

ORIGINAL ARTICLE

Changes in Daily Life of Iranian Patients with implantable Cardioverter Defibrillator: A Qualitative Study

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ABSTRACT

Background: Although Implantable Cardioverter Defibrillator (ICD) saves the life of patients with life-threatening ventricular dysrhythmias, it causes various challenges in their life span. Considering the increase in the number of ICD users, more knowledge is required regarding changes in the patients' life after device implantation. The aim of this study was description of changes in daily life of patients after ICD implantation

Methods: This qualitative study was conducted through content analysis method. The participants were selected through purposive sampling. They included 3 women and 9 men whose ages ranged from 24 to 74 years, with the mean age of 42.58±1.55 years. They had implanted ICDs in order to treat life-threatening dysrhythmias. The study data were collected through interview and field notes from November 2013 to October 2014. The data were simultaneously analyzed using constant comparative analysis.

Results: Through analysis of the study data, 2 categories were emerged representing dimensions of changes in daily life of the patients with ICD. These categories were changes in the social role and familial challenges after implantation. *Change in social role* included the following subcategories: "Change in manifestation of routines", "Shift in leisure time", "Change in job and education status", and "Change in interaction between the patient and society members". In addition, *familial challenges after implantation* consisted of 2 subcategories, namely "Difficulty in marriage" and "ICD implantation and a range of familial changes".

Conclusion: The study findings can be of great importance in nurses' clinical practice for providing the patients with holistic care, education, support, and follow-up. They can also be used as a guide assisting clinical treatment of the patients with ICD.

KEYWORDS: Arrhythmias, Cardiac, Defibrillators, Implantable, Qualitative research

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INTRODUCTION

Implantable Cardioverter Defibrillator (ICD) has been introduced as a life-saving device due to effective control of malignant dysrhythmias.¹⁻³ It has also been effective in preventing death resulting from fatal dysrhythmias⁴ as well as in reducing the incidence of sudden cardiac death.⁵ Patients have accepted this method as a treatment for cardiac arrest resulting from life-threatening dysrhythmias.⁶ Besides, researchers have considered this method as the gold standard in treatment of malignant tachydysrhythmias.^{7,8} Nonetheless, in spite of its life-saving role,^{1,9,10} this device can cause some social restrictions for patients.¹¹

A large number of patients with ICDs have reported changes in their lifestyle after implantation of the device.¹² Besides, they have referred to the necessity to adapt with restrictions in driving and reduction in the ability to do hard tasks and retain sexual activity.¹³ Patients have also been encountered with limitations in leisure time,^{14,15} change in body image,¹⁶⁻¹⁸ reduction in physical activities,¹⁹ and reduction in sexual activity.¹ In fact, familial life, social activities, and ability to work can be affected by anxiety and depression.¹¹ Eventually, patients have to adapt with a wide range of physical and psychosocial changes resulting from ICD implantation.²⁰

Having knowledge about changes in daily life of the patients with ICD can play a major role in providing them with holistic care. Yet, the main part of the available information about ICD has focused on technical function of the device, and patients' life after device implantation has been less taken into account. Additionally, most of the studies in this field have been performed in other countries focusing on the patients' quality of life²¹⁻²⁴ and living status.^{1,20,25} However, no studies have been found on changes in daily life of the patients receiving ICD in Iran. Considering the fact that investigation of changes in daily life of ICD recipients may depend on the context, the present qualitative study aimed

to describe the changes in daily life of such patients after device implantation.

MATERIAL AND METHODS

Considering the study objective, this research was performed qualitatively using content analysis method. This method is one of the most common methods used in analysis of qualitative data²⁶ and has been developed for interpretation of latent content.²⁷ Recently, three approaches have been proposed in content analysis, namely directed, conventional, and summative, which are mainly different in coding schemes, origins of codes, and threats to trustworthiness. In conventional content analysis, coding categories are directly extracted from the data.²⁸ In this study also, conventional content analysis was employed.

The participants were selected using purposive sampling among the patients who had referred to the cardiology clinics of two hospitals affiliated to Shiraz University of Medical Sciences. Since the participants' physician had better knowledge about and longer interaction with the patients, his suggestions were considered in selection of the participants.

The inclusion criteria of the study were having lived with ICD for almost a year, being above 18 years old, speaking and understanding Persian, being aware of time and place, and not suffering from cognitive disorders (with physician's confirmation). After all, 12 patients (3 women and 9 men) were enrolled in the study. It should be noted that the patients were selected by taking their age range; sexual differences; and different cultural, economic and social conditions into account. Afterwards, the participants received the necessary information about the study objectives and signed written informed consents for taking part in the research. The interviewees' consent was also obtained before starting the interviews.

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 codes, sub-categories, and categories. Then, sampling was discontinued. The study data were collected through semi-structured in-depth interviews with the ICD recipients and all the interviews were recorded using a voice recorder. Field notes were also written simultaneously.

