Redefining Life While Forestalling Death: Living With an Implantable Cardioverter Defibrillator After a Sudden Cardiac Death Experience

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Secondary analysis is a resourceful approach for making further use of existing data sets to answer questions not previously addressed or to expand on content not specifically examined in the original study. Using Heideggerian hermeneutics, the author analyzed transcripts of the stories of individuals with implantable cardioverter defibrillators (ICD) from three of her earlier phenomenological studies to obtain a description of the experience of living with an ICD after a sudden cardiac death experience. Three related themes emerged: (a) losing control: technology as lifesaving yet changing everything; (b) getting on with living: regaining control or conditional acceptance; and (c) creating a new vision: transformation or tentative truce. The constituent pattern was redefining life while forestalling death.

I am their bionic friend.” Through this statement, a woman portrays a self-view that was altered after receiving an implantable cardioverter defibrillator (ICD). The ICD is a lifesaving device that protects individuals at high risk for recurring fatal arrhythmias. Sudden cardiac death (SCD) is a major health problem in the United States, accounting for 225,000 deaths each year (American Heart Association [AHA], 2000). The technological development of the ICD continues to expand the potential for sustaining life through technology. From 1985 through 1996, more than 120,000 ICDs were implanted worldwide. 31,000 in 1997 alone (AHA, 2000). Therefore, support of patients with ICDs is an ongoing concern for health care providers. There is a need to understand the individuals’ common meanings and shared experiences and practices of ICD technology as it is lived. The purpose of this study, therefore, is to describe the experience of living with an ICD after SCD; the method used is secondary analysis of the transcripts of individuals’ stories about help seeking.

LITERATURE REVIEW

Researchers have found difficulties in adaptation after ICD implantation for both the patients and their families. The incidence of anger and anxiety is higher in the ICD population than in either the general population or other ill populations (Vlay, Olson, Frisch, & Friedmann, 1989). Hegel, Groedel, Black, Goulden, and Ozahowski (1997) performed a longitudinal study on 38 ICD patients and found
that 30% reported clinically significant anxiety that persisted over time. People with ICDs can develop severe anxiety that focuses on fear of inappropriate shocks (Burgess, Quigley, Moran, Sutton, & Goodman, 1997) or fear of future shocks and depression (Bourke, Turkington, Thomas, McComb, & Tynan, 1997; Dougherty, 1994; Heller, Ormont, Lidagoster, Scicca, & Steinberg, 1998). Dunbar, Warner, and Purcell (1997) described the experiences of 22 patients after device discharge and reported that fear was associated with the lack of warning prior to device discharge and with the intensity of multiple shocks. Patients also fear death, ICD malfunction, and loss of control, and these fears often lead to decreased physical activity, which in one study was related to low self-efficacy, a greater number of symptoms, and lower ejection fractions (Schuster, Phillips, Dillon, & Tomich, 1998).

James (1997, 1999) concurred that the fear and uncertainty associated with living with an ICD is related to its unpredictability and to the fear of device malfunction. Dunbar, Jenkins, Hawthorne, and Porter (1996) reported greater distress, greater perceived threat, and evasive coping strategies in ICD patients with pessimistic personalities, and they suggested cognitive therapy (Dunbar & Bannister, 1997) to reduce fear and improve psychological outcomes. In a longitudinal study of the first 3 months after ICD implant, Dunbar et al. (1999) concluded that patients’ symptoms, level of cardiac function, perceived illness appraisal, and coping behavior affect the recovery outcomes of functional and mood disturbances. The outcomes of ICD recipients continue to be studied.

In addition to fear, ICD patients have identified physical concerns, including the sensation of being shocked, having to take medications with side effects, and difficulty sleeping. Psychological concerns are fear, including fear of driving; changes in mental functioning; changes in lifestyle; loss of control, and spousal overprotectiveness (Doolittle & Suave, 1995; Sneed & Finch, 1992). Craney, Mandie, Munro, and Rankin (1997) found that young and less emotional ICD recipients had better physical functioning, but the majority (74%) of respondents experienced psychological distress and poor social and domestic adaptation.

