

Research Article

Living with cardiac resynchronization therapy: Challenges for people with heart failure

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Abstract

The number of people with heart failure requiring implantation of a cardiac resynchronization device is increasing in Iran. Although this intervention is an effective life-saving treatment, several challenges are associated with patients' lifestyle after insertion. This study identified the challenges and coping mechanisms of Iranians with heart failure living with cardiac resynchronization therapy. A qualitative approach using conventional content analysis was adopted. Seventeen people with heart failure and three nurses were recruited between December 2014 and November 2015 from a teaching hospital and a private clinic in Rasht, Iran. Participants were interviewed using semi-structured interviews lasting 30–60 min. Five themes emerged: (i) fear of implantation, (ii) the panic of receiving a shock from the device, (iii) lack of control over life, (iv) inadequacies of the healthcare system, and (v) psychosocial coping. A heightened understanding of these challenges and coping strategies could prepare healthcare professionals to provide better routine care, education, and support to the recipients of cardiac resynchronization therapy prior to implantation, during the recovery period, and for long-term management.

Key words

cardiac resynchronization therapy, cardiovascular nursing, heart failure, Iran, patient perspective, qualitative study.

INTRODUCTION

The prevalence of heart failure in developing countries like Iran is reported to be 3,500 cases per 100,000 people, three times the prevalence of this disease in the United States (US) (Hekmatpou *et al.*, 2010). The number of patients who require cardiac resynchronization therapy (CRT) is increasing in Iran as a result of the increasing prevalence of heart failure (Hekmatpou *et al.*, 2010).

Cardiac resynchronization therapy is a pacing method that maintains ventricular contraction to improve cardiac output. People with heart failure undergoing CRT should be considered for an implantable cardioverter defibrillator (CRT-D implant) (Jensen *et al.*, 2007). Since its approval by the US Food and Drug Administration in 2001 (Trupp, 2004), many quantitative studies and clinical trials have proven the effectiveness of CRT for the treatment of heart failure (Abraham *et al.*, 2002; Linde *et al.*, 2008; Young *et al.*, 2003) and improvement of quality of life (Botto & Russo, 2012; Chen *et al.*, 2012). Although these findings provide evidence to support CRT efficacy, recipients still experience challenges in daily life, such as physical difficulties,

family overprotection, changes in sexual relations, emotional challenges, employment difficulties, dealing with device shocks, lifestyle changes, costs, and fears of device longevity (Tagney *et al.*, 2003; Williams *et al.*, 2007; Palacios-Ceña *et al.*, 2011).

Studies have shown that recipients use restrictive behavior (Lemon *et al.*, 2004), seek help (Conelius, 2015), practice concealment (Humphreys *et al.*, 2016), and apply positive thinking (Williams *et al.*, 2007) to cope with the challenges of living with implanted devices. Welstand *et al.* (2009) urged nurses to survey people with heart failure on their experiences and to listen to their stories in order to better plan nursing care. However, to our knowledge, no studies have investigated the challenges that people face after implantation of a CRT device, including physical, mental, social, cultural, and economic challenges. CRT is a new treatment for heart failure in Iran and data in this area is limited (Assadianrad *et al.*, 2013). Iranian people with implanted devices have reported insufficient education and support (Rakhshan *et al.*, 2013). This qualitative study details concerns from the perspective of Iranians with heart failure living with CRT.

STUDY PURPOSE

The study explored: (i) the challenges of living with CRT, and (ii) how recipients cope with such challenges.

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METHODS

Design

This qualitative study is part of a doctoral dissertation to explore the process of living with CRT. A conventional qualitative content analysis (CQCA) approach was employed (Graneheim & Lundman, 2004). A CQCA allows categories to flow from raw data without using predefined categories (Hsieh & Shannon, 2005). The aim is to obtain a condensed and rich description of the phenomenon under study (Elo & Kyngäs, 2008). A CQCA was employed as insufficient literature and theory have focused on this topic (Hsieh & Shannon, 2005).