The interviews were conducted in Iran between November 2013 and October 2014 and began with the following question: "How are the changes in daily life with an ICD?" and "How has ICD affected your daily life?" All the interviews were conducted in the researcher's office and cardiology clinics of the two hospitals when the participants were comfortable. All the interviews were done once, each one lasting for 35-85 minutes (average 50 min).

The data were simultaneously collected and analyzed. Each interview was checked several times for complete understanding. Data analysis began by reading each interview for several times and immersion in the data. In doing so, all the interviews were read word by word and rethinking about field notes was conducted. Then, primary coding was done and the codes were categorized based on similarity and appropriateness after review and abstraction. After more review and analysis and comparison of the categories, their internal meanings were abstractly named. In addition to observing internal and external consistency, the researchers attempted to maintain internal consistency in each category and difference among various categories. After all, with respect to the meanings of all the categories, the concept of patients' changes in daily life was comprehensively expressed.

In order to facilitate coding, categorization, merging, and organization, MAXQDA qualitative software, version 2010, was used. Moreover, in order to ensure trustworthiness, credibility, and accuracy of the findings, in addition to insistent involvement, the researcher continued the study for a long period and spent enough time for data collection and patients'

follow-up. Besides, field notes were used to better understand the patients' viewpoints regarding the study objective.

It should also be mentioned that dependability was gained by precise documentation of the data, methods, and decisions about the research. Besides, several techniques, such as prolonged engagement, peer debriefing, and member checking were used to enhance the study's credibility. Additionally, a maximum varied sample was recruited to improve the transferability of the study findings. Audit trails also helped the researchers establish the dependability and confirmability of the research.

All the research processes were performed according to Declaration of Helsinki and approved by the Ethics Committee of Shiraz University of Medical Sciences, Shiraz, Iran (ethic code: CT-92-6757). Before beginning of the interviews, the research objectives were explained to the participants and their written informed consents for taking part in the study were obtained. They were also reassured that they could withdraw from the study at any stage.

Moreover, the participants were provided with some information about the objective, using voice recorders, and recording the conversations. They were also assured about the confidentiality of their information. Thus, the participants' demographic information, conversations, and notes were kept quite secret.

RESULTS

This study was conducted on 12 patients between 24 and 72 years old with the mean age of 42.58 ± 1.55 years who were purposively selected based on the inclusion criteria of the research. The patients' characteristics are presented in Table 1. After investigation of the participants' rich and profound descriptions, 269 primary codes were extracted. After all, 2 main categories were derived as follows: change in social role and familial challenges after implantation.

Table1: The characteristics of the participants

ID code	Age (years)	Sex	Marital status	Education level	Employment status
1m	72	Male	Married	Illiterate	Disability leave
2m	30	Male	Married	High school	Disability leave
3m	26	Male	Married	Primary school	Disability leave
1f	24	Female	Single	Academic	Employed
4m	45	Male	Married	Academic	Employed
5m	52	Male	Married	Academic	Retired
2f	49	Female	Married	High school	Homemaker
6m	29	Male	Married	Middle school	Disability leave
7m	47	Male	Married	High school	Employed
8m	25	Male	Single	Middle school	Employed
9m	56	Male	Married	Middle school	Retired
3f	56	Female	Married	High school	Homemaker

1. Change in Social Role

1-1. Change in Manifestation of Routines

Change in habits, modification of daily activities, and joining self-care were the main axes of this category. Change in habits resulted from the patients' restrictions and inability to do physical activities. Thus, the patients attempted towards self-care through self-relaxation, quitting smoking and drug abuse, maintaining balance, taking care of ICD, following medical advice, seeking for social support from physicians and other patients, and consultation: "ICD has restricted my sports activities and affected my life" (5m), "I can't work fast. I can only work hard with my right hand. My left hand has no power; it seems as if its stamina has gone" (2f), "In the past, I wrestled with everybody, but now I can't. I always say 'be careful not to touch me'. When I walk in the street, I always say 'be careful' to everyone" (9m), "I didn't care much before, but from now on I will. My experience of shock the other day was really worrying. I try not to get excited" (7m), "The more relaxed I am, the better my status will be" (2f).

1-2. Shift in Leisure Time

The patients' leisure time manifested through being with family, staying home, role of TV, and change in sports activities: "We go wherever my wife says. Who can help me except for my wife and children?" (6m), "I don't dare to go anywhere. I'm afraid of

shocks. I'm frightened" (1m), "I sat in front of TV and thought all the time. Our TV also broke down" (2m), "I used to exercise heavily before, but now I do light exercises. Practically, I can't do sports much. I go to swimming pool, I wear my swim suit, but I don't get into the water, I sit and watch" (4m), "Sports? only mild walking. For example, I exercise for 10 minutes" (7m).