Although these studies identified fears and concerns, few qualitative studies have described the personal experience of living with an ICD. Using a grounded theory approach, Burke (1992) described the experience of 24 patients during the first 6 months after implantation and found that once the individuals became aware of the need to secure life through technology and chose to have an ICD implanted, they began a process of integrating this technology, often through the use of social supports and by learning from other people with ICDs. They began to reconcile their quality of life and attempted to minimize negative aspects.

ICDs have been implanted since the late 1980s, and many individuals have lived with these devices for many years. During subsequent episodes of therapeutic firings, they continue to need support, which is a concern for health care providers. There is a need to understand the long-term experiences of these individuals from a personal perspective.

Furthermore, obtaining a deeper understanding from a Heideggerian perspective of the ongoing experiences of individuals with ICDs would help us uncover presuppositions about what constitutes the possibility of meaning of living with an ICD. Hermeneutic analysis is based on the understanding that people's interactions can be interpreted through their use of language and can be used to illuminate people's experiences or modes of being in the world (Dickelmann & Ironside, 1998).
This provides rich data for exploration of the human condition in our changing reality. Understandings and possibilities are the outcomes of interpretations, which are linked to cultural norms (Plager, 1994). My goal, therefore, is to reveal common meanings and shared practices in the experiences of individuals with ICDs.

RESEARCH DESIGN

Textual data from my three earlier studies were examined using the interpretive phenomenological approach of Heideggerian hermeneutics, a method rooted in the understanding that humans comprehend and operate contextually within a set of historical and temporal relationships that are rendered explicit by interpretation through language. Heidegger (1927/1962) explained that through a hermeneutical process, one can systematically interpret and bring to light the meaning of people's experience: "Discourse is the meaningful articulation of the understandable structure of being-in-the-world" (p. 204). Through the interpretation of the narrative stories of individuals, we as researchers can be involved in and understand their everyday lives and thus attain background understandings of the individuals' practical knowledge of their world. From this background, possibilities and potentialities that are part of our culture and society emerge. This understanding of what is possible allows us to be engaged in the participants' practical world, a world that is usually unarticulated (Plager, 1994).

Thus, the purpose of a Heideggerian hermeneutical study is not to predict but to understand the contextual meaning of a situation. For that reason, the study begins with the consideration of the practical activity of living with an ICD in these individuals' everyday lives. All the texts from the three previous studies, which we want to make sense of, have meanings that are expressed in everyday practices and are significant for those with an ICD.

This holistic approach considers the temporality, contextuality, possibilities, and potentialities that are very different from the Cartesian subject-object view. Thus, this study revealed what was important for individuals with an ICD, their issues, concerns, and understanding (Plager, 1994). The natural science model, which relies on exact measurement and precise representation of scientific phenomena, is valuable for looking at phenomena from a detached, objective standpoint. However, objectifying and reducing phenomena to cause-and-effect modeling cannot account for everyday human experiences, which are historical and temporal, based on participating in language and cultural practices (Benner, 1985). Hermeneutics enables researchers to move beyond traditional logic structures with the goal of revealing and explicating otherwise hidden relationships and meanings (Diekelmann & Ironside, 1998).

This practical knowledge is important for us to bring about new ways of understanding the lives of individuals living with ICDs. Recurring themes or common knowledge identified by hermeneutical studies embody the practical knowledge or wisdom that is familiar to the individuals with an ICD. By reflecting on their experiences, the investigator can identify the issues and problems, as they are best understood in that particular context. Thus, through hermeneutic inquiry, we are able to describe the experience of living with ICDs after an SCD experience.
Secondary analysis is a resourceful approach for making further use of an existing data set to answer questions not previously addressed or to expand on content that was not specifically examined in the original study (Hinds, Vogel, & Clarke-Steffen, 1997; McArt & McDougall, 1985; Szabo & Strang, 1997; Thorne, 1994). Because I was the primary investigator in the previous studies, I understood their contexts. Researcher bias was reduced by careful attention to the text, the use of a team approach for analysis, and the verification of findings with a group of individuals with similar experiences and a clinical expert in ICDs. The secondary analysis study proposal, which included the three sources of data, was approved by the Health Science Institutional Review Board (IRB) at the university. The original consent forms approved by the IRB had contained provisions for continuing analysis. The secondary analysis was also bound by the confidentiality measures outlined in the primary analysis. These three data sources were used because the narratives all reflected personal experiences of living with an ICD.

