O R I G I N A L   P A P E R

Experiences of patients with implantable cardioverter defibrillator in Turkey: A qualitative study

Hatice Mert, PhD
Assistant Professor, School of Nursing, Dokuz Eylül University, Turkey

Gülümser Argon, PhD
Professor, Ege University School of Nursing, Turkey

Özgür Aslan, MD,
Professor, Dokuz Eylül University Medical Faculty, Turkey

Correspondence: Hatice Mert, PhD, Assistant Professor, Dokuz Eylül University School of Nursing, 35340 Inciraltı, Izmir, Turkey. Tel.: +90 232 412 47 53; fax: +90 232 412 4798   E-mail address: merthatice@yahoo.com

Abstract

Background. There has been an increase in the number of patients with implantable cardioverter defibrillator (ICD). It is important to understand ICD patients' experiences with it.
Aim. The aim of this study was to describe experiences of patients with implantable cardioverter defibrillator (ICD).
Methodology.   A qualitative approach was used. Focus group interviews were used to obtain data from 19 patients who were implanted cardioverter defibrillator at two centers in Izmir, Turkey. The patients were assigned into four groups. The data was analyzed using qualitative content analysis.
Results.   The analysis revealed six main themes: activities of daily living, social life, familial relationships, emotional changes, implantable cardioverter defibrillator shocks and experiences with receiving information and counselling from health care providers.
Conclusions. It can be concluded that patients with ICD experience physical and psychological problems and are not offered the education they need. To reduce the fears of the patients and their families and to prepare them for possible life style changes, comprehensive training programs that start in the pre-implantation period and continue into the post-implantation period should be organized.

Keywords: nursing; qualitative research; implantable cardioverter defibrillator

Introduction

Sudden cardiac death (SCD) is an important health problem in Western countries, including Turkey. It has been reported that high mortality in patients with SCD is due to a delay in cardio-pulmonary resuscitation (CPR) and defibrillation (Gollob & Seger, 2001; White, 2000). Advances in diagnostic and treatment alternatives, especially implantable cardioverter defibrillators (ICDs), have increased the survival of patients with ventricular arrhythmia and SCD (Dougherty et al., 2000; Gemici et al., 2000; Dougherty et al., 2001; Kupersmith, 2002).

In view of these technological developments, clinical studies have estimated that there will be an increase in the number of patients with an ICD (Swygman & Wang 2002). Therefore, problems associated with ICD treatment are of particular interest to health professionals. Although this new technology has been effective clinically, some patients and their relatives have experienced psychosocial and physical problems following implantation (Dunbar et al., 1993; Dougherty,1995; Burke, 1996; Craney et al., 1997; Schuster et al., 1998). The difference between ICDs and other implants, such as pacemakers, is that the patients with an ICD experience unexpected sudden shocks released by the equipment. These shocks can lead to fear and anxiety in patients due to their unpredictable nature (Dunbar et al., 1993; Molchany & Peterson 1994).

Although patients with an ICD experience a shock immediately after implantation which is administered to check the instrument in the catheter laboratory, this experience is insufficient to prepare patients for what they will experience outside hospital (Dougherty et al., 2000; Dougherty et al., 2001). To ensure effective nursing care, possible physical and psychosocial post-implantation problems in ICD patients need to be well understood. There have been many studies on this topic. However, the findings of these studies are not reflective of the situation in Turkey. There has been little research on ICD patients in Turkey and those studies that have been reported are not qualitative. Therefore, there is a need for qualitative studies to identify and understand the lived experiences of patients with an ICD in Turkey. The findings of such studies can provide the basis to design out interventions to assist patients and their families make appropriate physiological and psychosocial adjustment to ensure better quality of life. The purpose of this study was to, investigate the experiences of patients with an ICD.

Methodology

A qualitative descriptive approach was chosen as most appropriate for the determination of an individual's feelings, interactions, perceptions and behaviours (Speziale & Carpenter 2007). As this study was designed to seek understanding of the experiences of patients with an ICD, a qualitative design and data collection through interviews was selected to allow participants to freely express their thoughts and feelings (Speziale & Carpenter 2007).

