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The Long-Term Lived Experience of Patients with Implantable Cardioverter Defibrillators

Recent studies suggest implantable cardioverter defibrillators (ICDs) are the preferred treatment option for life-threatening arrhythmias. Nurses have a role in guiding ICD recipients and their families in the long-term management and care following device placement. The purpose of this investigation was to understand the long-term lived experiences of patients 1-2 years after ICD implantation.

In the United States, 350,000 deaths occur annually as a result of malignant ventricular arrhythmias. Implantable cardioverter defibrillators (ICDs) have become the preferred option to treat these arrhythmias for people of all ages, as opposed to anti-arrhythmic drug therapies (Ezekowitz, Armstrong, & McAllister, 2003). In studies comparing ICDs and anti-arrhythmic drugs, the use of ICDs was associated with improved quality of life as compared to medical management. However, research also suggests patients with ICDs experience anxiety and fear, and report avoidance behaviors, changes in lifestyle, concerns about intimate relationships, reduced income, and loss of independence (Carroll & Hamilton, 2005; Lemon, Edelman, & Kirkness, 2004; Steinke, Gill-Hopple, Valdez, & Wooster, 2005; van Ittersum et al., 2003). While these recent studies have begun to explore the untoward consequences of ICD use, little is known about the long-term experiences of individuals who undergo ICD placement. This study utilized a phenomenologic approach to understand the lived experiences of patients who had an ICD for 1-2 years.

Literature Review

Multi-centered clinical trials were initiated to determine the effectiveness of ICD compared to drug therapy in preventing fatal arrhythmias. These included The Antiarrhythmic Versus Implantable Defibrillators (AVID), Canadian Implantable Defibrillator Study, and the Cardiac Arrest Study Hamburg (Ezekowitz et al., 2003). These large studies found the ICD was effective in decreasing mortality rates in patients enrolled in the studies, particularly in those patients with ejection fractions of less than 35% (AVID Investigators, 1997; Connolly et al., 2000; Kuck, Cappato, Siebels, & Ruppel, 2000). In some early clinical trials on ICDs, mortality rather than quality of life was the primary concern in deciding which treatment should be implemented. As a result of the lower mortality or improved survival in these studies, the use of ICDs to treat and prevent fatal arrhythmias increased. Subjects, especially those who experienced ICD shock, had variable responses including poor quality of life, increased anxiety, decreased well-being, and diminished physical functioning (Carroll & Hamilton, 2005; Shea, 2004).

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Note: This article was funded by Alpha Chi and Eta Tau Chapters of Sigma Theta Tau International, and the American Association of Critical Care Nurses.

The long-term effects of ICDs on quality of life are not well understood despite the potentially large impact on lifestyle, such as driving, occupation, recreational activities, relationships, and sexual concerns, that are recognized as possibly affected as a result of ICD placement and firing. Clinicians who care for patients with ICDs realize more knowledge is needed about affected patients, including their gender, age, activity restrictions, psychosocial factors, support systems, learning styles, and end-of-life care (Carroll & Hamilton, 2005; Goldstein, Lampert, Bradley, Lynn, & Krumholz, 2004; Nambisan & Chao, 2004; Shea, 2004; Walker et al., 2004). While some recent efforts examined quality of life with an ICD, Draper (2005) suggested this term is too variable and therefore does not contribute to an understanding of how better to care for the involved person. Instead, the broader patient experience related to the ICD needs to be understood to allow nurses to appreciate the patient experience and thus plan and advocate for care.

Methodology

The purpose of this investigation was to understand the lived experiences of patients 1-2 years after ICD implantation. Van Manen's (1990) hermeneutic, phenomenologic method guided this study. This interpretative inquiry focuses on the actual lived experience of each patient and not generalizations, theories, or opinions that may exist or be imposed on the individual. This method allows each patient to share his or her experience as it is perceived without scripted questions or judgment, with the story unfolding uniquely for each person. In analyzing the data, the researcher captures the essences of the experience through themes as they arise from each subject's story. In this type of hermeneutic phenomenologic inquiry, themes are developed in a two-step process that occurs first within each case and then across all cases with interpretation of overall meaning.