Setting

Participants were recruited from an outpatient clinic at a teaching hospital and a private office of an interventional electrophysiologist in Rasht, Iran. The first author conducted all interviews at a location of the participant's choice (home, hospital, private office, or workplace).

Participants

Seventeen people with heart failure (nine men, eight women), ranging in age from 25 to 93, who had lived with CRT for two to 108 months were recruited (Table 1). Three nurses with 5–14 years' experience in the electrophysiology and pacemaker ward were also included in the study. Participants were selected

through maximum variation sampling, which is a purposive sampling method (Patton, 1990). Inclusion criteria were patients with a cardiologist's diagnosis of heart failure who underwent CRT-D, able to communicate, and willing to share their feelings and experiences. People with cognitive dysfunction, hearing problems, and malignancy were excluded from the study.

Data collection

Twenty-four semi-structured in-depth interviews were conducted between December 2014 and November 2015. The interview began with some general and open-ended questions about the research topic, including "Explain your life after placement of a CRT device," "What kind of problems have you experienced living with a CRT device?" and "How have you coped with the CRT device on a daily basis?" Probing questions were also asked in order to clarify the content of the interview. Open-ended questions are superior for providing data on interviewee's feelings or experiences (Green & Thorogood, 2004). The interviews lasted 30–60 min and were digitally recorded.

Data analysis

Data were analyzed using Graneheim and Lundman's (2004) CQCA method. The first and second authors analyzed the interview data together. The content of each interview was immediately transcribed verbatim, and the whole session was reviewed several times to gain overall comprehension.

Table 1. Patient characteristics ($n = 17$)

Code	Gender	Age	Education	Marital status	Employment	City of residence	Duration of heart failure (before implant)	Time since implant	No. of shocks
P.1	Male	93	Literate (reading and writing)	Married	Coffee shop manager	Rasht	2 years	7 months	0
P.2	Female	58	Diploma	Married	Housewife	Rasht	6 months	13 months	0
P.3	Female	74	Associate	Widowed	Retired teacher	Rasht	20 years	2 years	0
P.4	Male	72	Degree Elementary school (5th grade)	Married	Building painter	Another city	2 months	4 months	0
P.5	Female	70	Elementary school (5th grade)	Widowed	Housewife	Another city	1 year	9 years	0
P.6	Male	74	Illiterate	Married	Farmer	Another city	2 weeks	6 months	0
P.7	Male	63	6th grade	Married	Taxi driver	Another city	1 year	13 months	2
P.8	Male	59	Diploma	Married	Carpenter	Another city	3 years	6 months	1
P.9	Female	56	Diploma	Remarried	Elderly caregiver	Another city	6 years	18 months	1
P.10	Female	39	Diploma	Married	Disabled, was hospice staff	Another city	18 months	1 month	0
P.11	Male	53	Master's degree	Married	Employee	Another city	2 years	4 months	0
P.12	Male	25	Diploma	Married	Taxi driver	Another city	4 years	3 years	4
P.13	Female	45	Bachelor's degree	Married	Shopkeeper	Rasht	1 month	9 years	5
P.14	Female	60	Diploma	Married	Housewife	Rasht	10 years	3 years	0
P.15	Female	46	High school	Married	Housewife	Another city	1 year	19 months	0
P.16	Male	67	Illiterate	Married	Disabled, was farmer	Suburb	22 months	2 months	0
P.17	Male	48	Illiterate	Married	Disabled, was farmer	Another city	6 months	3 years	6

Meaning units were then identified in the form of sentences or paragraphs, and initial codes were extracted. Finally, the codes were integrated and classified according to similarities and differences to form categories and subcategories (Graneheim & Lundman, 2004). MAXQDA 10 software (VERBI GmbH, Berlin, Germany) was used to manage the data and resulting analysis.