Sample

Purposeful sampling technique was used. Inclusion criteria were as follows: (a) older than 18 years, (b) able to speak Turkish, and (c) agreeing to participate in the study and to have his or her conversation audiotaped during the interview. Those who had severe psychiatric or cognitive problems were excluded. The study included 19 volunteering patients who were implanted cardioverter defibrillator at two university hospitals, in Izmir, Turkey. Out of 19 patients, four were females and 15 were males with a mean age of 53.57±13.44 years. The majority (84.2%) were married, 63.1% were primary school graduates. The mean number of months since ICD implantation was 15.47±9.82 months. Most of the patients (68.4%) had 1-5 discharges. Ten patients (52.6%) had experienced a previous sudden cardiac arrest. Left ventricular ejection fraction ranged from 20% to 79% (mean=37.5%, SD=10.8%). The majority of patients (84.2%) had not comorbidities.

Data collection

The approval was obtained from the ethics committee of the Ege University School of Nursing and the two hospitals. In addition, the purpose of the study was explained to the patients included in the study and their consent was sought for recording interviews. Focus-group interviews were used to investigate the experiences of patients with an ICD. The objective of the focus group interviews was to understand the attitudes, feelings, beliefs, experiences and reactions of individuals. These types of investigations are especially useful for revealing different views (Holloway & Wheeler 1996; Morse & Field 1996).

To identify volunteers for the focus groups, ICD patients who attended outpatient clinic were contacted and was explained the objective of the study. The phone numbers of ICD patients were obtained and patients who volunteered to be included were asked to specify a date for the interview. The interview date was decided at the end of the phone calls. Four groups were formed each consisting of 4–5 individuals, an appropriate size for a focus group (Kitzinger 1995). In the interviews, semi-structured interview forms were used that involved open-ended questions for the determination of patient's experiences. The interviews began with the broad question: What is it like to live an ICD?. Other questions included: How has it had an impact on your life? Tell me about your experience of receiving defibrillatory shocks? Have you needed to look for more information about ICD?

The interviews were conducted in the meeting rooms of the two university hospitals and lasted for 60–90 minutes.

Data analysis

At the end of the interviews, the records were transcribed verbatim and an analysis was immediately carried out. The data was analyzed using qualitative content analysis. Two researchers conducted the content analysis independently. The data was first separately coded by both researchers and then compared. The researchers continued discussing each case until they reached a consensus (Morse & Field 1996; Emiroğlu 2002; Yıldırım & Şimşek 2006).

Following the coding stage, the data was then classified according to the themes. Later, all the information was interpreted in a report.

During the planning for the research, six main themes had been established from the literature and according to the perception of the researchers: Regular activities of daily life, social life, familial relationships, emotional changes, ICD shocks and experiences related to receiving counseling and information from health care providers. It was seen that the raw data was compatible with the previously determined themes.

Results

Six main themes were determined: regular activities of daily life, social life, familial relationships, emotional changes, ICD shocks and experiences related to receiving counseling and information from health care providers.

Experiences in the regular activities of daily life

Regular activities of daily life were considered to include physical activities, shopping, household chores and self-care. The patients noted that they restricted their daily activities and received support from their family members during these daily activities as they feared that shocks may occur and that the ICD may dislocate. One of the patients noted that he refrained from quarrels and remained unresponsive for fear that physical contact might damage the ICD. Patients also reported that the fear of a shock stopped them from showering by themselves in case they experienced problems during the shower. Patients who did not experience shocks or who experienced less shocks reported that their daily activities had not changed. Some patients stated that they were reluctant to go outside alone as there were worried about unforeseen events occuring. The following statements exemplify the patients' experiences while carrying out regular activities during daily life:

"I always feel that I carry a battery on me, I feel its weight and I limit myself".

"I cannot take a shower alone. I think that the ICD will give a shock, when I get under the shower it feels like I am drowning. My mother stayed in the bathroom while I was having a shower in the bathroom".

Experiences related to social life

The patients noted that the ICD affected their social life and that they were unable to continue the social activities that they had participated in previously. One of the patients noted that he was unable to leave the home due to the fear of damage to the ICD from cellular phones and that his social relationships had therefore diminished. The patients who had driven before treatment with the ICD stated that they continued to drive after the implantation. Only one patient reported that he could not drive in case he became excited. Four patients reported that they did not work due to their illness and one patient noted that he changed his job because of his illness. The following comments exemplify the patients' experiences regarding their social life:

"ICD restricted me like... I ...used to do sports until my illness appeared; I had to stop doing sports. I mean, I can't do things which require much effort. My social life was restricted".

"I can never go outside, everybody is using cellular phones. I don't know how much distance I am to keep with cellular phones, he walks on the other side of the road with a cellular phone and I immediately change my route. I can't go out in public, I don't work, I stay at home, and there is no one else to talk except my spouse. I am afraid that the instrument gives shocks while I am sitting next to someone in a public transport vehicle, that's why we can't go out to anywhere. We have been psychologically exhausted."