Data from the first study (Dickerson, Poslusny, & Kennedy, 2000) included individual and focus group interviews, which were stories of help seeking in a face-to-face support group. The support group members were asked to tell stories about living with an ICD and to explain how the support group helped. The details of the personal experiences of living with an ICD were not fully interpreted in the first study because the focus of that analysis was on the experience of seeking help. The texts included were excerpts of the experiences from seven individual interviews and two focus groups of 3 and 5 participants. The experiences of support persons were omitted. In this data source, the investigator established a dialogue with the patients with ICDs. The dialogue, which occurred through conversations (individual interviews or focus groups), became the narrative stories that constituted the text for analysis.

The second data source was electronic bulletin board (EBB) postings from a cardiac site for ICD recipients from a study on help seeking on the Internet (Dickerson, Flagg, & Kennedy, 2000). Initial IRB approval was obtained to collect data through the public domain, with measures taken to protect the identities of those using the public EBB. More than half the responses were anonymous. Of the 369 postings gathered over 15 months, 49 included descriptions of experiences with ICDs. These stories of personal experience with an ICD were often the introductions to postings and served to set a common ground for the communications. These descriptions were the focus of the analysis. The dialogue took place among individuals who have an ICD and who communicated their experiences to each other on the EBB. The initial study focused on the interactions between participants.

The third data source was an outcome study (Dickerson, Wu, Kennedy, Nahigian, & Shipkey, 2000) consisting of written comments attached to a quality-of-life survey sent to individuals who received an ICD at a local medical center. Of the 112 surveys returned, 27 had written narratives. This source involved the individuals' written communications to the researchers. The question stated, "Is there anything you would like us to know about your experience?" This opening question gave the participants an opportunity to tell their stories. In these written comments or narratives, they explained their experiences and personal thoughts about living with an ICD, and these provided the texts for analysis.

All the texts expressed stories of living with an ICD. Of the individuals who told their stories, 18 were female, 41 were male, and for 3 we did not know the gender.
The average age was 57.8 years, and the age range was 40 to 76, with the younger informants being predominantly female. The amount of time since ICD implantation ranged from 1 month to 9 years, with an average of 3.24 years. Seventy-five percent of the individuals had some experience with a support group either online or face-to-face. Thirty-two (51.5%) of the informants reported an SCD experience, 10 (16%) reported experiences with lethal arrhythmias, and the remaining did not describe any SCD events. Thirty-one percent of the individuals had no firings, 15% had one, and 38% had more than one. The missing data were due to the anonymity inherent in the Internet postings (Dickerson, Flaig, et al., 2000).

METHOD

Texts were interpreted by the seven-stage hermeneutical process described below (Diekelmann, Allen, & Tanner, 1989; Diekelmann & Ironside, 1998).

Stage 1 involved each member of the research team examining the three text sources as a whole to gain an overall understanding of the text. The team consisted of the principal investigator and two researchers with master's degrees trained in qualitative research techniques. At Stage 2, each researcher wrote an interpretive summary that described the possible common meanings of the texts, with excerpts from the text to support their interpretation. These summaries were discussed at weekly meetings to reach consensus. In Stage 3, the principal investigator and the team compared their individual interpretations at weekly meetings. Further clarification of interpretations was reached by returning to the original text. During Stage 4, we reread all texts to uncover common meanings and their relational themes, which link common meanings between the texts. At Stage 5, the researchers described a constitutive pattern that showed the relationship between relational themes across all texts. In Stage 6, the themes were validated by a group of individuals with an ICD, some of whom were participants in the initial studies, and a clinical expert who worked with individuals with an ICD. Finally, at Stage 7, the principal investigator produced a final summary report, which represented the current understanding of living with an ICD after an SCD experience and used quotes that allowed for validation by the reader. The multiple levels of interpretation served to expose conflicts and inconsistencies in the analysis and to eliminate unsubstantiated meanings. Although there is no single correct interpretation, continuous examination of the whole and the parts of the text with constant reference to the text ensured that interpretations were grounded and focused (Diekelmann & Ironside, 1998).

