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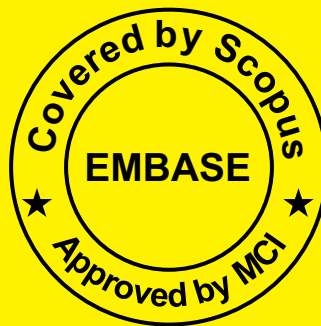
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# Lived Experience as Perceived by Patients with Implanted Cardiac Devices: A Phenomenological Study

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## ABSTRACT

**Objective:** Cardiac implantable electrical devices are the most effective modality of treatment for different life-threatening dysrhythmias. However, living with these devices is associated with many multidimensional challenges.

**Aim:** the aim of this study was to explore the lived experience as perceived by patients with implanted cardiac devices at Cairo University hospitals.

**Method:** A descriptive phenomenological approach was utilized; 30 participants were interviewed; the interviews were audiotaped and transcribed verbatim, then analyzed using a phenomenological content analysis.

**Results:** Four main themes were emerged: feeling near to death; facing ongoing challenges; adopting coping behaviors; and Reaching adaptation.

**Conclusion:** Cardiac devices recipients are facing many biopsychosocial challenges that need to be addressed before and after device implantation. Therefore, provision of ongoing counseling and support are essential to help cardiac devices' recipients achieve adaptation and continue their roles after device implantation.

**Keywords:** *lived experience, cardiac implantable devices, challenges, adaptation, phenomenology.*

## Introduction

Cardiac dysrhythmias are a major type of cardiovascular diseases. They remain a source of morbidity and mortality in developing countries. Approximately 80% of deaths results from ventricular arrhythmias.<sup>1,2</sup> Cardiac implantable electrical devices (CIEDs) such as permanent pacemakers (PM), implantable cardioverter defibrillators (ICDs) and cardiac resynchronization therapy (CRT) have become an integral part of modern cardiovascular

medicine and one of the greatest important advances in treatment of cardiovascular patients suffering from acute cardiac problems.<sup>3</sup>

Problems associated CIED treatment are of particular importance to health professionals. Critical care nurses as members of the health care team must have the ability to assess and manage patients' biophysical, emotional, and socio-cultural problems that may result from different treatment modalities. They can play a key role in improving and designing effective and comprehensive quality care that meet patients' complex and varied needs.<sup>7</sup> Therefore, the present qualitative study aims to explore the lived experience as perceived by patients with implanted cardiac devices at Cairo University Hospital.

## Material and Method

**Design, participants and setting:** A qualitative phenomenological research design was utilized in the

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current study. It is concerned with understanding the meanings and describing life experiences from the perspective of persons involved in specific phenomenon (8). A purposive sample consisting of 30 participants was involved according to these criteria; Adults ( $\geq 18$ ), of both genders, and after at least three months since implantation. The current study was conducted at a follow up unit affiliated to critical care medicine department in Kasr Al Aini- Cairo University Hospitals, Egypt.

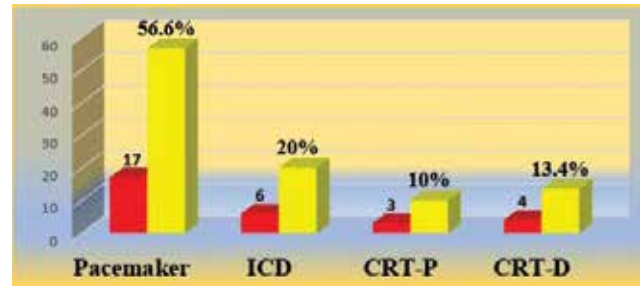
**Data Collection and Analysis:** Data collection was fulfilled over a period of eight months. Semi-structured face-to-face interviews were conducted using pre-prepared interview guide, which involved open-ended questions to help elicit and capture participants' experiences, activities, and attitudes. Each interview lasted for 30–50 minutes. Data collection continued until data saturation was reached (the point where no new information emerged). All interviews were audio recorded and verbatim transcription was done by the researcher. A second interview via telephone were conducted after data analysis to make sure that the study findings reflects the participants' own experiences. Data was analyzed following the guidelines for phenomenological analysis as proposed by Giorgi (2009).<sup>8</sup>

**Ethical Considerations:** Approvals were attained from the ethical committee at faculty of Nursing - Cairo university and the director of the selected critical care unit. Participation in the study was voluntarily and based on the participants' agreement. Purpose and nature of the study were explained for all participants and informed consents were signed before recording the interviews.