Rigor

To ensure credibility, participants with a rich experience of living with CRT were included. Prolonged engagement with the study and maximum variation sampling were further techniques used to ensure credibility. A member check was conducted to promote dependability. The participants reviewed their transcribed interviews and codes to ensure accuracy. An independent reviewer examined the data analysis. All authors reviewed the codes, subcategories, and categories to ensure dependability. Confirmability of the study was established through an audit trail. To ensure the transferability of the findings, the context, sampling, and participant's characteristics, and the process of data collection and analysis are clearly described.

Ethical considerations

The ethics committee of Tehran University of Medical Sciences approved this study. The interview sessions began with an introduction and explanation of the objective of the study. Written consent was obtained from all participants, as well as permission to record the interview. The audio files were kept on a computer with password protection. Confidentiality was achieved through anonymization of the audiotaped interviews.

RESULTS

The challenges of living with CRT were condensed into five categories: (i) fear of implantation, (ii) the panic of receiving a shock from the device, (iii) lack of control over life, (iv) healthcare system incompetency, and (v) psychosocial coping. Each category is composed of subcategories (Fig. 1).

Fear of implantation

A fear of implantation describes the recipients' psychological and behavioral responses toward recommendations for CRT and the fear that recipients experience during the surgery. General anesthesia is suggested for CRT implantation in people with heart failure; however, the participants of this study only received local anesthesia for their surgery (Cuculich & Joseph, 2011). Fear of implantation is composed of two subcategories: negative impression toward implantation and bitter experience of implantation.

Negative impression toward implantation

The data shows that recognizing the need for CRT placement is one of the most difficult stages for participants. Participants were shocked, worried, or sad to hear of their need for CRT. Concerns included life dependency on the device, gossip, young age, loss of employment, battery cost, and lack of support. None of the participants had been shown the device or had been presented the opportunity to hold and feel the device. Thus, they resisted the diagnosis of the disease and CRT placement:

I cried when the doctor told me that I needed this device. That was because of my young age, I was just 38! And then I was crying for my job because I really liked my work environment (P.10).

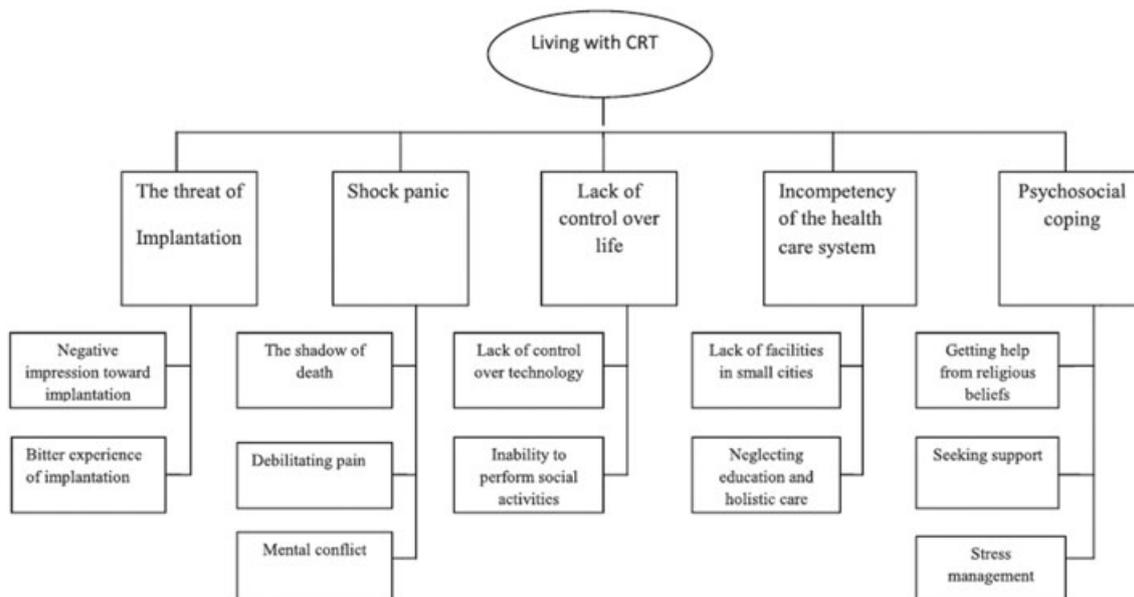


Figure 1. Summary of categories and subcategories. CRT, cardiac resynchronization therapy.

