Original Article

Challenges of Living with an Implantable Cardioverter-Defibrillator: **A Qualitative Content Analysis**

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role in supporting these patients.

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Parivash Karimi: 0000-0003-4116-0994 Background: Living with an implantable cardioverter-defibrillator (ICD) in the body can be challenging for patients. Identifying these challenges is, therefore, crucial for health promotion. Objectives: This study was conducted to explore the challenges experienced by patients living with an ICD. Methods: A qualitative content analysis study was conducted on 24 patients with an ICD. Purposive sampling and individual semi-structured interviews were conducted to collect the study data. After transcribing the interviews, content analysis was performed to analyze the data. Results: The participants were aged 35-60 years. Their education level varied between primary and tertiary levels. The participants had an ICD for an average of 35.70 ± 11.36 months. Three themes emerged, including "feeling disabled," "problematic adaptation," and "Financial constraints." These themes indicated the most important challenges experienced by the participants. Conclusion: Patients with an ICD suffer more from psychological and financial problems than physical problems. Nurses and other health-care workers play a key

KEYWORDS: Defibrillators, Implantable, Qualitative research

Introduction

n implantable cardioverter-defibrillator (ICD) is a device used to rapidly diagnose and treat high-risk ventricular arrhythmias.[1-3] As an electrical generator, an ICD is implanted for the primary prevention of sudden death in patients with left ventricular dysfunction and a history of cardiac arrhythmias.^[4] In the United States, ICDs are implanted in 114,000 patients annually.^[5]

Studies confirm that ICDs are superior to medical treatment in controlling cardiac arrhythmias, prolonging patients' lives, and improving their quality of life.[2,6] However, ICD implantation affects all aspects of the patient's life, including individual functioning, social

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and family relationships, physical activity, lifestyle,

and diet.[7-9] Studies have reported fear and anxiety,[10]

depression,[5] sleep disorders,[11] lifestyle changes, loss of control, and a diminished sense of safety[12] in patients

living with an ICD. Some studies have investigated the

prevalence of anxiety and depression in patients with

ICD:[4,5] Some studies have examined the effects of

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psychoeducational interventions on the quality of life of patients with ICD.^[7,10] A number of studies have also explored the experiences and perceptions of patients living with an ICD,^[8,9,11,13] but concluded that more studies are yet needed to better understand the challenging aspects of living with an ICD.^[13] Such studies can provide detailed knowledge to help health professionals, especially nurses, plan more effective interventions for the care of patients with an ICD.^[14] Therefore, questions remained about the challenges faced by patients with ICD? Qualitative research helps researchers explore patients' experiences^[15,16] and therefore appears to be the best way to delineate the challenges of living with an ICD.

Objectives

This study aimed to explain the patients' experiences and perceptions of the challenges of living with an ICD.

METHODS

Study design and participants

This qualitative content analysis study was conducted from August 2020 to August 2021 on patients with an ICD who were referred to Seyed Al-Shohada Cardiovascular Center, Urmia, Iran. Inclusion criteria had an ICD for ≥ 6 6 months, an age of ≥ 18 years, and willingness to participate in the study. Purposive sampling was performed to select 24 patients with an ICD from Urmia in the northwest of Iran.

Data collection

Semi-structured in-depth individual interviews were conducted to collect data. Interviews were performed by phone to prevent transmission of COVID-19. The interviews began with the following question: "What challenges or problems have you faced since the implantation of the cardioverter-defibrillator? Please explain." Depending on the participants' responses, probing questions such as "What do you mean by that?" "Could you elaborate more?" "Could you elucidate?" "Why?" and "How?" were asked. The participants consented to have the interviews audio-recorded. Twenty-four interviews were conducted with 24 participants. Times to schedule an interview varied according to the arrangements made with the participants. Each interview lasted about 60 min and continued until data saturation was reached.