FINDINGS

From thematic analysis of texts from 85 discourses of 62 individuals with an ICD, three relational themes and one constitutive pattern emerged from the data to explain living with an ICD after an SCD experience. The themes were (a) losing control: technology as lifesaving yet changing everything; (b) getting on with living: regaining control or conditional acceptance; and (c) creating a new vision: transformation or tenuous truce. The constitutive pattern was redefining life while forestalling death.
Theme 1. Losing Control: Technology as Lifesaving yet Changing Everything

For the participants, the initial experience of discovering their inclination toward recurrent fatal arrhythmias was often unexpected and brought with it a profound realization that their lives had suddenly changed. They were forced to consider the possibility of their own death, and with that realization came a feeling of losing control. Many discourses began with a description of an SCD experience or the discovery of recurring ventricular arrhythmia, in which the individual’s described facing their own mortality and feeling “very vulnerable and fragile.” The situation became a source of anxiety; one informant described being “scared as hell” as the fear of death became more of a reality, and the experience became “very sobering.” One participant related these feelings after his cardiac arrest:

I was so fragile, I woke up, my impression was something’s going wrong real fast because I saw the paddles and that whole day really stuck with me. I was very depressed after I got out of the hospital; it really knocked the spokes out of me.

The participants’ sense of loss of control of their previous life was magnified when they first became immersed in the health care system because professionals often assumed that they should choose the use of technology (ICD) over death. An electronic device now regulated and controlled whether they lived or died. Health care workers believed that the use of wonderful technology such as the ICD saves lives, and many patients were “told to get it.” Patients were not offered a choice, as one said, “The doctor says, ‘Do you want to live or die?’ Its either black or white, not a lot of gray.” It was not acceptable not to want the device implanted (choose life) despite their unwillingness or fear of having their lives controlled by a machine. In this situation, death becomes a symptom to be treated, not a state of nonbeing. The participants were uncertain, were fearful of the alternative, and did not know what to expect; they were losing control and feeling powerless. As one person related,

I mentioned about a belief that some day you are going to go [die], and you have nothing to say or do; and when that time comes, you have no power within you to stop anything that’s going to happen, so you just kind of accept it. But it is always in the back of your head, you do have this and something can happen.

Once the device was implanted, the informants often described sensations of “knowing it was in there,” which was a constant reminder of their mortality. Initially, they felt this as mild physical discomfort or a sense of bulkiness. It was an invasive procedure that changed their sense of self. This was expressed in the statements “it’s a foreign object in my body, close to my heart” and “I need to get used to its presence.” Some thought of the ICD as becoming part of their body. One woman described her friend’s referring to her as “their bionic friend.” Some personalized the device, naming it “sparky,” “zapper,” “old boy,” or “my own paramedic.” Some told of how the device became a central focus of their thoughts, for example, “I am being controlled and regulated by a machine” and “I am waiting for it to fire.”

The presence of the device was not easily forgotten. It was a double-edged sword, one that they were glad to have but that they also feared (“It keeps me alive and keeps me in constant fear”). Many described these contradictory feelings as a
"love-hate" relationship with the device ("I would rather not need it, but rather not be without it"). Although it was described as a comfort and reassurance, there were also discomforts to be endured ("I am not glad to have the kicks, but I do accept them and I must and will endure them"). It was a protection, an insurance, but with "cruel and unusual punishments (firings)." One individual said,

It's actually comforting, I don't live with the fear that I'm going to drop somewhere and not have the help. It took a little bit of adjustments, the nervousness at first, what it's going to feel like with the firing and stuff, and then once I started having them, I learned that it wasn't the end of the world, that things were going to go on.