The assumptions for this inquiry are that the researcher is open to and focused on the

patient's experiences surrounding the event of receiving an ICD; will read, re-read, and reflect on the essential themes as they are discovered in the data; will keep field notes to reflect on the overall inquiry and process; and will highlight, write, and rewrite examples that characterize the experience as well as ones that are unique. For the patients, the assumption is they will share openly their reflections related to the experience of receiving an ICD.

Sample

After institutional review board approval from the hospital in which this study took place, the researcher contacted each participant by telephone and read the hospital-approved consent form, reviewed any questions, and obtained verbal informed consent/assent. Participants were recruited from a large medical center in the northeastern United States, where approximately 320 patients undergo ICD implants annually in an electrophysiology cardiovascular center. ICD recipients receive follow-up care from the cardiologist at 6-month intervals, and quarterly either in person or over the phone from a nurse who specializes in patient monitoring following ICD placement. The nursing care involves an overall review of device functioning as well as an opportunity to address patient questions and concerns.

Fourteen participants (eight men, six women) were purposively recruited for this study. Inclusion criteria included having had an ICD in place for at least 1 year, being able to speak English, being willing to speak about their experience by phone, being willing to have the conversation recorded, and being over age 18. Participants ages 21-84 were recruited to the study. Within the sample, four participants had the ICD placed for a primary indicator and 10 for a secondary indicator. A primary indicator is the prevention of a first life-threatening arrhythmia, while a secondary indicator means the recipient has survived sudden cardiac death and the ICD was placed to prevent a subsequent fatal arrhythmia (Ezekowitz et al., 2003).

Confidentiality was assured by coding of all data to de-identify participants and using pseudonyms to identify participants. The interviews were conducted via the telephone at participant convenience. To ascertain the experience of living with an ICD, implant participants were asked, "What has it been like for you to have an implantable cardioverter defibrillator in place?" Follow-up questions were kept broad and were based on individual participant's responses. Participants often responded to this first question by asking, "Where should I begin?" or "Can I tell you what was going on in my life just before I needed the ICD?" They were encouraged to convey their stories from whatever time they felt would be most meaningful.

Setting

All interviews were conducted via telephone at a time that was mutually convenient for the participant and researcher. All the participants chose to be interviewed from their homes. A miniature recording device was utilized to capture all conversations. While the device recorded conversations well, two of the tapes did not maintain their quality; this made it difficult for the researcher to listen repeatedly to the recorded conversations on those tapes. In these two cases, observation notes kept by the researcher during the interviews had to be the primary source of data.

Data Analysis

All interviews were conducted by telephone and recorded. They lasted 20-70 minutes with the average interview lasting 55 minutes. Although initial saturation occurred after 10 interviews, the researcher sampled four more participants from multiple age groups due to variations that began to emerge related to age. The researcher transcribed all data verbatim, and thematic analysis was completed according to Van Manen's phenomenologic approach method (1990).

Initial analysis included reading through each transcript and reflecting on individual stories. This was followed by a period of

Table 1.
Demographic Characteristics of Participants (N=14)

Gender	Males (n=8)
	Females (n=6)
Age	Range 21-84
	Median 58.5
	Mean 55.7
Education	High school diploma (n=4)
	Completed college (n=7)
	Graduate-level degree (n= 3)
Marital status	Married (n=9)
	Single (n=3)
	Divorced (n=1)
	Widowed (n=1)
Employment	Full-time (n=9)
	Part-time (n=1)
	Retired/disabled (n=4)
Experienced ICD shock in first 12 months after placement	Yes (n=6)
	No (n=8)
ICD replaced	Yes (n=2)
New York Heart Association Classification	I (n=9)
	II (n=3)
	III (n=1)
	IV (n=1)
Ejection fraction (percentage)	Mean 35.45%
	Median 33%
	Range 10%-68%
Etiology of disease	Ischemic coronary artery disease (n=2)
	Heart failure (n=3)
	Genetic/idiopathic (n=5)
	Other (n=3)
	Dysplasia (n=1)
ICD placed for primary indicator	4
ICD placed to prevent secondary event	10

listening to each tape for voice inflection, tone, emotions, mood, and pauses. Once all transcriptions had been read and tapes reviewed, the researcher underwent a period of reflection and then began a process that involved writing and rewriting individual stories several times to capture the essence of individual experiences, including overall mood and shifts in emotions. Themes were derived through this writing process.