Data analysis

The data were analyzed according to the content analysis method proposed by Graneheim and Lundman. In the first step, the researcher became familiar with the data and identified initial ideas through immersion and reading the transcripts multiple times. In the second step, initial codes were created through a line-by-line examination of the transcripts. The initial codes were then grouped based on

their similarities and differences to develop subcategories. In the fourth step, the categories were examined to identify the relationships between the categories and subcategories. In the fifth step, the emerged categories and subcategories were described and labeled. The coding and categorization process was frequently reviewed, and the results were reported at the last step.^[17]

Data trustworthiness

To ensure the trustworthiness of the data, the criteria of credibility, dependability, confirmability, and transferability were used.[18] Credibility was ensured by establishing appropriate rapport and close interaction with the participants. Interview transcripts were handed to the participants and their comments were applied. In addition to prolonged engagement with the data, a colleague reviewed all the research steps and his comments were applied. Maximum variation was observed when selecting the participants. To ensure dependability, all the study steps were reviewed and examined by the research team by exchanging ideas. As an external check, comments of a faculty member familiar with qualitative research and clinical practice were also applied in all steps, and the results were confirmed. To ensure confirmability, the study steps were documented and made available as a reference for future research. To ensure transferability, all steps were described in detail so that the findings could be generalized to other populations with similar characteristics.

Ethical considerations

This study began after receiving approval from the Regional Ethics Committee in Medical Research (IR. UMSU.REC.1399.060). After introducing himself to the participants and briefing them on the study objectives, the researcher asked all of them to sign written informed consent forms. They were also assured of the confidentiality of their data. All the recorded files were deleted after the interview was fully transcribed.

RESULTS

Of the 24 participants aged 35–60 years, 15 were male and 9 were female. Their education level varied between primary and tertiary education, and they had an ICD for about 35.70 ± 11.36 months [Table 1]. Finally, 3 categories, 10 subcategories, and 34 main concepts were extracted. According to the participants' experiences, the top three challenges in living with an ICD were "feeling disabled," "problematic adaptation," and "financial constraints" [Table 2].

Feeling disabled

The debilitating look of others, disrupted roles in the family, disrupted marital relationships, and disrupted daily routines triggered a sense of disability in patients.

Table 1: Descriptive characteristics of the participants

ID	Age	Gender			ICD duration
	(years)	Gender	level	statue	(months)
P1	48	Male	Tertiary	Married	24
P2	52	Male	Tertiary	Married	52
P3	38	Male	Primary	Single	36
P4	40	Female	Tertiary	Married	42
P5	57	Female	Secondary	Married	21
P6	60	Male	Secondary	Married	52
P7	59	Male	Primary	Married	36
P8	46	Male	Tertiary	Married	36
P9	45	Female	Tertiary	Married	30
P10	57	Male	Secondary	Married	36
P11	39	Female	Tertiary	Married	28
P12	60	Male	Secondary	Married	53
P13	53	Male	Tertiary	Married	32
P14	60	Male	Primary	Married	48
P15	58	Female	Secondary	Married	30
P16	49	Male	Tertiary	Married	49
P17	55	Male	Tertiary	Married	43
P18	54	Female	Secondary	Married	47
P19	35	Female	Secondary	Married	12
P20	49	Male	Tertiary	Married	33
P21	53	Female	Secondary	Married	41
P22	39	Male	Tertiary	Married	18
P23	56	Male	Secondary	Married	36
P24	44	Female	Tertiary	Married	22

ICD: Implantable cardioverter-defibrillator

The debilitating look of others

In their daily interactions, participants identified views of others that were sometimes debilitating. Patients described their experiences using terms such as disability stigma, pitying looks, and others' misconceptions about the device's functioning.

"In our community, people look differently at someone with a problem. They pitied me and saw me as disabled, which annoyed me" (P2, man). "People didn't have correct information about this device. Everywhere I went, they asked me if I had replaced my heart with a battery!', and this annoyed me" (P8, man).

The disrupted role in the family

Almost all patients identified a disrupted role in the family as a major challenge in living with the device. This challenge originated from the disrupted breadwinner's role, the disrupted graybeard's role, and the disrupted parental role. The participants explained their experiences as follows:

"Before implantation, I used to show up for all family events or help them with all their problems. I was even the one who solved all their problems. But now I try to avoid excitement to remain healthy. It works for me, but now I feel unable to play my role as a graybeard in the Table 2: Categories, subcategories, and primary concepts emerged from the data

