Illness Experience: Living with Arrhythmia and Implantable Cardioverter Defibrillator

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Purpose: To describe the illness experience of patients living with arrhythmia and implantable cardioverter defibrillator (ICD) and evaluate their experience after implantation of the device for gaining insight on care suitable for their condition.

Methods: In this qualitative descriptive study, we conducted semi-structured interviews of 22 outpatients who were visiting certified implant facilities.

Results: Three categories and seven subcategories emerged from the interviews. The ICD patients were (1) Bewilderment Stemming from Arrhythmia and ICD Implant, (2) Facing the Reality of Arrhythmia, the ICD and Being Able To Continue Life, and (3) Giving Meaning to Living With Arrhythmia and an ICD. The ICD patients first experience bewilderment in the form of [Uncertainty about One's Own Bodies], [Fear of Arrhythmia Ending My Life], and [Dissatisfaction with Unforeseen Results of the ICD]. After discharge from the hospital following ICD implantation, they slowly resumed their own lifestyles and [Facing the Reality of the ICD and Being Able to Continue Life] and [Confirming and Managing Lifestyle Activities]. As they recognized, objectified, and faced changes in their lifestyles, they began to practically see themselves as living with arrhythmia which required ICD-aided treatment, [Giving Meaning to One's Illness] and [Recognition of One's Disease]. And so, they reknit their lives integrated with arrhythmia and an ICD. We expressed these results in a schematic model as "Learning to Live with Arrhythmia and the ICD".

Conclusion: These results can be used to provide a perspective for assessing care to help patients adapt to life after ICD implantation.

INTRODUCTION

Patients with an implantable cardioverter defibrillator (ICD) feel assured that sudden death caused by fatal arrhythmia is prevented by the ICD implant and thus live with aspiration and hope. However, according to various reports, almost half the patients experience an ICD attack within 1 year of implantation (9). ICD patients live with the fear and anxiety of recurrence of attacks and have to restrict their daily activities and alter their lifestyle to keep their device working; therefore, they exercise excessive self-restraint over daily activities, get depressed, and/or find themselves unable to adapt to post-implantation

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recuperation. As a result, their quality of life (QOL) deteriorates (7). For ICD patients to maintain or improve their QOL, it is necessary that they adapt to changes in their lifestyle that accompany ICD implantation. Care in a chronic condition focuses on *living with the condition* and not on curing it (13). Therefore, patients should appropriately deal with the problems they face while incorporating the restrictions that implantation entails to their lifestyle and establish their own recuperative lifestyle that integrates ICD. To educate patients with chronic illness, it is necessary to provide concrete information that is in keeping with the patients' illness experience (15). Educating patients and their families regarding how an ICD functions and how their daily activities should be adjusted should be an integral part of the overall support provided (6). It is necessary to provide them such information in a way that is in keeping with their illness experience. For this, one has to understand their experience comprehensively and in temporal progression according to their illness and treatment rather than fragmentarily focusing only on their physical or psychological aspect or on their perception or behavior. Therefore, it is extremely important to determine the experiences of ICD patients during their recuperation.

Previous studies have examined ICD patients' psychosocial aspects, such as anxiety, depression, and QOL as well as their underlying reasons, and suggested that approximately 70% of them had some sort of psychological problem, approximately 30% of them had been diagnosed with anxiety, and approximately same percentage of them had been diagnosed with depression. In total, they concluded that ICD patients tended to have psychosocial problems, particularly those who experienced an attack and those who were young. (1,3,4,16,19,20,22) In addition, qualitative studies on these psychosocial aspects reported the adaptation processes of patients with first-generation devices (2), changes in patients' perception over a period of 1 year(8), and patients' apprehension of the device(5), among other things. Although studies have been conducted focusing on a single aspect, psychological or perceptional, what remains to be revealed is when, why, and how ICD patients seize being concerned and/or anxious, how they actually live, and as a result of all of this how they perceive ICD in their effort to adapt to post-implantation life. In other words, the illness experience encompasses their feelings, responses, perception, and living.

Therefore, the present study aimed to shed light on various factors of illness experience, such as day-to-day living and emotions including concern, anxiety, and hope/aspiration, of ICD patients before and after implantation to help them to comprehend their condition, deal with problems that they would face in the process of incorporating restrictions, and establish their own recuperative lifestyle that integrates ICD.