1-3. Change in Job and Education Status

The participants pointed to changes in job status and the resultant economic problems as follows: "For a worker, this device means not earning a living, not having a job." (5m), "Well, I'm jobless now. I sleep or watch TV at home all the time" (6m), "There are a lot of changes. I can't work like before. I'm home all the time. I'm retired now. In case of disease, everything is messed up. We also had many financial problems. If I was not sick, Oh ..." (9m).

One of the participants (f1) referred to the difficulties in education as follows: "One of my challenges in B.Sc. courses was omitting 'workshop operations' (welding, turning) and 'physical education'. Dr. ... told me not to go. Or I couldn't go camping with other students".

1-4. Change in Interaction between the Patient and Community Members

The community members' interactions with the participants were both efficient and inefficient. These interactions varied from

receiving emotional support from one's beloved, friends, and colleagues to isolation, jealousy, ridicule, curiosity about the device, undue requests for not considering the restrictions, undue empathy, and exaggeration of the patient's status. In this regard, one of the participants expressed: *"My friends do not leave me alone. A lot of my friends visited me every day for three months. They treated me so that I didn't feel disabled. They accompanied me all the time"* (4m). In contrast, another participant mentioned: *"I don't spend time with my friends as I did before the implantation. Now I don't have my old friends. They don't behave me the same way as they did before. When I was in the hospital, none of them came to visit me and ask what was wrong, what happened. For example, I want to go out with someone. My friends say "Don't go along with him. A problem arises and we have to be responsible. For example, we have to take him to the hospital"* (6m).

2. Familial Challenges after Implantation

2.1. Difficulty in Marriage

Difficulty in marriage can be considered as a change in social life. In this regard, families disagreed with the patients' marriage due to their disease. For example, one of the participants said, *"At the time of marriage, my family completely disagreed. They said due to the ICD, I could not marry"* (2f). *"I have loved a girl for five years, but my family does not agree. They called her and said "this gentleman is sick, has problems, and is not the right person for you". She said "Why", and they answered "He is sick"* (8m).

Other reasons for difficulty in marriage included rejection of the suitors' families, ambiguity regarding the patient's sexual ability, and fear from disease complications. In this regard, one of the participants mentioned: *"I had three suitors in the summer. When the first one heard this, he said he couldn't. I said why. He said he couldn't marry a sick person; this was a risk. I am afraid that a problem rises after marriage. I cannot marry someone who is sick. My wife's health is important to*

me and my children. The next suitor also said if he told his family, they would not accept. The third suitor asked whether we could have sex despite ICD. The excitement is bad for me. He was scared. All went" (1f).

2.2. ICD Implantation and a Range of Familial Changes

In the patients' descriptions of changes in their daily life, the role of family with new emotions, familial conflicts, and familial support was of great importance. After ICD implantation, the patients' families experienced emotions, such as hopefulness, fear, doubt, assuredness, sadness, worry, and disability, which resulted in new interactions with the patients: *"My family was happy at first that I have such a device which can be of use in case something happens. But they were also sad that I always had to be careful"* (9m), *"When shock occurred, the children didn't know what had happened and couldn't do anything. They were very afraid"* (7m), *"My mom was unhappy. She did everything she could to avoid the operation, but I had to undergo the operation after all. She burst out crying that my daughter is young; it is possible that she doesn't undergo implantation"* (1f).

After the implantation, interactions between the patients and their families were both efficient and inefficient. The patients' irritability and the families' excessive care led to familial conflicts by creating the feeling of loss of independence: *"I make her angry more than she does. Why? Because I'm under pressure. I have to empty myself somehow. I vent my anger on my wife. There is no other person except for my wife"* (2m), *"I want to go to street but they don't let me. They say something may happen to me. When it's raining, they say don't go out, you may catch a cold. Don't sleep like this. Sleep like that. Do this. Don't do that. Don't go to the store. Your battery may mix up and give you a shock. It may kill you. We sometimes argue hard up to a huff"* (1f), *"This woman is guilty. I can't call her mother even for a second"* (8m).

On the other hand, the families' efficient

support was expressed as follows: *“If the family doesn’t support me, I’m dead. If I’m not supported and encouraged by the family, how can I come to the hospital?”* (9m), *“When I have a problem, my wife is more worried than I am. This intimate relationship between us is very important. We have both accepted the conditions and she is very careful”* (5m), *“All through this, my family has been with me”* (4m) (Table 2).

DISCUSSION

This study aimed to identify and describe the changes in the patients’ daily life after ICD implantation. The study data resulted in emergence of two categories, namely change in social role and familial challenges after implantation. These results confirmed those of the previous studies and highlighted the changes in such patients’ life.

The first category derived from the present study data was *“Changes in social role”*, which included four subcategories; i.e. *“Change in manifestation of routines”*, *“Change in job and education status”*, *“Change in interaction between the patient and community members”*, and *“Shift in leisure time”*.

