dependence on others after shock were

observed among the patients. For example, a 72-year-old man said: "I don't dare to go anywhere. I'm afraid of shock. I'm very scared. I don't dare to go anywhere alone. Even when I want to go farming, I take one of my children with me".

## Discussion

According to the findings of the present study, shock has an important role in all aspects of life of the patients with ICD.

**Table 1.** The characteristics of the participants

ID code	Age	Sex	Marital status	Education level	Employment status
1	72	Male	Married	Illiterate	Quit due to disability
2	24	Female	Single	Academic	Employee
3	45	Male	Married	Academic	Employee
4	52	Male	Married	Academic	Retired
5	30	Male	Married	High school	Quit due to disability
6	26	Male	Married	Primary school	Quit due to disability
7	49	Female	Married	High school	Housekeeper
8	29	Male	Married	High school	Quit due to disability
9	47	Male	Married	High school	Employee

expressed as a double-edged sword. In spite of perceiving the worst conditions after shock, from electric shock and explosion in the chest to death, the patients admitted the life-saving role of shock. They had found out this role by experiencing shock discharge.

Shock was an unpleasant experience for most of the patients and the alarming signs of shock or aura are one of the special findings of this study. Some authors reported the patients' general experiences of shock as "a blow to the body" or "a spasm causing the entire body to jump".<sup>30</sup> The patients considered shock as a highly frightening, life-altering, painful, and stressful experience and described it as an explosion in the chest, explosion of mind, and an impact of death.<sup>17</sup> Nevertheless, the patients tolerated the shock because of its life-saving role.<sup>30</sup> In fact, although shock reminded the patients of death, they considered ICD as their survivor and felt

secure.<sup>37</sup> Also, the patients mentioned horrible feelings about shock along with their appreciation of the device as their survivor.<sup>38</sup>

Shock with its special surviving function has great effects on the patients' lives. Recourse to God and holy prophets at the moment of shock discharge represents the spiritual effects of shock on the patients. Nonetheless, most studies have mainly focused on the physical, mental, and psychological effects of shock on the patients.

In line with the present study results, some authors stated that shock resulted in fear and anxiety and mentioned the effects of shock as one of the themes of their study.<sup>26</sup> Some researchers also mentioned fear from shock as one of the general themes in ICD receptors.<sup>39</sup> Moreover, physical signs, such as dizziness, general weakness, nausea, vomiting, palpitation, chest pain, and chest soreness,<sup>31</sup> and psychological signs, such as fear, anxiety,

depression, aggression, anger, and stress levels, were higher among the patients who had experienced shock compared to other patients.<sup>37,40</sup>

Anxiety may result from unfamiliarity with the experience of shock.<sup>9</sup> Consistently, some researchers believed that anxiety was associated with shock due to unknown time and place of shock discharge, experience of shock, and recovery.<sup>14</sup> Fear from shock discharge is one of the factors affecting the patients' restriction of activities.<sup>22</sup> Also, in some previous qualitative studies, the patients who had experienced shock within the last year had restricted their daily activities due to physical or mental problems.<sup>11</sup> Similarly, some researchers reported more limitations in patient's leisure activities,<sup>24</sup> reduction of physical activities for prevention of shock, fear from loneliness and dependence on one's partner after shock among their study participants.<sup>37</sup>

It should be noted that the previous studies mainly focused on experience of living with ICD, and shock was expressed as one of the themes of the studies. Furthermore, experience of heartbreak, uncertainty about future,<sup>14</sup> uncertainty about shock, tendency to remove ICD in case of continuation of shock discharge, breakability due to the probability of future shocks, and regaining control through acceptance of life changes have been mentioned in various studies. It is important to note that the patients finally considered ICD as their survivor and accepted the uncertainties.<sup>37</sup>

## Conclusion

The present study revealed the experiences of the patients with ICD regarding shock discharge referred to the cardiology clinics of two hospitals affiliated to Shiraz University of Medical Sciences. According to the main research question, the patients' experiences of shock were classified into two categories of "with a parachute for life" and "Faced with nuisance". Identification of

the patients' experiences of shock and the effects of shock on various dimensions of the patients' lives can help healthcare professionals to efficiently play their roles and provide the patients with holistic care.

It is also of great help in designing programs for strengthening financial resources, facilitating reduction of tensions, and helping psychosocial adaptation in these patients. Hence, healthcare staff can change the patients' views toward shock by designing behavioral and cognitive interventions, informing, training, supporting, and consultation, which eventually accelerate the patients' adaptability. Yet, further studies are required to be conducted on the issue to open new horizons regarding this phenomenon for directing holistic care for such patients. One of the limitations of the present study was that all the patients were Muslim. Thus, the experiences of ICD receptors with other religious backgrounds should be investigated, as well.

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## Ethical issues

None to be declared.

## Conflict of interest

The authors declare no conflict of interest in this study.

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