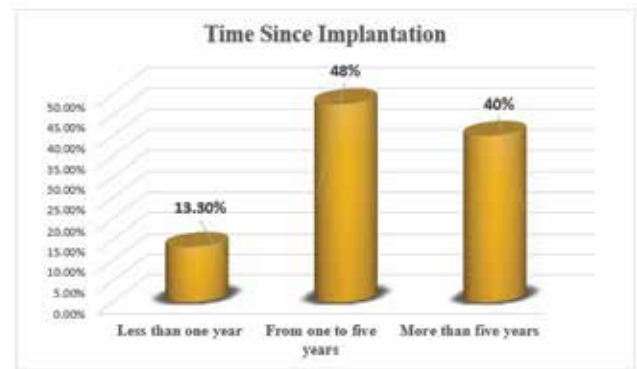
**Findings**

The current study revealed that more than one half of involved participants were adults (in the age group between  $\leq 40$  -59 years with a mean of  $51.77 \pm SD 13.89$ ), males, employees, had secondary school education, and came from urban areas in percentages of 53.3%, 60%, 50%, and 63% respectively. The great majority (83.3 %) of participants were married. As Regards medical data, the most common type of implanted cardiac devices was pacemaker. It was found among more than one half (56.6%) of participants, followed by the ICD among 20% of participants (Figure 1). More than half (56.6%) of the participants had undergone devices implantation once. The time since device implantation for nearly half of participants (48%) ranged from (one to five years) post implantation (Figure 2). Four main themes were identified

through analysis and interpretation of obtained data: feeling near to death; facing ongoing challenges; adopting coping behaviors and reaching adaptation (Table 1).



**Figure 1: Percentage Distribution of the Participants As Regards Type of Implanted Cardiac Device (N = 30)**



**Figure 2: Percentage Distribution of the Participants as Regards to Time Since Implantation (N = 30)**

**Table 1: The Emerged Main Themes and Subthemes in the Current Study**

Main Themes	Subthemes
Feeling near to death	Unpredicted life event
	The device as the only choice
Facing ongoing challenges	Dependency on the device
	Imposed life restrictions
	Experience with ICD Shock
	Social role change
Adopting coping behaviors	Avoidance Behavior
	Seeking information/counseling
	Having social support
Reaching adaptation	Feeling of security
	The feeling of gratefulness toward the device

**Feeling Near to Death:** Feeling near to death is the first main theme emerged from data analysis. It describes the initial impact of diagnosis and pre-implantation time as reflected by many of participants who indicated that, the

deterioration in their heart function was considered as a near to death experience that in turn led to many life alterations and psychological disturbances. This theme covers two sub-themes: unpredicted life events; and cardiac device implantation as the only choice

**Unpredicted Life Event:** Involved participants reacted differently to their diagnosis and cardiac devices. Approximately, one quarter (26.6%) perceived their medical diagnosis as a serious and unpredicted event. They used different terms to describe their feelings when cardiac devices were suggested, such as getting shocked, being in crises, fear, panic and psychologically disturbed when cardiac devices were suggested. e.g. ‘When I knew that I need a device, I just collapsed... I didn’t expect that my condition requires a device...The doctor told me that I’ll live with device forever which made me shocked’ (Participant: 17).

**Cardiac Device Implantation as the Only Choice:** Getting a cardiac device was not an easy choice for involved participants. More than one third (40%) indicated that, they were faced with decision making regarding getting cardiac devices or not. Participants believed that their doctors knew and selected the best for them, so they decided to accept doctors’ recommendations. One of participants reflected that: ‘I didn’t have another choice. .. He tells me (physician) either to die or to implant the device. What can I do? I had no choice rather than having it inserted’ (Participant: 19).