Once all themes were developed within each of the cases, the second part of the process involved a period of data reflection and a total re-reading of the transcripts to isolate themes across all cases. In addition, the researcher kept field notes during and after interviews with the participants and included these in the interpretations. These field notes tracked consistencies and discrepancies in the stories, as well as ease and flow of conversation.

Van Manen (1990) suggested people should be able to relate to phenomenologic description as an experience they could have had in their lives. This indicates the trustworthiness or credibility of the data. Trustworthiness of the data for this study was achieved by the researcher's use of reflection and through member checking by clinical experts to determine if the themes matched their experiences in caring for patients with ICDs. The experts included a clinical nurse specialist and a clinical educator, both with over 20 years' cardiac nursing experience.

Creswell (1998) suggested there are several ways to achieve rigor in qualitative research, and at least two should be operationalized. Peer debriefing, member checking, an audit trail, and a reflective journal were used to achieve trustworthiness in the current study. Peer debriefing was achieved by sharing the findings with two expert cardiology nurses who confirmed findings were consistent with their patients' experiences. Member checking was completed with participants on an ongoing basis. Throughout the research process, a reflective journal was kept to record researcher observations and notes (see the discussion of methodology for identified use of the audit trail).

Findings

Five themes were realized after analysis of the 14 stories describing living with an ICD for 1-2 years. These themes capture the essence of the experience for participants, but variation also is described as it arose.

Theme 1: Appreciation versus apprehension. Participants consistently described the ICD as a life-saving device that potentially prevented them from sudden death. They expressed gratitude that such technology existed in their lifetimes, recognizing only years earlier such an option was not even available. All participants expressed some fear and concerns about the device, but reasons for these emotions differed based on whether the ICD had shocked the patient.

All patients who received a

shock from the ICD (n=6) expressed anxiety about the following: when the device may shock again, potential loss of independence, embarrassment over the reaction of others when the device shocked, and fear about routine activities that may trigger the ICD. For example, one person who had a cardiac event while swimming prior to the ICD placement was afraid showering or swimming might somehow trigger the ICD to shock. She reported being fearful in the shower, and she avoided the beach and pools. Another participant, who was an automobile mechanic, described being fearful while working on cars because an event prior to the ICD placement had occurred when he was working on a car. These fears were present irrespective of educational level, living arrangement, or employment, but they were more evident in younger participants ages 20s-40s (n=3). The fear in younger participants seemed to correlate with a concern about loss of independence because of restrictions that may be placed on them as a result of the shock and/or a concern that at a certain point the shocks themselves may cause further debilitation. Those who had received a shock, however, also expressed relief the device worked. Because the ICD worked, many doubts were erased regarding the need for the device. As one person noted:

I am so lucky to be able to have something like this. I mean, it has saved my life, but I am always worried, you know, that it will shock. How will I act? How will others respond? It is always on my mind...it can shock at any time.

Those who had not experienced shock expressed a different type of anxiety, including doubt about if they really needed the device and if it would work. One of two persons who had not experienced shock described his feelings in this way:

You know, it is like a blessing and a curse. I am lucky to be alive when a technology like this exists. You know? I mean, my dad just dies suddenly of this same thing. There was

nothing like this, so it's a blessing. But the curse is knowing it's there. It makes me nervous to think about it. Will it fire? When? How will I react? How will people with me react? Will it hurt? I mean, those things are always running through my head. I cannot pretend it's not there.

Theme 2: Maintaining structure and routine as a way of maintaining a sense of self. Many participants described a strong need to maintain routines, often manifested as superstition. Participants described getting out of bed at the same time in the same way, showering at the same time with water at the same temperature, and being afraid to alter any typical morning routine, such as making coffee before cooking something for breakfast. Participants described having a "lucky routine," and variations from this were unsettling. One participant who wanted to maintain his pre-ICD routine and was fearful of abandoning it described this feeling:

You know, when I first got it, I just ignored it. I did not want it to deter me. I call that phase one – just pretended nothing had changed. Before I got the ICD, I was really driven, worked 14-hour days 7 days a week...and so I did that at first, pretended nothing had changed, same routines, same job and I was tired, real tired, but I thought if I ignored it everything would be okay.