Theme	Sub-theme	Primary concepts		
Induced	Debilitating	Stigma of disability		
sense of	look of others	Merciful look		
disability		Incorrect assumption of others about		
		the device functioning		
	Disrupted role	Disrupted breadwinner's role		
	in the family	Disrupted graybeard's role		
		Disrupted parental role		
	Disrupted	Disrupted marital role		
	marital	Fear of having sexual intercourse		
	relationship	Reduced libido		
		Sexual dysfunction		
	Disrupted	Limitations in carrying heavy objects		
	everyday tasks	Limitations in saying prayers		
		Limitations in bathing		
		Limitations in driving		
		Limitations in sleeping positions		
Problematic	Alienation	Presence of an abnormal object in		
adaptation	from the device	the body		
		An object separate from the body		
	A fragile	Little enjoyment of life		
	psyche	Fear of untimely discharge		
		Gloom		
		Aggression		
		Stress		
	Fear of device	Feeling unguarded		
	failure	Fear of damage to the implantation		
		site		
		Fear of device breakdown		
		Fear of device life coming to an end		
Financial	Costly	Costly medications		
constraints	treatment	Costly implantation		
		Costly periodic visits		
	Difficulty	Inadequate income		
	in earning	Paralysis		
	livelihood	High living costs		
	Inadequate	Inadequate support by public		
	financial	organizations		
	support	Inadequate insurance support		

family" (P23, man). "I am now the breadwinner of a family of six. Being unable of working as before is my main challenge" (P10, man).

Disrupted marital relationship

Participants' experiences showed that they were afraid of untimely shocks during intercourse due to arrhythmias induced by sexual excitement after the implantation. This fear had diminished their desire for sexual intercourse. Some participants also reported taking medications that reduced their libido or even caused sexual dysfunction.

"Once, the device caused a shock during my intercourse. My wife and I are now scared and have experienced some emotional and sexual problems since then" (P1, man). "Medications have reduced my libido and caused me certain sexual problems" (P3, man).

Disrupted everyday tasks

According to the participants' experiences, the implantation disrupted their daily activities and restricted their ability to carry heavy objects, pray, bathe, and drive.

"I must avoid going out when it's cold. My doctor told me not to drive because of my heart health" (P13, man). "Doing physically-demanding works hurt me. At the hospital, I was told not to lift anything weighing over 1 kg because the battery may drop. I even find it hard to bathe and say prayers, and can't do my daily chores perfectly" (P9, woman).

Problematic adaptation

This theme described the postimplantation problems patients encounter when accommodating to the device (adapting to the device), especially psychological issues. These problems were described as alienation from the device, a fragile psyche, and fear of device failure.

Alienation from the device

This concept referred to the presence of an extraneous object in the body, which was extremely difficult and challenging to be accepted by the patient as part of their own body.

"I feel something foreign, separate and unusual in my body. It's hard to get used to it" (P14, man).

A fragile psyche

Some of the participants explained their experience of not enjoying life, although the device had survived them. Their daily life was filled with a fear of untimely discharge, gloom, aggression, and stress.

"I'm afraid because I don't know when or where the shock will occur! It's very stressful. Sometimes I lose my temper over the slightest matters" (P11, woman).

Fear of device failure

The participants were always worried about damage to the implant site, device failure, and the end of the device's life.

"I feel vulnerable, like I'm on the battlefield without armor. I always have to make sure my baby doesn't fall on the device or I hit the wall or something when walking. People should take care not to make any jokes; I'm very sensitive to this issue" (P17, man). "The device will work for 3 more years. It can work for 7 years in total. The less the remaining lifetime, the more my fear and stress" (P14). "I'm always worried that the wires

may cut off or the device might break down if I use my arm a lot" (P18, woman).

Financial constraints

According to the participants, costly treatment, difficulty in earning a livelihood, and inadequate financial support provided by governmental organizations and insurance companies caused financial bottlenecks.

Costly treatment

Expensive medications and implantation and periodic doctor visits made the patient's life financially difficult. A participant described his experience as follows:

"My costs are growing month by month and include doctor visits and medications. Two pill cases cost over 1 million IRR, and prices is rising constantly. Earning this money and affording the medications account for huge problems" (P5, man).

Difficulty in earning livelihood

After the implantation, the participants faced difficulties in earning livelihood owing to their disability, income problems, and high costs of living. They described their experiences as follows:

"I haven't worked for 2 years. I used to be a driver. About 2 years ago, my doctor told me not to work anymore because my left arm was under lots of pressure while driving, and this made all my body ache. How am I supposed to live with this inflation and unstable economic situation?" (P13, man).