The firings are a reminder of the possibility of death. Often unexpected, they leave the person with "a sense of panic each time," as one informant put it. Another stated, "When I do experience a firing, that moment I have the fear but it subsides when everything's said and done, and I calm down and the heart's back to the regular beat." Over time, some develop a trust that the ICD will work to save them. The trust is arbitrary and related to their experiences. As one participant said, "Well, it's [ICD] there to save your life. It's going to save your life. And if it goes off, you know, it's working, and if you're still living after it goes off, it's working." The discomfort inherent in the firings is different for each person and treatment setting, varying from the sensation of "being kicked by a large mule" to a mild fluttering that is "not as bad as I thought." Initially, informants feared being alone due to the unexpected nature of the firings and were bothered by the question of "will it work" to save their lives. The illness and resultant device implant created a new sense of boundaries in their lives, changing the possibilities and making them rethink their normal routines.

Theme 2. Getting on With Living: Regaining Control or Conditional Acceptance

Over time, the individuals came to terms with the changes caused by the insertion of the ICD. They knew they must get on with the business of life and sought some type of normalcy. As one said, "I try to live a normal active life, I have too much living to do." They often began setting goals, living within boundaries, and managing the fears that go along with the possibility of SCD and firings. The main goal was to learn to live with and manage the fear of possible death, and individuals described different styles and techniques for doing so. Some found help by gathering meaningful information about what to expect, what is normal, and what to do, which helped them develop contingency plans for potential problems ("initially I needed information, and I was hungry for knowledge about the device, what to do and what to avoid"). Some gained this information from online and face-to-face support groups or from someone who has an ICD. One related, "I was depressed and frightened. And I overcame that, part of me overcame that, by going to the support group." This practical knowledge of dealing with the device was very meaningful to others "in the same shoes," with whom they felt a connection or sense of community. Group members had long discussions about activities of living, informing the rescue squad about the ICD, working restrictions, driving policies, avoiding exposure to electromagnetic fields, what to do if it fires, and what causes the firings so they can avoid them. One stated, "The support group helps me understand my
health concerns in a way that no Dr. Office or family contact has been able to do. ... A voice of experience can teach more than a book." Some individuals managed this fear and uncertainty by not attending to it or not thinking about it. "Putting it out of my head, not think about it and lead[ing] a full life." One informant stated, "You try to keep your mind off it. I keep myself busy. If [the ICD] works, it'll bring you back, if not, there's nothing you can do." Another one reasoned, "If you can do something about it then, then do it; if you can't then forget it. No sense worrying about it. Take a deep breath and let it go." Another said, "Now I do not think about it as much, it is a part of my life." Others were afraid to go out, to sleep, or to be alone. This fear can be paralyzing. Some informants shared their experiences of recognizing the fears of being alone. One stated,

I was at the point where I was depressed, frightened. I was afraid to be home alone; I totally refused to be home alone. Wouldn't take a shower if no one was home. I wouldn't do anything, you never lock the door, in fact, I still don't lock the door at least 911 [rescue squad] can get in.

It was a process that took time and sometimes required the informant to start over again, gaining some confidence in their abilities and learning to trust the device. As one put it, when the symptoms return, "I get it out of my head, until the next firing." However, with increasing frequency of firings, it becomes harder to regain a sense of normalcy.

Others manage the fear or the feeling of having lost control by giving it over to a higher being. They have faith that God will take care of them—after all, they survived the first SCD experience. As one participant said, "I think God is giving me a second chance." Some described their rescue as some sort of a miracle of timing:

My faith in God [helped me], I do believe that, when I was lying on the floor in my house, I could hear people talking, and they took me out with no pulse. My dog saved my life; if it wasn't for my dog alerting them, I would be gone.

Other aspects of their illness also had to be managed. Some dealt with memory loss associated with the arrest, describing, "I don't remember a thing. My memory is fogged. ... I lost two whole weeks before [the arrest]. I was at a wake, and I don't even remember her dying." The cognitive processing changes remained over time, and some reported that "I still have to write notes to remind myself."

They were concerned about how the ICD would affect others around them and their relationships with them. Some worried that others might view them as weak and unable to perform, which might in turn lead to overprotectiveness. As one informant said,

It has taken time for those around me to realize I can handle "stressful" scenarios ... They are always worried that my "heart" is not OK ... I think it is critical to educate others.

Others worried about harming others if a firing were to occur while they were driving. ONE informant related,

I have mixed emotions about driving—damn if you do and damn if you don't. I would terribly hate to cause injury to someone else as we all would—but I just can't
sit here at home and dry up on the vine. It's a matter of conscious and personal choice. God help us all in this.