METHODS

Data generation

In this qualitative descriptive study (17), data were generated by semi-structured formal interviews. All data were generated by the first author. The following questions were focus of the interviews: along the pre- and post-implant ICD,(i) tell me what and why you concern about; (ii) tell me how you live one day, job, hobby, going out somewhere and so on; (iii) tell me how you have feelings, emotions, or expectation; et al.

Participants

In this qualitative descriptive study, data were generated by semi-structured formal interviews with 22 patients with ICD. Participants were twenty male and two female, with 14.0 months passed after implant (Table I).

Table I. Description of the sample **(n=22)**

Gender		Disease etiology N (%)	
Male	20	OMI	8(36)
Female	2	Brugada Syndrome	8(36)
Age(years)		DCM	6(28)
Mean±SD	61.26±13.4	Time with ICD(months)	
Range	35-79	Mean±SD	14.0±6.2
Marital status N (%)		Range	6-24
Married	20(90)	Received shock N (%)	8(36)
Separated/Single	2(10)		
Working status N (%)			
Full-time	9(40)		
Retired	13(60)		

＊SD=standard deviation

Ethical considerations

All processes of the research were carried out in accordance with the Declaration of Helsinki. In addition, they were carried out with the approval of the Medical Ethics Committee of the A University involved.

Data analysis

Transcriptions of tape-recorded interviews were corded for each element of illness experience. All codes were examined and compared for any similarities and differences, and sorted codes formed categories.

The rigor of the present study was assessed based on the criteria of credibility, applicability, consistency, and confirmability, which were proposed by Lincoln and Guba, 1985 (12). To establish credibility, member checking was used. After completing the analysis, the first author second interview for ten participants to ask them if the categories described their experiences living with ICD. All ten participants agreed with the findings and supported the interpreted data. To establish the consistency, the decision trial and study activities were recorded for the entire process of the present study, and the results were discussed between the researchers. Confirmability was established by discussions held among an expert panel, including the two nurse researchers.

RESULTS

Three **categories** and seven **[subcategories]** emerged from the data analysis. Each category is discussed briefly.

Bewilderment Stemming From Arrhythmia and ICD Implant

ICD patients have to deal with reconstruction of their recuperative lifestyle in addition to the underlying condition(s) ensuing fatal arrhythmia and drug therapy. Under such circumstances, they first experience bewilderment in the form of [Uncertainty about One's Own Bodies], [Fear of Arrhythmia Ending My Life], and [Dissatisfaction with Unforeseen Results of the ICD].

[Uncertainty about One's Own Body]

Patients' reaction to ICD could be summarized as "What's going on with my body and my treatment?" This expressed their **<Uncertainty about fatal arrhythmia occurring>** and <**Uncertainty surrounding the necessity of the ICD**>.

  <**Uncertainty about fatal arrhythmia occurring**> arose from the complexity of the

pathogenesis of *their own* arrhythmia and its treatment, the ambiguity of its subjective symptoms, and the unpredictability of their future.

> *"I don't know what causes fatal arrhythmia. Is it related to other kinds of heart disease?"*
>
> *"(During a doctor visit) I was told that I had an arrhythmia attack, but I didn't feel anything."*
>
> *"I wonder about my long-term prognosis and how long my heart can endure the arrhythmia. I wonder whether or not artificially stimulating my heart with a machine might eventually further damage my heart."*
>
> *"The ICD must give my heart additional strain, mustn't it? I sometimes wonder whether or not this machine will work and whether or not it will help me survive."*

<**Uncertainty surrounding the necessity of the ICD**> and their inclination to suspect it represented their lack of understanding of the function of an ICD and its relationship with drug therapy.

> *"Even after my ICD implant, I still have bouts of arrhythmia and I am taking more medication than before. So I don't feel the ICD is working."*
>
> "*After my ICD implant, my doctor has been encouraged that my arrhythmia hasn't persisted. But I wonder, did I really need the ICD implant? I wonder if taking medication would have been enough."*
>
> *"I don't feel the presence of the ICD, so I wonder if it is actually working and therefore doubt whether it would work if it is needed."*
>
> *"My ICD implant controls my arrhythmia but does not cure it. I'm fully aware of that. But, I often wonder about the true necessity of an ICD implant."*

[Fear of Arrhythmia Ending My Life]

Patients had experienced loss of consciousness and/or defibrillation and knew that arrhythmia could be *fatal*. Therefore, they felt <**Fear of arrhythmia which might trigger death**> and <**Anxiety related to the ICD shock**>. Those who had not yet experienced an ICD shock were anxious about the unknown and those who had experienced an attack were anxious about the recurrence. They also expressed concern about how they would respond to arrhythmia and an ICD attack. Fear and anxiety of death persisted even after the implantation.