Bitter implantation experience

Most participants remembered the CRT implantation surgery as a bitter experience accompanied by great pain and suffering. The fact that patients were conscious during the surgery caused an unpleasant experience, severe pain, pressure, and feelings of disgust at having a foreign object inserted into their body:

I saw *Azriel* [the death angel in Islam] the night I was taken to the operating room. It was so tough to me that I cannot describe it. It was so painful that I kept screaming (P.9).

Panic at shocks from the device

Six participants reported receiving a shock from the CRT device. Discussion focused on the unpleasant experience and emotion of receiving a shock, particularly the first time. Shocks were reported to have occurred after heavy physical activity, dancing, and arguing, although two participants experienced shocks when at rest.

Participants experienced feelings of fear, anxiety, and confusion and consequently retreated from daily life activities. "Shock panic" entailed "the shadow of death," debilitating pain, and mental conflict.

The "shadow of death"

Receiving a shock was so unpleasant and disturbing to some participants that they felt "the shadow of death" over their lives and suffered a great deal of distress. Thinking about "confronting death" was associated with frustration and anguish:

It happened suddenly. It [the device] was slamming me from side to side so badly that I lost consciousness. I saw death there! I died, and I came back to life (P.7).

Debilitating pain

The recipients who received a shock from the CRT device described it as a sudden push or a heavy blow, a brain vibration, or an electrical shock accompanied by severe and unbearable pain. The pain was unexpected and unimaginable:

I cannot compare any pain with this one. The feeling of your brain being vibrated is really awful. It is as if someone slams you with an unending pain (P.13).

Mental conflict

The panic experienced after a shock was not limited to the time the shock actually occurred. Participants suffered from mental conflict and turmoil in fear of a shock occurring again and coped by removing themselves from normal activity. One of the participants who experienced a shock during sexual activity avoided sexual relations for a year following. One of the recipients explained her state after experiencing the first shock:

I haven't felt well for a week. My children used to call or visit me, and I only told them to leave me alone! I was restless! I couldn't bear anyone. I was praying all the times. Even remembering those days upsets me (P.9).

Lack of control over life

Participants expressed the reality of having a mechanical device in their body and the disruption it caused as a lack of control over their life. This category is composed of two subcategories: lack of control over technology and inability to perform social activities.

Lack of control over technology

Many participants were concerned about possible malfunction, abnormal sound, or technical failure of the device. Thus, they felt that the CRT device had control of their lives:

Sometimes I wonder how many years would this device help me survive. What if a technical problem occurs? In any case, it isn't smart; it is just a piece of plastic or metal (P.8).

Inability to perform social activities

Some participants felt that they had lost control over their lives because certain careers, such as working in care centers for the handicapped and farming, could not be continued after CRT implantation. Recipients were forced to quit their job upon their doctor's recommendation. This was a negative change for people who were considered socially active before CRT implantation.

Healthcare system inadequacies

It was apparent that the healthcare system failed to meet the expectations of participants. Inadequacies in the healthcare system entailed: lack of facilities in small cities and neglecting education and holistic care.

Lack of facilities in small cities

Apart from high care costs, such as frequent device checks and doctor's visits, participants also expressed difficulty accessing healthcare services. This was a result of limitations of medical support centers, and a lack of medical facilities and equipment in some small cities:

I have to travel all the way from Langrud to Rasht. (two different cities) for every doctor visit. There is heavy traffic, and the cost is high. I have to arrange the appointment in a way that we can find a car for returning home at night (P.6).

Neglecting education and holistic care

The majority of participants agreed that nurses provided a general information pamphlet without any oral education. The greater part of the written material was devoted to describing forbidden activities, such as heavy physical activity, holding a cell phone on the side in which the CRT was implanted, and passing through high-tension wires.