By perceiving the limitations after ICD implantation, the study participants maintained their daily activities albeit with modifications, paid attention to the limitations, did not do heavy activities, and sometimes did not consider some of the limitations. Palacois et al. (2011) also pointed to the change in patients’ daily activities and habits, limitation of functional capacity and independence, and effects on patients’ abilities to perform daily activities.²⁹ Reduction in physical activity,^{6,30-32} change in

lifestyle, and necessity to adopt with lifestyle modifications, such as driving restrictions or decrease in the ability to do hard tasks¹³ have also been mentioned in other studies, being in agreement with our study findings.

The study patients attempted towards self-care by self-relaxation, quitting smoking and drug abuse, maintaining balance, taking care of ICD, following medical advice, and seeking for social support. Similarly, patients in other studies used stress coping strategies (talking with others, limiting normal activities, acceptance, denial, taking part in educational games, and positive thinking strategies),³³ sought for social support up to one year after discharge, and took part in consultation in outpatient clinics.⁶

The results of the current study revealed the patients’ focus on their families, particularly in recreational activities. Besides, some patients mentioned staying home and they highlighted the role of TV. Yet, all the patients expressed a change in sports activities. In line with our results, some researchers referred to isolation or perceiving home as a safe haven.⁶ Morken et al. (2010) also reported a decrease in physical activities in order to avoid shock among these patients.³² It should be noted that mainly the youth with active lifestyles complained about these restrictions.¹²

Changes in job status, particularly in the jobs requiring physical activity, were expressed by the current study participants. Similar results have also been obtained in other studies.^{5,33,34}

Difficulties in taking practical courses in the university, taking part in university’s side events, and getting married were among the noteworthy findings of the present study. Most

Table 2: The emerged categories and the related sub-categories in the present study

Categories	Sub-categories
Change in social role	Change in manifestation of routines
	Shift in leisure time
	Change in job and education status
	Change in interaction between the patient and society members
Familial challenges after implantation	Difficulty in marriage
	ICD implantation and a range of familial changes

of the studies conducted so far have assessed marital problems after marriage^{11,26,34,35} while ICD implantation may also disturb the acceptance of an individual as a partner.

Considering the results of our study, community members play a key role in emotional support of the patients by taking their conditions into account and expressing similar positive experiences. Nonetheless, some of the participants mentioned inefficiency of social interactions, undue curiosity about the battery, and stigmas such as ‘an electric status’ or ‘a tuned person’. This has been less taken into account in previous studies.

Emergence of new emotions, familial conflicts, and familial support play a critical role in the interactions between patients and their families. In addition to experiencing encouraging emotions towards patients, families may suffer from fear, doubt, sadness, and worry. Overall, they play a significant role by soothing the patients and providing them with empathy, love, and emotional support. Yet, serious familial conflicts are sometimes seen between patients and their first-degree relatives (mothers) which mostly result from excessive care that diminishes the patients’ tranquility, independence, freedom, and authority and leads to frustration and desperation.

In line with our results, various problems in the interaction between patients and families, familial conflicts,²⁰ increase in spouse’s anxiety,^{36,37} family’s worry and unpredictability,^{14,15} disruption of interpersonal relationships, feeling of loss of control,³³ effects on the patients’ social conditions³⁸ reduction of social interactions, increase of irritability towards one’s family and friends, aggression, feeling of loss of independence,⁶ family’s excessive care,^{6,34,39} and increase in the feeling of dependence and its resultant insecurity³¹ have been reported among the patients with ICD. These studies have also highlighted the need for talking with the family,³⁴ family and friends’ support in the form of empathy, listening to expression of emotions,³² and spouse’s supportive role.^{29,33}

Overall, by identification of daily life

changes resulting from ICD implantation, the findings of the current study can facilitate provision of patients with holistic care. This can, in fact, be achieved through encouraging the patients to maintain and improve their physical activities, enhance their interactions with their families and friends, and continue their social activities, which eventually reduces disruption of their life after ICD implantation. Considering the fact that the participants of the present study were Muslim, further studies should be conducted on changes in the daily life of patients with different religious backgrounds.

CONCLUSION

This study revealed changes in daily life of the patients with ICD referred to the cardiology clinics of two hospitals affiliated to Shiraz University of Medical Sciences. According to the main research question, changes in the daily life were classified into two categories, namely “Change in *social role*” and “*Familial challenges after implantation*”. By identification of the changes in daily life of the patients with ICD, this study provided a basis for evaluation of patients’ nursing after discharge. The results were also effective in determining the impacts of the device on the patients and their behaviors and attitudes after implantation. Moreover, changes in the patients’ daily life after ICD implantation and incidence of disruptions and problems showed the patients’ ability to successfully move towards future.

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