Familial relationships

In the interviews, three patients reported a decrease in sexual activities. The patients noted that their spouses were also uncomfortable. The patients also noted that their relatives looked out for them more, worried about them and in some cases prevented them from doing certain activities. Overprotection was particularly noted by patients who had SCD.

"All my children call me on the phone every day and ask me how I feel, whether I need anything and advises me not to do anything. My husband works 15 days at night shift and 15 days at day shift. He demanded to work at day shift in order to stay home at night. He is afraid."

Emotional changes

Fear, nervousness, anxiety, anger and changes in body image due to the ICD generator were the most frequently reported emotional changes. The patients reported the fear of receiving a shock, death, cellular phones and using electrical equipment. They also feared that the instrument

would fail or that its battery would become depleted. The patients who received shocks were found to be more anxious than those who did not. The patients expressed their fear of the instrument in different ways:

"I was very impressed by the battery when it was implanted; I thought I would live with a battery forever, with a continual fear. I don't know if this device works when my heart stops. Then, I die outside or everywhere. I'm 52 and I'm afraid that I will die suddenly".

Despite their fear of death, the patients were sure that the device would work in the case of a life threatening arrhythmia and that in these circumstances they would have a chance of survival. They noted that the device was a guarantee for their lives, that they feel safe, that the chance of survival would have decreased without the device and that they were grateful to the device. The following statements exemplify their positive feelings about ICD:

"The best thing in living with this battery is that I know that it will save my life and it will start to work when my heart stops beating and and it keeps me alive".

 "I thank God, I would be dead now, but now I am surviving. My heart stopped. Now my life is longer. I'm grateful, too, because I died and then I returned to life. This is a kind of gift".

However, the patients also stated that they felt anxious because the timing of shocks was not predetermined. The following statement illustrates their feelings of uncertainty about the timing of shocks:

"It always keeps my mind busy. I am always alert and feel uneasy because I wonder whether it occurs if I do this or that."

Experiences related to ICD shocks

The patients' experiences relating to ICD shocks were the worst of the difficulties they had undergone. They noted that prior to a shock they felt faint, hot and nauseous, and that their cardiac rhythm changed and they did not hear the ICD signal. Most of the patients reported that they did not feel the impending shock. Patients described a shock like an explosion, lightning, receiving a blow on their chest or an electric shock. Only one patient was reported to have lost consciousness during the shock.

 "I felt as if I received a blow on my chest, a feeling of a very severe blow and I see streaks of lightning on my eyes."

 "When it strikes my eyes radiate flames, my brain jumps in my skull. It strikes with such intensity that it tears me apart."

Patients stated that they felt anxiety, fear of death and helplessness during the shocks. Patients who experienced successive shocks experienced more severe pain.

 "I have already been tense because of my high heart rate and then I begin to fear that I will die all of a sudden, of course I began to pray. Especially during the third instance I began to pray and took my wife's blessing, she was fluttering around me and I thought that there was no escape that time but you can not be sure, too. At that moment you cannot realize it will work again".

The patients revealed that they sat or lay down during shocks. One patient said that he coughed during a shock and stopped the shock by coughing. The patients often expressed their faith in God while they were talking about their experiences with ICD. Some patients noted that they accepted their fate.

Patients' experiences relating to receiving information/counseling from health care providers

Patients emphasized that they had not received adequate information from health care personnel about the function of the defibrillator, how it would affect their lives and what to do during a shock. However, they noted that they were given both verbal and written information about the conditions likely to affect defibrillator function and advice about driving. They added that they themselves asked the doctors or the manufacturers to provide this information. Some patients reported that they did not have the opportunity to ask the health care providers questions and that they had received contradictory information.

 "This is crucial, if they had informed us before having been discharged from the hospital we would be psychologically more relaxed. They told me that they were going to implant the defibrillator. That's it. They never explained why they would do it and what I was diagnosed with. Without any explanations, the defibrillator was implanted. I should have been offered information about the issue."

"I didn't know what benefits the device would bring. Actually, I did not ask about the benefits of the device. I learned them as I lived with it."

The patients were asked about the occasions on which they had needed the help of health care providers after discharge.

They were also asked about the subject matters for which they had needed more information. The most frequently asked questions by the patients were about the life-span of the battery, using electrical devices and cellular phones, and about swimming.