> *"When, where, and under what circumstances will the ICD shock occur? What will it feel like? It frightens me because I can't imagine it."*
>
> *"I didn't realize just how scary the ICD shock was going to be and I am very frightened to think about when the next shock will happen."*
>
> *"I try not to think about the ICD shock as the more I think about it, the more I worry. However, I worry less about the ICD shock compared to my physical condition at the time of an arrhythmia attack. I worry more about becoming unconscious or whether or not someone could assist me during that time. It is difficult to stop thinking about death since that is a real possibility if I am not able to get the appropriate treatment at that time."*

[Dissatisfaction with Unforeseen Results of the ICD]

Patients talked about the limitations of ICD in terms of their resignation about its uncontrollability stemming from the fact that it was an instrument. They were experiencing <**Dissatisfaction regarding the limitations of the ICD instrument**> as well as the <**Discomfort of having a foreign object inserted**>; few examples being complications accompanying the implant, its battery life, the need for replacement, and its electromagnetic interference. They were also experiencing <**Dissatisfaction regarding lifestyle restraints**>, such as their profession, hobbies, and driving and the necessity to avoid electromagnetic interference.

> *"Since it's an instrument, it has its own limitations, like complications, malfunctioning, and its battery dying, and so on. I know it can't be helped, but it still bothers me. I wish it wasn't like that. But what can I do? It's not something I can do anything about."*
>
> *"It feels strange to have a foreign object inside my body and I often suffer from a stiff shoulder and uncomfortableness in the area that the ICD was implanted. I also feel uncomfortable when I see the implant area. I worry that these feelings have continued throughout my recovery."*

> *"Because I have an ICD implant, there are all kinds of dos and don'ts, aren't there? I feel it doesn't help me to speak to someone about my condition so I feel depressed about that."*

Facing the Reality of Arrhythmia, the ICD and Being able to Continue Life

After discharge from the hospital following ICD implantation, the patients slowly resumed their normal life and **[Facing the Reality of the ICD and Being Able to Continue Life]** and **[Confirming and Managing Lifestyle Activities]**.

[Confirming and Managing Lifestyle Activities]

After ICD implantation, through cautious trial and error, the patients set about finding out the <**Permissible range of safe lifestyle activities**> that would not trigger arrhythmia and thus ICD and activities that would not interfere with the proper functioning of ICD. They were greatly concerned about <**Evaluating the expansion of lifestyle activities** (period of time, procedure)> and required < **Information on other patients**>.

> *"You teach us general dos and don'ts but in reality, I want to hear more specific advice and counseling regarding my individual condition and a more detailed course of action in order to control my illness."*
>
> *"How long is this lifestyle change going to last? Is my condition going to affect me for the rest of my life? I was told in the beginning about some of the dos and don'ts but I wonder about certain limitations and specific activities. Further, I want to know when and how can I increase my own activities but I can't make that decision without your advice. I feel that you cannot give me specific advice unless you speak to other patients in order to find a more collective answer for us all. I feel that I should speak to other patients in similar situations in order to get more concrete answers."*

[Facing the Reality of the ICD and Being Able to Continue Live]

Our study revealed various self-images that the patients created as they adjusted to their daily activities and <**Difficulties in involvement with those around me**> and <**Objectification of themselves as something being kept alive**>. In their bewilderment about entrusting their lives to ICD, patients saw themselves as being kept alive by a machine. They also spoke of various difficulties they faced in their daily lives, such as carrying an ICD booklet for the physically disabled and one for the ICD patients and those around them not understanding ICD or their condition or not being considerate because of the invisibility of their condition.