**Facing Ongoing Challenges:** Despite providing significant benefits for many of participants, cardiac devices implantation created new challenges for different aspects of life:

**Dependency on the Device:** All Participants (100%) were aware that they became totally dependent on their devices forever. This caused feeling of vulnerability and uncertainty over their lives with greater emphasis on keeping and monitoring the device’s functioning for maintain surviving and facing death. For example: participants stated: ‘Sometimes my son sits next to me and asks:’ Mum, won’t you remove the device and live like us?’ I tell him that If I removed the device I would die’ (she seemed sad) (Participant: 20).

**Imposed Life Restrictions:** Imposed life restrictions were emerged among approximately two thirds (60%) of participants who perceived that many routine activities of daily living, sports, and work as unsafe for their devices’ functioning. Therefore, they put limitations on activities, sleep and occupations. ‘After device implantation, I

cannot carry heavy things or practice exercise. .. I like playing football, but now I cannot play even with my children... even sleeping, it (pacemaker) prevents me from sleeping on lateral side’ (Participant: 16).

**Experience with ICD Shock:** In the current study, some of implantable cardioverter defibrillator recipients (30%) described the given electric shock as an event which is extremely painful, traumatic, anxiety-provoking and scary for both participants and who are witnesses at shock time. Participants used terms such as explosion or blow of bomb, feeling like a strong electric current, or seeing light flashes, to describe high intensity of pain associated with shocks. ‘I wish that shock not to be experienced by any one ... It looks like if you are holding high electricity ... anyone stands in front of me at the time of delivering shock must cry from the horror and pain that I feel’ (Participant: 17); and ‘Shock is very strong and painful ... I felt pain like a gas tube explode in my chest’ (Participant: 22).

**Social Role Change:** Many participants experienced significant changes in their social roles because of illness and having ICDs. Also, they felt incompetent in performing roles they had within their family or work duo to imposed changes of the devices on employment or work, for example, some participants worked part-time in spite of full time, while others left their work and were concerned about finding more suitable jobs. ‘I stopped working because I am strictly forbidden from working as a driver... This was the decision of medical committee... and I have no other job other than driving which I had worked for 37 years’ (Participant: 19).

**Adopting Coping Behaviors:** This third main theme implied problem-focused and emotional-focused coping strategies that were used to achieve adaptation and to tolerate the negative feelings associated with device related stressors.

**Avoidance Behavior:** This subtheme was indicated by 50% of participants who avoided certain behaviors as a main coping strategy for self and device protection. Therefore, they avoided engaging in certain activities that were considered risky. ‘I avoid things that affect the device ...I must avoid being near to towers of electricity and electronic corridors ... I always keep the mobile far from the pacemaker’. (Participant: 25)

**Seeking Information/Counseling:** Participants in the current study indicated their need for understanding, as well as seeking information and guidance regarding their devices’. In particular, ICD recipients indicated their

need to more detailed instructions regarding ICD shock. e.g. one participant reported that seeking information offered an opportunity to share and compare experience with others who have the same condition; ‘I wish I could sit with someone who has the device even if by chance to ask ‘what is happening to him/her’...when I want to know any information about pacemaker I access the internet and watch it” (Participant: 7).

**Having Social Support:** More than two thirds (63.3%) of the current study participants expressed their receiving adequate support. Family, friends, and health care professionals were the main sources of social support. e.g. ‘All people including my family and my colleagues or anyone who know that I have an implanted device offer me help, they always ask me not to carry or do anything”. (Participant: 7)

**Reaching Adaptation:** Approximately 70% of participants showed and clearly verbalized adaptations to life after their devices’ implantation. This appeared especially prominent after passing the first few years post implantation. Participants also expressed a sense of acceptance of their altered health status and device-imposed limitations.