Moreover, patients reported that they had had questions about the possible changes in their lives, medicines and how they should exercise. One patient noted that they needed education about first aid.

"It is relaxing to listen to the doctors and the nurses, even if they utter only a few words. The advantages of device should be explained to us. Besides, first aid training should be given, first aid saves lifes."

Discussion

After implantation of a cardioverter defibrillator, life style changes include: the need for assistance in regular daily activities, the inability to continue certain hobbies, possible overprotection by relatives, changes in sexual activity and decreased time spent outside. Patients and their relatives exert considerable effort adjusting to such changes in daily life (Dougherty 2001).

The results of this study are similar to those previously reported in the literature. As reported in previous studies, we identified uncertainty in patients about the timing of shocks and this anxiety caused changes in behavior (Dunbar et al., 1993; Dougherty 1995; Heller et al., 1998; Dickerson et al., 2000; Eckert & Jones 2002; Tagney et al., 2003). In the hope that the number of shocks will decrease, patients often decrease their activities while trying to overcome their feelings of helplessness. Receiving shocks causes ambivalent feelings. Patients are worried about ICD shocks, but at the same time they want to avoid the risk of sudden death. Many studies on this topic have revealed that the device is well-tolerated and that patients believe that the ICD is necessary although they are afraid of receiving shocks (Dunbar et al., 1993; Dougherty 1995; Thomas et al., 2001).

This study is the first to reveal "cellular phone phobia" among patients with an ICD. Cellular phone related fears may be explained by the fact that cellular phones are widely used in Turkey, that the patients were not given adequate information on this subject matter or that the information provided was misinterpreted. In addition, patients who drove before implantation of the device continued driving although they were not recommended to do so. It may be that the patients did not fully understand the implications of their disease and that there are no official regulations regarding driving for ICD patients in Turkey.

Three patients reported a reduction in sexual activity, which is consistent with the literature (Schuster et al., 1998; Heller et al., 1998; Tagney et al., 2003; Steinke 2003). Changes in sexual activity occur as a result of fear of harming their partner and provoking a discharge during sexual activity (Zayac & Finch 2009). As sexual activity is a sensitive subject for many people, the number of patients who mentioned their worries about their sexual life was low. Therefore, problems related to sexual activity may be easier to discuss in one-on-one interviews.

The patients emphasized that they received insufficient information regarding how the device operated and how it would affect their life. This study indicates that the physical and psychosocial preparation of the patients prior to implantation and discharge were inadequate. The information given to patients related to technical aspects of the appliance and this did not prepare the patients for life with an ICD and issues relating to psychosocial preparation were not duly emphasized. It also appears that nurses did not play a role in the education and follow-up of these patients.

The timing of the information and the manner in which it is given is extremely important for these patients. Many patients experience neurological changes leading to cognitive disorders following sudden cardiac death. Fear, confusion and anxiety caused by life-threatening arrhythmia may prevent the patients from learning and remembering the information given. In addition, the patients and their families may not predict their long-term needs before discharge and it may therefore not be appropriate to provide the patients and their families with excess information in the early stages (Dougherty et al., 2000; Tagney et al., 2003).

Conclusion

It can be concluded that patients with ICD experience physical and psychological problems and are not offered the education they need. To reduce the fears of the patients and their families and to prepare them for possible life style changes, comprehensive training programs that

start in the pre-implantation period and continue into the post-implantation period should be organized. These training programs could include the use of videos, written material and role plays to convey the messages effectively. A multidisciplinary team approach is important for enhancing the quality of life of patients with an ICD, allowing for the physiological and psychosocial adaptations required by the patient. Support groups allow patients with an ICD to discuss their experiences, fears and expectations. It is recommended that support groups are formed and that the patients and their relatives are encouraged to join these groups, where they may learn effective coping strategies for ICD-related problems.

Acknowledgments

References

Burke L.J. (1996). Securing life through technology acceptance: The first six months after transvenous internal cardioverter defibrillator implantation. Heart Lung, 25: 352-366.

Craney J.M., Mandle C.L., Munro B.H. & Rankin S. (1997). Implantable cardioverter defibrillators: physical and psychosocial outcomes. American Journal of Critical Care, 6: 445-451.

Dickerson S.S., Posluszny M. & Kennedy M.C. (2000). Help seeking in a support group for recipients of implantable cardioverter defibrillators and their support persons. Heart Lung, 29: 87-96.