Nurses reported a lack of time, patients were not capable of being educated and cultural barriers as the main reasons for neglecting education:

We provide necessary education in oral and written form but we don't have enough time to evaluate the provided education (P.20).

A majority of the participants believed that their cardiologists and nurses paid more attention to medical treatments in an attempt to alleviate their physical needs, but neglected non-device related issues:

Every time I go for analyses, they [doctor and nurse] say your device is ok. They don't ask any questions about whether I have [a] problem or not. This device is in my body; therefore they must pay attention to me (P.13).

PSYCHOSOCIAL COPING

The participants used strategies to cope with the challenges of living with CRT, including: seeking solace in religious beliefs, seeking support, and stress management.

Seeking solace in religious beliefs

The most important identified coping strategy was seeking solace in religious beliefs. Most participants said prayers, read the Holy Quran, went to the mosque, and prayed when experiencing challenges after implantation. Adopting these methods helped participants to remain calm and cope:

When I have a problem with my battery... I pray to God and the prophet. I read *surah Al-Hamd* [from the Holy Quran] and then slowly slip... (P.9).

Seeking support

Female participants sought emotional support from family, friends, and peers to overcome challenges:

I was very sad after having my battery. They [family] protected me. My husband fed me and combed my hair. He didn't allow me to carry heavy things (P.10).

Each time I go for my device check, I ask questions from other people like me and listen to their experiences. What a pity that we don't have meetings to share our experiences (P.15).

Stress management

Another strategy adopted when facing challenges was stress management. Participants engaged in a number of behaviors to help adjust to stress, including device concealment and distraction. Participants concealed their device for different reasons: to prevent embarrassment, compassion from others, and negative reactions. Some participants diverted attention from negative thoughts and bitter memories related to their disease by engaging in positive thoughts or activities:

I am trying to think about the good things... I think [about] my children, my grandchildren (P.3).

After my battery insertion, I keep myself busy. I plant vegetables and flowers in my garden. I enjoy it (P.7).

DISCUSSION

Unlike previous qualitative studies, we explored the challenges faced by recipients before, during, and after implantation of a CRT device (Palacios-Ceña *et al.*, 2011; Rakhshan *et al.*, 2013). The participants' negative impression toward implantation suggests that health professionals need to better prepare recipients to accept the implantation. Ågård *et al.* (2007) reported that patients have passive roles in decision-making regarding the implantation and follow the cardiologist's recommendation without being provided the necessary information. A clear and detailed explanation of the indications and function, shape, size, and positioning of the CRT device would help to alleviate patient fear.

None of the previous studies of CRT investigated the challenges faced during the implantation procedure (Beery *et al.*, 2002; Chen *et al.*, 2012; Conelius, 2015). The need to implant an additional lead through the coronary sinus in the left ventricle renders implantation more difficult than implantation of pacemakers and defibrillators (Jensen *et al.*, 2007). Patients need to be made aware of all complications prior to surgery, particularly in situations where local anesthesia is used.

One of the challenges in living with a biotechnical device is the fact that recipients have no control over technical function (Beery *et al.*, 2002; Mert *et al.*, 2012). In some studies, patients reported avoiding performing activities that were not recommended by the medical team, such as the participants of this study refraining from using cell phones (Lemon *et al.*, 2004). Some recipients had to quit their job, despite their desire not to. This result was contrary to other studies where patients considered quitting their job as a positive experience (Williams *et al.*, 2007; Palacios-Ceña *et al.*, 2011). Financial challenges were an important factor related to participants seeking to continue employment.

The participants of this study believed the healthcare system did not adequately provide facilities, education, and holistic care. Similarly, in a qualitative study, participants complained about access to healthcare services and sufficient and trained professionals in Iran (Abedi *et al.*, 2010). The participants of our study felt they did not receive the necessary information about CRT. The nurses in this study reported that they provided the necessary information for patients at the time of discharge, but recipients indicated that such education was inadequate. Patients and their families are not able to predict long-term needs; therefore, providing a large amount of information after implantation is redundant (White, 2000; Tagney *et al.*, 2003). Nurses need to educate recipients regarding special precautions in living with CRT and ongoing evaluation is needed to ensure that effective patient education has occurred.