Further, participants consistently indicated the routines they established allowed them enough independence from family to be free to go where they chose when they chose. They developed very structured days in which they went to the same shops, stopped at the same coffee shop, and ate in places they were "known" to see people they knew, even if only as acquaintances. They described waiters and grocery clerks whom they only knew very casually as the people who would "expect to see them" in the course of the day and would "wonder what happened" if they did not arrive on any given day. Participants seemed to develop this routine in reaction to and as a way of intercepting fam-

ily members' need to interfere and control, while at the same time reassuring family that someone was checking on them. Participants preferred people who were casual connections to notice if they did not go to the coffee shop or grocery store, for example; this helped maintain a sense of self while not allowing family to hover. While participants believed they had to keep a very rigid routine, they described being annoyed with a family member who "is always checking on me and telling me what to do or what not to do." One participant described:

My sons are always hanging around to check on me and it drives me nuts. I was independent before this and I am determined to be now, so if I tell them I am seeing my friends at the shop, they think at least someone is checking in on me and stop bugging me. They don't know the clerk doesn't really even know me, but I tell you, I think she'd notice if she did not see me for a few days.

Theme 3: Isolation and vulnerability. Each participant described in a different way a desire to be in touch with other people who had the same procedure. However, they also consistently expressed a lack of desire to be part of a support group because they would have to attend and viewed the meetings as something for people who just want to complain. Three participants utilized on-line chat rooms to connect with other people who had an ICD. One participant noted, "At first I was, like, is there anybody out there? And then I found the Web to be a helpful way to talk to people." Another participant who did not have Internet access said, "I am feeling a little vulnerable and there is no one who understands it." Overall, participants described a need to make connections with others but remain anonymous while doing so. They described a need to talk about new routines and fears, and to ask questions, but "without sounding like I'm a nut." One thing they liked about the follow-up visits to have the ICD checked, despite the time required to get to

the appointments, was that they believed they could ask some questions of the nurse; they also described a need to be able to do this in between visits. Further, they described the nurse as being very matter-of-fact so “you sort of don’t care what she thinks of you.” Participants described being overwhelmed by a sense of isolation from friends and family, but also identified a need to be independent and self-sufficient. These contradictory feelings appear to be related to a need to maintain self-respect, as if the sudden cardiac episode caused participants to feel less dignified. They reacted to this by pushing away people who were close while seeking help from strangers or people who were more distant toward them.

Theme 4: Being abandoned and still grieving. Most of the participants in this study described experiencing a significant loss during the time of the sudden cardiac event. Several of them spontaneously revealed this during the first few interviews. As more participants enrolled, this became a predominant part of their stories. Participants were asked specifically about major events in their lives around the time they became ill. Of the 14 participants, 13 described a significant loss, often in terms such as, “It was a heartbreak,” “It just broke my heart,” or “I was heartbroken.” Participants discussed specific losses, such as a son’s suicide, a mother’s commitment for behavioral health care, a husband’s sudden and unexpected death, and another spouse’s death from a motor vehicle accident. Participants described the person with whom they lost a connection as being the most important person in their lives, which may explain some of their resistance to accepting help from people after ICD placement and their sense of isolation. When participants described themselves as “heartbroken,” the word choice did not seem obviously linked to their situations; this was noted through questions such as, “Did you notice the words you chose to describe this loss?” When this was identified, participants responded matter-of-factly. A typical response

was, “Well, a part of me did die that day, so it makes sense I would say that. I guess it literally did break my heart.”

While participants continued to grieve the loss, others who were close to them often did not recognize this, at least not that the participants noticed. Participants who described a loss also said it was difficult to connect strongly with other people; some of them even realized they feared losing another person so they avoided making connections. Others seemed to avoid getting close to other people to protect them from the hurt they had experienced. The participant whose mother was committed for behavioral health care talked about nearly drowning due to a sudden cardiac event while swimming with her brother, who pulled her from the water and saved her life.