**Feeling of Security:** This subtheme was frequently mentioned by many participants. They recognized the benefits of cardiac devices as “a mean of defence’ and ‘source of security. This feeling seemed to be more obvious in participants who experienced loss of consciousness or previous cardiac arrest. Thus, they felt that their initial insecurity and near to death attacks changed to a feeling of security. ‘I was afraid to be alone at home because the doctor told me that it is possible to die at any moment to the extent that I thought to change my apartment and live next to a hospital ... But praise be to God who guided me to the device, thus it gives me reassurance ... The best thing it provided for me is a feeling of safety” (Participant: 12).

**The Feeling of Gratefulness Toward Device:** Several participants consistently showed positive emotional responses toward their devices and verbalized feeling of gratefulness to advanced technology. They described the device as a valuable life-saver which helped them for being alive. ‘This (pacemaker) is my breathing... one is considered as if he is living by artificial heart, this is what helps me to live Praise be to God for presence of the device ‘” (Participant: 27)

## Discussion

The current study showed that cardiac device implantation represented a stressful and unpredicted event. It also represented life crisis and caused a feeling of near to death among many participants. In this regards Pasyar revealed that, having an ICD is considered a new situation that leads to ambiguity and surprise for patients. It results in an unknown feeling of uncertainty and leaving patients alone in permanent anxiety.<sup>4</sup> Cardiac illness “from the researchers’ point of view” is considered as a turning point in individual’s life, during which patients may face overwhelming feelings of fatigue, helplessness, or long-term changes in their abilities.

Facing challenges was the second main theme in participants’ experience of living with pacemakers and/or ICDs. These challenges were reported in form of different physical and psychosocial problems associated with devices. In this regards Ghोजazadeh et al. reported that physical, financial and socialization problems, where participants intended to limit their physical activities to keep their devices’ functioning.<sup>3</sup> In contrary, Conelius studied the experience in living with ICDs and indicated that participants described the process of device implantation as easy and nothing changed in their everyday lives.<sup>9</sup> This contradiction “from the researchers’ point of view” could be related to the type of device, diagnosis, associated comorbidities, lifestyle and cultural background.

Participants reported multiple sources of anxiety and fear while living with pacemakers and/or ICDs, one of these sources was anxiety about device malfunction. Therefore, they were cautious when performing usual activities. Similarly, Abbasi et al. indicated that most participants were concerned about device’s malfunction and possible displacement of the leads.<sup>10</sup> Excessive fear of device malfunction may be due to conflicting or unclear medical advice. Also, in some instances concept of having a foreign device inside of the body forever, might cause fear and insecurity feelings.

Social support was evident in every aspect of participants’ coping and contributed to better adaptation after device implantation. In this regards, previous studies have emphasized the importance of psychological support from family members, friends, peers, and health professionals. In addition, professional therapeutic relationship is beneficial for ICD recipients and found that non-constructive support is associated with increased post-traumatic stress disorder (PTSD) symptoms.<sup>11</sup> However, other studies.<sup>12,13</sup> have showed contradicting

findings where they indicated that not everyone was comfortable to receive help as occasionally some participants reported their feeling of overprotection and imposed restrictions from family members, so by time they rejected family members' overprotective behaviors and struggled for independence. Despite having contradicting findings, it is important to emphasize the role of social support resources in optimizing coping behavior and developing positive psychosocial adjustment in patients with chronic diseases.

Although Participants complained of life restrictions imposed by the device, many of them expressed positive emotional responses toward device and verbalized their appreciation to such advanced technology. Similarly, Starrenburg et al. found that participants appreciated the device for its lifesaving abilities and improvement of symptoms.<sup>14</sup> Thus, when experiencing life threatening symptoms, these devices may be seen as gifts which give them a new chance for better quality of life. Hence, feeling gratefulness was prominent among many of the participants.

### Conclusion

Findings of the current study have provided understanding for how patients with cardiac implantable electrical devices are affected physically, socially and psychologically after their devices' implantation. Therefore, establishing planned discharge teaching and providing supportive care are important for this category of patients.

**Conflict of Interest:** The authors declare that there is no conflict of interest.

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