Participants expressed the need to be treated as a whole person of mental, psychosocial, and spiritual dimensions. Today, health facilities in Iran offer psychological consultancy for better adjustment to CRT (Kohn *et al.*, 2000). Previous studies have reported that heart failure patients expect to be treated as multidimensional individuals with specific needs (Welstand *et al.*, 2009; Skaperdas *et al.*, 2014). CRT recipients may benefit

from holistic care, which health professionals could incorporate into routine care.

One of the most significant findings was the impact receiving a shock from the device had on the participants of this study. Unlike other studies in which recipients viewed a device shock as “life insurance” or a “security blanket” (Conelius, 2015; Palacios-Ceña *et al.*, 2011), the participants described the experience as being under “the shadow of death.” The participants of our study, two of which were taxi drivers, continued driving after receiving a shock, because they were not forbidden to do so. According to the American Heart Association, patients with an implantable defibrillator are restricted from driving for six months following implantation; however, there are no official regulations regarding driving for recipients of an implantable cardioverter defibrillator or CRT in Iran (Kim *et al.*, 2015).

The participants used different strategies to cope with the challenges of living with CRT. The stress process began for our participants with a fear of CRT implantation. This way of coping appears similar to the cognitive model of stress and coping developed by Lazarus and Folkman (1984; revised in Folkman, 1997), a theoretical model often used as a framework for understanding the coping process when stress is encountered. Coping influences an individual's appraisal of the consequence of a situation. Primary appraisal includes evaluating the challenges that people with heart failure experience, which are influenced by the person's beliefs and values. Seeking solace from religious beliefs was the most important coping strategy employed by the participants of this study. This is not surprising, as reliance on God and religion are usual strategies that people in distress use in an Iranian context. Health professionals can incorporate reliance on religious beliefs to assist recipients to cope.

Contrary to the results of a study in Sweden, participants in this study were satisfied to be overprotected by their families (Flemme *et al.*, 2011). This could be explained by Iranian culture in which familial connections are strong. Our participants requested support not only from families and friends but also from peers, suggesting the need for support groups.

LIMITATIONS

This study was qualitative; therefore, it is not generalizable to a larger population of people with CRT and populations in other health systems or ethnic groups. Our approach was limited to one-on-one interviews; therefore a wide range of opinions was not explored, as, for instance, a focus group discussion could have presented. However, lengthy and semi-structured interviews explored the participants' perspectives, offsetting this methodological limitation.

Some of the participants in this study were interviewed after two to nine years of CRT implantation. The delay between implantation and interview could have negatively affected the data. However, helping participants share challenges they had experienced during many years of living with CRT.

Finally, the English translation represented a limitation; however, we attempted to resolve this by seeking help from a native English-language editor.

CONCLUSION

This study has highlighted the specific challenges and coping mechanisms employed by Iranians with heart failure before, during, and after CRT implantation. The participants experienced fear of implantation, panic associated with a shock from the device, a lack of control over their life, healthcare system inadequacies and psychosocial coping.

Healthcare resources need to be more adequately distributed in various parts of the country and special facilities need to be provided for CRT recipients during surgery and follow-up periods. To prepare recipients for living with CRT, comprehensive education and psychological preparation should be organized prior to implantation. It is also important that nurses and cardiologists share the responsibility of individual-centered education and holistic care of recipients during the recovery period, and for long-term management.

Psychological support from family members, friends, peers, and health professionals was very important to the participants of our study. The establishment of support groups for recipients of CRTs where they may share effective coping strategies is recommended. Our findings warrant screening recipients, especially those who have experienced device shocks, for psychological symptoms in order to provide appropriate counseling interventions. Additional studies would therefore be of great value to examine possible interventions.

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CONTRIBUTIONS

Study Design: SD, NDN.

Data Collection and Analysis: SD, NDN, SV, JK.

Manuscript Writing: SD, NDN.

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