He’s my younger brother and I have to be strong for him. Everyone else (in my family) is so messed up. My brother, though, he knows how it just broke me apart to have my mother committed. I have to protect him, though. So I don’t let on anything that worries me. The last thing I want is for him to be worrying about whether he will lose me. So I always act like, yeah, I can do anything. I’m fine. Sort of like I don’t need him, you know? But I do.

Theme 5: Seeking advice, making decisions. Participants had many unanswered questions and utilized the interview as an opportunity to raise them. One factor that seemed to contribute to participants’ ease in asking questions was being involved in a research study. They indicated their participation in a research study in which their opinions about care were sought provided them an opportunity to be equal partners in care. They contrasted this experience with the more typically hierarchical system of health care in which patients are recipients of care but not active participants. Participants in this study indicated they were not passive receivers of care, but rather people who were able to provide the health care team with a personal account of living with an ICD.

Through this process, they believed they were able to give a voice to other patients with ICDs. As a result of participating in research, they felt less judged by the health care team and indicated a belief they were being treated equally in a give-and-take relationship. This factor seemed to increase their comfort in asking a wide variety of questions.

Another contributor to their increased comfort was the sense of being heard. Many participants described the experience as the “first time someone asked me what it was really like for me.” Participants wanted to share their stories about not only getting an ICD and life with the ICD, but also events prior to the ICD and other important events in their lives. In the process, participants described “wanting to be heard” and wanting to know if there “was anyone out there like me.” Further, participants indicated they enjoyed talking “with and not to,” which addresses mutuality in the dialogue. As one participant noted, “I like talking with you because it is just like a conversation back and forth.” This may address further the idea of removing hierarchical barriers, as well as anonymity. As a nurse with knowledge of but no direct involvement in the care of the participants, the researcher found it hard to know if candid discussion made people feel more comfortable. Participants were asked about this specifically and several suggested the time to do this was not available in the structure of the current care environment. Several participants reported that they were “looking for this.” One gentleman stated:

It’s not like you can ask these questions to her (the nurse responsible for follow-up testing of the ICD). She is there to test the device and she can’t be stopping to answer my questions. She’s not like that.

Participants’ questions had important implications for decision making in their care. Some described questions about sexual function and expressed fear about shocking a partner during intercourse. Others described choosing to drive despite having experi-

enced a shock because not driving would mean loss of employment. They wanted to know the implications of driving despite knowing they should not: what would happen to them and what would be their legal liability? Other participants described having an altered memory as a result of the original cardiac event and wanted to know how long this would last or if it was typical.

Another concern many participants expressed was a lack of involvement in discussing their care management. They described moving from the “haze of sudden death to just doing what I am told will save my life.” This process included their tests for and decisions to receive an ICD, although they indicated not “really remembering too well.” Although most described not believing there were many alternatives or knowing the alternatives may not have been desirable, they expressed concerns about their inability to remember being involved in the decision. They also feared potential future events and not being included in the decision making process at that time. This concern seemed to be focused around palliative care and was raised despite age or other comorbid conditions. One younger participant commented:

Well, I'm just wondering and these are the things no one talks about, but what if I was to get in a car accident and I was really dead, but now because of this (the ICD), I would just keep getting shocked. And no one would want to turn it off because I'm young, but I'm dead so why wouldn't they? And then they would say I had never said I wanted that, but no one ever asked. It just terrifies me to think about it because I know what the shock feels like and it's painful. So here I'd be trying to die and this thing would keep shocking me and making it an awful, just awful, painful death, but no one asks me what would you want if and I feel like if I bring it up, they'll tell me I'm just being anxious. Well, of course I am. I already died once and I know what that is like. That is not the

part I am afraid of; it's more the way people are so afraid of everything with me now and they won't talk about the possibility.

Strengths and Limitations of the Study

Strengths of the study include participants' willingness to share openly by a recorded telephone conversation about their experiences of living with ICDs. One limitation of this study is that the sample was purposeful and findings may reflect only the concerns people wanted to share about the ICDs. Although each participant's story is considered unique in qualitative research and there is no goal to generalize results, findings are considered more trustworthy or credible if they are transferrable to other ICD recipients (Creswell, 1998). This means persons with the same experience would find the results resonated with them. This could be achieved by verifying findings with other patients. The results of this study have not been shared with other patients who have undergone placement of ICDs, and this presents another limitation of the study findings.