Inadequate financial support

Participants expected support from governmental agencies and insurance companies given the high costs of treatment and, more importantly, the disability caused by the implantation. However, their experiences showed that they were disappointed with the results:

"We expect to be supported by the government. We cannot work and have no source of income. I feel embarrassed that I can't support my family, and this stress and anxiety damage my heart. They should give us a loan, an advance, or some kind of facility that would help" (P16, man).

DISCUSSION

Efforts were made to explore and describe the challenges of living with an ICD based on patients' experiences. Our results revealed a sense of disability, problematic adaptation, and financial constraints as the major challenges. Patients' feelings of being disabled were rooted in how others saw them, their dysfunctional role within the family, the breakdown of the marital relationship, and their disrupted daily routines. Perceived disability was also associated with lower

tolerance to the device. Perceived disability might also be an independent risk factor for psychological disorders in these patients, ultimately undermining their sense of identity, self-respect, and self-esteem, and making them feel unworthy and dependent on others.[13,19] A qualitative study by Murray also reported challenges such as altered identity and roles, physical discomfort, and reduced ability to adapt to the current situation.^[20] Abbasi et al. also reported varying degrees of physical limitations in patients with an ICD.[14] In the present study, patients also experienced challenges related to fulfilling their roles, performing physical activities, and adapting to the device. The present study found others' debilitating and stigmatic views to cause loss of control and induce a sense of helplessness in patients with an ICD. Some studies suggest the effectiveness of receiving empathy from the family and social networks in patients' adaptation to ICD.[21,22] However, strong sympathy may disrupt the patients' sense of control over the situation. Kim et al. reported a sense of dominance over the current and future situations as a facilitating factor in improving the performance of patients with an ICD.[23]

Sexual concerns related to ICD are rarely addressed in the literature, which can be explained by the patients' discomfort when discussing such sensitive topics. A meta-synthesis reported cases of reduced sexual intimacy in marital relationships in patients with an ICD, which further distanced the couples emotionally.^[13] In this study, we discovered the fear of intercourse due to untimely discharge during intercourse and the effect of sexual excitement on the development of cardiac arrhythmias.

Our patients experienced problematic adaptation due to many issues, especially psychological problems, and difficulty in adjusting to the device after the implantation. Patients identified the ICD as an alien object that they could not easily cope with. A study also showed that some patients found it difficult to tolerate and accept the device, as it made them feel being kept alive by machines.[24] In our study, patients experienced different psychological problems, including little enjoyment of life, fear of untimely shocks, gloom, aggression, and stress. Research suggests that the patients' anxiety mainly results from unawareness of how the ICD works. This factor disrupts their everyday life and exacerbates their mental obsession.[25] Some studies attribute this fear to a classical conditioning pattern, in which certain stimuli or behaviors are associated with the ICD shock. As a result, some patients increasingly limit their activities due to their fear of shock at present or in the future, which will undesirably reduce the biological benefits of ICDs.[26,27] In contrast, some other studies have reported

that the high anxiety levels in patients with an ICD might be associated with catastrophic cognition rather than the electric shock.^[28,29]

Financial constraints developed mainly due to the patients' disability and inability to work and earn money. The situation was exacerbated by the rising cost of living and treatment. These patients need to receive financial support from governmental organizations and insurance companies. Research shows that financial problems act as a major stressor in patients with an ICD, which can dramatically change all aspects of their quality of life.^[14,30]

This study was conducted in a small group of patients with an ICD. Although this limitation exists in all qualitative studies, patients in different cultural and socioeconomic settings may express different experiences and challenges. The participants recounted their experiences since the time of implantation. Given the long time that passed since the implantation, in some cases, they might have failed to completely recall all their experiences.

CONCLUSION

Feeling disabled, problematic adaptation, and financial constraints were the main challenges in living with an ICD. The findings clarified that patients with an ICD suffered more from psychological and financial problems than physical problems. They, therefore, need extensive support in these dimensions. Nurses and other health-care workers play a key role in supporting these patients. Still, the major part of this support is shouldered by the community through culture building and changing the views of the community, family, and relatives, for which the community, governments, and mass media play a pivotal role.

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Conflicts of interest

There are no conflicts of interest.

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