> *"My life depends on this machine, right? Whether that is good or bad, I realize that I am a human being that depends on a machine to live my life."*
>
> *"I feel like something from a movie. I am like a cyborg robot which is kept alive by a machine."*
>
> *"I can appreciate that I am kept alive by a machine. But on the other hand, I feel that I cannot die as long as this machine works. What happens when I die? Everyone dies when their heart stops."*
>
> *"Because of my arrhythmia and implant, I am handicapped, right? The ICD implant is a necessity and it is useful, but I have resistance to accept it."*
>
> *"It is difficult to understand arrhythmia and the ICD implant. Therefore, it is difficult for me to explain my condition to others and also difficult for others to understand my condition."*
>
> *"I want to tell people around me what might happen if my arrhythmia occurs. For example, I might faint or my ICD implant may make a loud noise when starting. However, I worry about talking to people about this since I don't want to surprise or scare them."*
>
> *"I've been having a hard time dealing with my condition and I feel that I have endured so much. And now, after my ICD implant, my family feels relieved. However, this gives me mixed feelings."*
>
> *"My condition is not visible like a person who uses a wheelchair or cane. So having an ICD is not obvious to other people. Because of this, when I am on a train or in public, people don't recognize that I have to be careful around cell phones or take care to not bump into other people. Because my condition is not visible, I feel I have to face these problems by myself."*

Giving Meaning to Living with Arrhythmia and an ICD

As ICD patients recognized, objectified, and faced changes in their lives, they began to practically see themselves as living with arrhythmia which required ICD-aided treatment, **[Giving Meaning to One's illness]** and **[Recognition of One's Disease]** . And so, they *reknit* their lives integrated with arrhythmia and ICD.

[Giving Meaning to One's Illness]

ICD patients gave meaning to their illness experiences in their biographies, as they faced the change in their lives. They did so by <**Giving meaning to the value of the ICD to me**> and <**Coming to terms one's own lifestyle**>, as they compared their lives before and after implantation and.

> *"The ICD is somewhat bothersome, but I am able to accept this as necessity guardian."*
> *"I feel I was healthier without the ICD. The ICD is, as was expected, bothersome for me."*
> *"I feel this life is okay as I am able to live not so differently from the time before I got my ICD. I hope I can continue to feel this way."*
> *"My life has changed and I am not able to do what I like to do. There are many troubles and changes."*
> *"My life and work have changed after the implant. But I guess that is the way it is, and that is my life. I have come to accept that this is okay."*

[Recognition of One's Disease]

Once the patients began to return to their original lifestyle, despite the changes in their daily living, they were able to do <**Objectification of one's disease**> and the cause and become less uncertain about it by gaining knowledge and a new perspective.

> *"In the beginning, dealing with my arrhythmia was very troublesome. But after some time, I learned to accept many of the lifestyle changes that came along with my condition. And now, I feel that I am better able to understand and deal with my condition."*
> *"I don't know what is going to happen to me going forward. But I suddenly came to the realization that I have arrhythmia and I have to depend on my ICD."*
> *"I was able to acknowledge my illness and recognize my need for an ICD."*

Learning to Live with Arrhythmia and the ICD

The process that the patients went through after the implantation was revealed from the study; from getting trapped in "Bewilderment Stemming From Arrhythmia and ICD Implant" to "Facing the Reality of Arrhythmia, the ICD and Being able to Continue Life", and being kept alive during post-implantation recuperation to "Giving Meaning to Living with Arrhythmia and an ICD". The structure of the illness experience of ICD-implanted patients was described as *"Learning to Live with Arrhythmia and the ICD"* with seven subcategories constituting a schematic-model (Figure 1).

The ICD patients had fatal arrhythmia during treatment because of some underlying condition(s) and experienced loss of consciousness and life-threatening danger. Shortly after they had come out of the crisis, they had been told of the necessity of ICD implantation and were asked to make a decision. Under such circumstances, the patients, not quite being able to grasp what was happening to them nor have any prospect for the future, got trapped in "Bewilderment Stemming from Arrhythmia and ICD-implant", where three negative thoughts were meshed together like so many gears, namely [Uncertainty about One's Own Bodies], [Fear of Arrhythmia Ending My Life], and [Dissatisfaction with Unforeseen Results of the ICD]. After they were discharged from the hospital and returned to their own living, they were "Facing the Reality of Arrhythmia, ICD, and Being Able To Continue Live". In other words, they attempted to "Confirming and managing lifestyle activities" in "Uncertainty about one's own body" due to lack of prospect regarding arrhythmia and ICD-aided treatment as well as lack of concrete information about tips for daily life.