Dougherty C.M. (1995). Psychological reactions and family adjustment in shock versus no shock groups after implantation of internal cardioverter defibrillator. Heart Lung, 24: 281-91.

Dougherty C.M. (2001). The natural history of recovery following sudden cardiac arrest and internal cardioverter defibrillator implantation. Progress in Cardiovascular Nursing, 16: 163- 68.

Dougherty C.M., Benoliel J.Q. & Bellin C. (2000). Domains of nursing ıntervention after sudden cardiac arrest and automatic internal cardioverter defibrillator implantation. Heart Lung, 29: 79- 86.

Dougherty C.M., Crowley J., Lewis F.M. & Thompson E.A. (2001). Theoretical development of nursing interventions for sudden cardiac arrest survivors using social cognitive theory. Advances in Nursing Science, 24: 78-86.

Dunbar S.B., Warner C.D. & Purcell J.A. (1993). Internal cardioverter defibrillator device discharge: experiences of patients and family members. Heart Lung, 22: 494-501.

Eckert M. & Jones T. (2002). How does an implantable cardioverter defibrillator (ICD) affect the lives of patients and their families? International Journal of Nursing Practice, 8: 152-157.

Emiroğlu O.N. (2002). Kalitatif araştırma yöntemleri (Qualitative research methods). In: Erefe İ. (Ed.).

Hemşirelikte Araştırma: İlke, Süreç ve Yöntemleri (Research in Nursing: Principles, Process and Methods). Odal Ofset, İstanbul, Turkey, 103-112.

Gemici K., Aydınlar A. & Cordan J. (2000). Primary and secondary treatment of sudden cardiac death. Turkiye Klinikleri Journal of Cardiology, 13: 322-326.

Gollob M.H. & Seger J.J. (2001). Current status of the implantable cardioverter-defibrillator. Chest, 119: 1210-1221.

Heller S.S., Ormont M.A., Goster L.L., Sciacca R.R. & Steinberg J.S. (1998). Psychosocial outcome after ICD implantation: A current perspective. Pacing and Clinical Electrophysiology, 21: 1207-1215.

Holloway I. & Wheeler S. (1996). Qualitative Research for Nurses. Oxford: Blackwell Science.

Kitzinger J. (1995). Introducing focus groups. British Medical Journal, 311: 299-302.

Kupersmith J. (2002). The past, present, and future of the implantable cardioverter defibrillator. American Journal of Medicine, 113: 82-84.

Molchany C.A. & Peterson K.A. (1994). The psychosocial effects of support group intervention on AICD recipients and their significant others. Progress in Cardiovascular Nursing, 9: 23-29.

Morse J.M., & Field P.A. (1996). Nursing Research The application of Qualitative Approaches. London: Chapman & Hall.

Schuster P., Phillips S., Dillon D.L. & Tomich P.L. (1998). The psychosocial and physiological experiences of patients with an implantable cardioverter defibrillator. Rehabilitation Nursing, 23: 30-37.

Speziale H.J.S. & Carpenter D.R. (2007). Qualitative research in nursing. Advancing the humanistic imperative. Lippincott Williams and Wilkins, Philadelphia.

Steinke E.E. (2003). Sexual concerns of patients and partners after an implantable cardioverter defibrillator. Dimensions of Critical Care Nursing, 22: 89-96.

Swygman C. & Wang P.J. (2002). Advances in implantable cardioverter defibrillators. Current Opinion in Cardiology, 17: 24-28.

Tagney J., James J.E. & Albarran J.W. (2003). Exploring the patient's experiences of learning to live with an implantable cardioverter defibrillator (ICD) from one UK centre: A qualitative study. European Journal of Cardiovascular Nursing, 2: 195-203.

Thomas S.A., Friedmann E. & Kelley F. (2001). Living with an implantable cardioverter-defibrillator: A review of the current literature related to psychosocial factors. AACN Clinical Issues, 12: 156-163.

White E. (2000). Patients with implantable cardioverter defibrillators: Transition to home. Journal of Cardiovascular Nursing, 14: 42-52.

Yıldırım A. & Şimşek H. (2006). Sosyal Bilimlerde Nitel Araştırma Yöntemleri (Qualitative Research Methods for Social Sciences). Seçkin Yayınevi, Ankara, Turkey.

Zayac S. & Finch N. (2009). Recipients of implanted cardioverter-defibrillators actual and perceived adaptation: a review of the literature. Journal of the American Academy of Nurse Practitioners, 21: 549–556.