Discussion and Implications

Participants shared similar fears related to shocking by the ICD. While some worried that it may not work when needed, others worried about where and when the shock would occur as well as the reactions of others. All generally feared a loss of independence and felt some degree of anxiety from others who were close to them. This sense of loss was unrelated to age, gender, employment status, or living/marital situation. Other concerns around sexual relationships, driving, and avoidance of activities they feared would trigger a shock were reported and are consistent with findings from other studies of ICD recipients (Carroll & Hamilton, 2005; Kuhl, Dixit, Walker, Conti, & Sears, 2006; Lemon et al., 2004; Steinke, 2005; van Ittersum et al., 2003).

Concerns related to follow-up care are particularly relevant to nurses. Most participants reported having questions but perceiving no

one to ask, being alone, and feeling somewhat abandoned by the care team. These concerns are in the purview of nurses, but participants did not view nurses as the providers who would or could address them. Participants generally viewed nurses as technical experts rather than advocates, listeners, and advisors. This finding is supported by the work of Tagney (2004), who found cardiology nurses did not feel competent to provide discharge teaching related to ICDs. Shea (2004) suggested nurses have a pivotal role in patient/family-centered care by providing teaching and support, and recognizing some patients may benefit from support groups and/or counseling.

Several participants described events prior to and concurrent with recovery from the ICD placement that may have warranted further follow up. However, most reported being a participant in the study allowed them to feel “listened to” and “supported” by being able to talk about the overall experience and the impact it had on their lives. Most described feeling normalized by being able to discuss their experience with a researcher who was knowledgeable about their experience yet not involved in their direct care. The ability to discuss concerns over the telephone allowed them to verbalize issues in a way that seemed anonymous and safe.

Recent advances in ICD technology also have implications for follow-up care, including ICD monitoring by telephone. While this type of follow-up care is clearly convenient, it detracts from direct care and time spent with provider teams knowledgeable about ICDs in general and the specific patient and his or her medical history. Guidelines released by the American College of Cardiology, the American Heart Association, and the Heart Rhythm Society (Epstein et al., 2008) suggested a need for follow up that includes technological checking related to the ICD functioning in conjunction with long-term follow up to address a patient's personal needs, up to and including end-of-life decision making related to the ICD.

Comprehensive follow up by care teams prepared to address the technical, physical, and emotional components of having an ICD is essential. Results of this study support the need for nurses to follow patients over time to address questions about sexual relationships, general fears, healing, and decision making, especially related to end-of-life care (e.g., turning off the ICD).

Farrell, Towle, and Godolphin (2006) reported the health care team is dependent upon the patient's voice in the delivery of health care, and providers and patients together can make shared decisions. Because many of the participants were critically ill at the time they received ICDs, however, they did not remember being involved in the decision-making process. This lack of ability to be involved in decision making at such a critical time may have been appropriate in the immediate critical phase but as they recovered from the event, participants expressed a desire to discuss options related to the ICD. Because they had already experienced death, participants indicated they wanted to discuss when and under what circumstances their ICDs should be turned off, including accidental death or worsening chronic illness. They feared the possibility of being continuously shocked while being otherwise clinically dead. The palliative care literature addresses this issue and suggests providers should have ongoing conversations with patients about the possibility of turning off the ICD when overall health declines (Goldstein et al., 2004; Nambisan & Chao, 2004; Sears et al., 2006). The ongoing fear of accidental death is a concern that is not explored. For example, a younger participant reported concern about being in an automobile accident and otherwise dead, but continuously shocked, alone, and in pain. This finding suggests further studies in this area are warranted. A need also exists for ongoing support by nurses to facilitate healing and provide patients with the opportunity discuss fears.

Conclusion

Nurses have a mission to be authentic, present, and caring advocates (Grace, 2001). Restructuring the care environment in a way that allows patients to process the entirety of their experiences, especially those that are traumatic and life-threatening, may allow patients to experience healing. Further, nurses should be a part of and develop comprehensive care management teams for patients undergoing ICD placement and encourage patients to share their concerns, re-evaluate their lives, and be partners in a decision-making process. Without nurses' involvement, ICD recipients could have prolonged anxiety and fear. ■

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