They broadened their horizon in their daily life while "Facing the Reality of Arrhythmia, the ICD, and Being Able To Continue Life" by objectifying themselves and dealing with difficulties that arose in their relationships with those around them. They overcame such bewilderment, adjusted their lives to the new circumstances, and dealt with ensuing difficulties. They slowly established their post-implantation lifestyle. By then, they were able to recognize the changes brought on to their lives by the implantation and objectify their post-implantation lives and themselves. By facing their condition this way, they were able to gradually Give meaning to one's illness], [Recognize of one's disease] and "Give Meaning to Living With Arrhythmia and An ICD". In other words, they are *"Learning to live with arrhythmia and the ICD"*.

Put another way, the illness experience of ICD patients consisted of giving meaning of living with arrhythmia and ICD as they broadened the horizon of their life, despite the never-ending feelings of uncertainty, dissatisfaction, and fear. This process of giving meaning was the process of coming to terms with fatal arrhythmia and ICD and living with them, i.e., the process of adaptation.
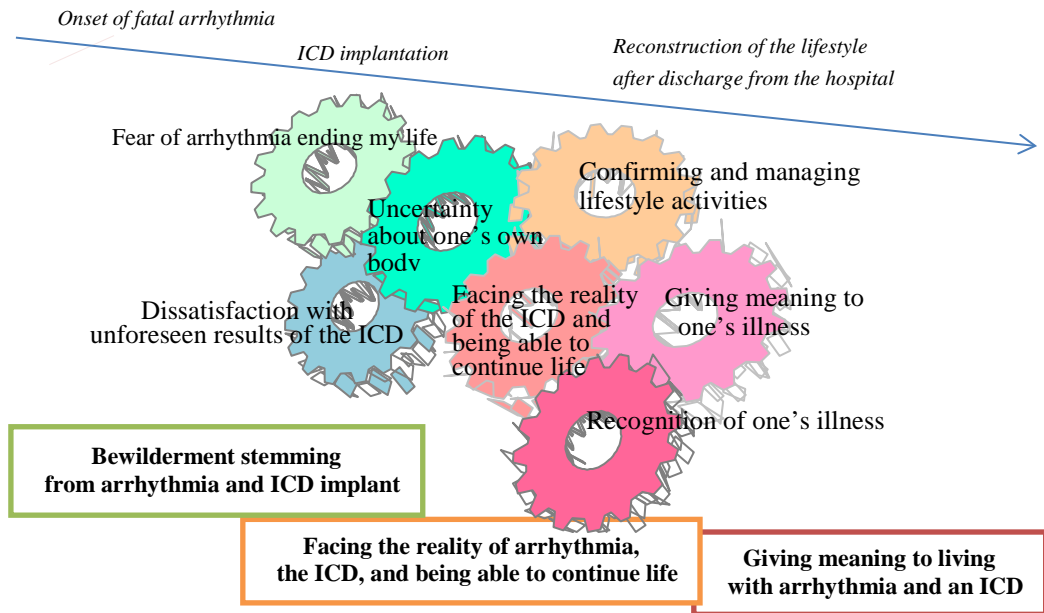

Figure 1. Learning to live with arrhythmia and the ICD

DISCUSSION

The focus of care for chronic disease is not curing but living with it. Patients living with a chronic disease come to terms with a variety of circumstances that accompany it. To that end, they alter their lifestyle and make several fine adjustments during changes in the illness course to perform their lifestyle activities. During this process, they have to undo their existing lifestyle and engage in *reknitting*. (10) Through this study, we were able to concretely show the nature of bewilderment that ICD patients faced when they made adjustments to their lifestyle activities and the sort of meaning they discovered as they reknitted them in their illness course involving fatal arrhythmia and ICD implantation.

Bewilderment Stemming from Arrhythmia and ICD Implant

It has been reported in studies on the psychological aspect of ICD patients that patients who experienced an ICD attack are extremely anxious and more than half of the patients concerned about the attack restrict their daily activities, resulting in a marked decline in their QOL (11). It has also been indicated that ICD patients experience uncertainty about unpredictable arrhythmia and ICD attack as a consequence of it (5). In this study, by asking the patients about the nature of their anxiety, their psychological state involving not only anxiety but also uncertainty and dissatisfaction was revealed. Similar to previous studies, patients in this study expressed anxiety about unknown factors such as when the ICD attack and the experience. In addition, it came to our attention in the present study that patients were greatly concerned about the post-attack procedure, suggesting that their fear and anxiety about death continued even after implantation. The uncertainty revealed in this study was consistent with the theory of uncertainty proposed by Mishel et al (14), because it causes ambiguity of the pathology, complexity of treatment and therapy, lack or inconsistency of information concerning the name and severity of the disease, and unpredictability of the course of the disease and its prognosis. In particular, the uncertainty arose from the lack of understanding of the pathogenesis of *their own* arrhythmia and ICD-aided treatment thereof––a reaction, not devoid of suspicion about the necessity of ICD in the first place and the fact that they didn't quite understand what was happening to their bodies. Their dissatisfaction was more like a sense of uncontrollability they were forced to experience with resignation toward ICD because of the limitations it had as a machine. Similar to previous reports, the limitations of ICD according to the patients was not just its limitations as a machine, such as its battery life, the need for replacement, and electromagnetic interference, or restrictions it imposed on their daily life, but also the discomfort of having a foreign object inserted in their bodies and the appearance it forced on them, which more than 40% of patients are said to complain about (18). In other words, to provide support to ICD patients with their emotional responses, it is essential to understand the feelings they are going through, such as uncertainty stemming from their own lack of understanding and/or awareness of the pathogenesis of arrhythmia and the necessity of treatment with or without ICD, anxiety about the ICD attack and fatality of arrhythmia, and dissatisfaction with ICD, a machine beyond their control.

Facing the Reality of Arrhythmia, the ICD, and Being Able to Continue Live

ICD patients were keeping their lifestyle activities safe by judiciously and ingeniously managing their lifestyle such that it wouldn't trigger arrhythmia or the ICD attack, or interfere with the device. Patients with chronic disease are concerned about how to incorporate the daily tasks required to control their symptoms and manage their conditions into their lifestyle, such that they can cope with their illness experience (13). In this study, we confirmed that the daily tasks of ICD patients coping with their disease included checking and adjusting their daily activities for safety, so that they wouldn't trigger arrhythmia, which in turn would trigger the ICD attack, or interfere with the device. Also, this study revealed the self-images patients created as they objectified themselves in the process of managing their lives, as well as the difficulties they experienced in their relationships with those around them. The former arose from the conflict that resulted from the fact that they had to entrust their lives to ICD while trapped in bewilderment as stated above. They had to face the images of themselves being kept alive by a machine. The latter came from the stigma of having to carry an ID booklet for the physically disabled and one for the ICD implant, in spite of the fact that it was difficult to explain the illness to people around them; they couldn't expect them to be considerate because of the invisibility of the device from the outside (21). In other words, to understand ICD patients' lives, one should take into consideration the kind of support they are getting from those around them as they broaden

and adjust their lifestyle activities judiciously. Knowledge and awareness of support-providers are just as important.

Giving Meaning to Living with Arrhythmia and an ICD

ICD patients objectified and accepted arrhythmia as a condition that inevitably required ICD implantation as they recognized changes in their lives and faced themselves. Patients with chronic disease not only adjust their lifestyle activities but also engage in internal adjustments called *reknitting*, which involve their personal life histories (10). We believe that for ICD patients, discovering the positive meaning of living with ICD was precisely this act of *reknitting*. Through giving *their own* positive meaning to living with ICD, they came to terms with the illness and decided to deal with it in their own way. Having been through such an experience, they came to realize that they have to live with the illness; therefore, might as well get adapted. It is important to be supportive of ICD patients, find out how they perceive the illness and the changes it has brought about in their own lives, and what sort of positive meaning they have derived.

In conclusion, through this study it has been revealed that ICD patients' illness experience follows the course from being trapped in bewilderment stemming from arrhythmia and ICD implant to facing the reality of arrhythmia, the ICD, and being kept alive during post-implantation recuperation to giving the meaning to living with arrhythmia and an ICD and learning to live with arrhythmia and the ICD before reconstructing a new lifestyle.

LIMITATIONS AND FUTURE PROBLEMS

The results obtained from this study can be used to provide a perspective for comprehensive assessment of ICD patients receiving care and support for post-implantation adaptations. However, the subjects in this study were limited to one facility. To implement finding from this study for care and support of ICD patients considering individual illness experience, we plan to investigate other factors, such as background factors, in future studies.

ACKNOWLEDGMENTS

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