Another reported,

I get a little nervous just in case something would happen. I don't know what to do. I would hate to injure somebody because you know you have a condition. So I just drive kind of on the slow side most of the time.

Living within the new boundaries in their lives promoted the participants' conditional acceptance of the need for the device, its restrictions, and the need to go forward and get on with living. This acceptance is on the condition that the device continues to work properly. They are always somewhat alert for problems, maintaining a vigilance that reafirms or discounts the trust in the technology. Even a battery change or change in the unit promotes vigilance: Will it work and fire appropriately? Some ponder, "Should I get it changed?" This consideration admits the possibility of choosing not to continue to live this way, which in turn opens a moral dilemma. If the battery is not replaced, is one choosing death? One individual described his situation with sad resignation: "It is just something I have to live with." He talked about his dream of retiring and playing golf; however, due to his disease, he was unable to fulfill this dream. The boundaries he faced did not allow an acceptable quality of life.

One individual reflected on what she would say to someone going through this:

I would say it is not as scary as it seems. If they are in doubt as to whether to do it, I would say, as fearful as they may have been for the reasons why they need it, the next time it happens, they might be dead. . . . If you want to give up on life just say no . . . . This isn't like a death sentence, to me it's not a matter of if they want to give up on life, it's a good way to do it. I've often said if I wanted to die, I wouldn't get it recharged, the next time they need it, it's not there, that's all.

Theme 3. Creating a New Vision: Transformation or Tenuous Truce

The individuals with an ICD learned over time to find some value in their newly defined life. They adjusted their thinking from the immediate distress about their mortality to the appreciation of more long-range issues. They learned to find value in their life as it is: "I am grateful for a second chance on life." One informant remarked,

I would think about the firings, and my stomach would get all knotted up, it would take quite a while before I would be more at ease talking about it, to me the firings were a real bad experience. I was just hoping I would never have to go through that again. Is this experience worth having a defibrillator? You know, but as time went by and I didn't have any more firings, and I felt better, but I still, I think about it, and I make myself think about something else, because to me it's a very frightening experience . . . . Then I had a new grandson, which was a surprise. So I really enjoyed him, so I think maybe, well, that's maybe why I was kept alive because, I don't know actually, I try to think actually, stare alive for him, enjoy him.
Others described a transformation of their worldview that changed from concern for everyday details to a deeper appreciation for life as it is lived. As one person related,

Discovering that life is short at the same time I have been given a second chance will allow me to lead a much fuller life than my healthy friends who are wrapped up in foolish day-to-day events that they have little or no control over. I want to have time to watch the wind blow through the trees or look at the stars at night.

Respondents were encouraged along this line of thinking by connecting with individuals with similar experiences and by having a forum to think it through, such as an online or face-to-face support group. It gave them an opportunity to tell their stories, put them in perspective, and recreate meaning in their lives or to decide that the life they were living was worth living. They were reshaping their lives, reevaluating, renegotiating, and recreating an acceptable meaning. The transformation involved an acceptance of this uncertainty and its boundaries as a way of life that includes appreciation for life.

Some respondents did not fully transform their thinking but rather formed a tenuous truce in which they would gain confidence over time until the next firing, when “it [firing-disease] rears its ugly head again.” The uncertainty of living with a chronic illness was repeatedly manifested in the firing of the device. One respondent referred to dealing with the firings as “fighting my dragons.” With this tenuous truce can come a resignation to this way of life as “just something I have to live with,” or, as one informant said,

Well, I’m past that stage of caring anymore now. It’s just something that I have to live with. Don’t let this thing be a burden to you or you’re going to suffer mentally and everything else. Because if you think about this thing 24 hours a day, you’re going to end up in a mental hospital. Get it out of your head as fast as you can. Just live a normal life.

Others manage the uncertainty by using their faith in God, handing over the control of their lives to God’s will. They find comfort and appreciation for their second chance at life, and this gives them a way of thinking that can open up possibilities beyond the fear. One respondent stated, “It’s okay to be afraid, scared, mad, whatever. Sometimes therapy helps, sometimes, just time, and most of all, keep your faith in God and keep your sense of humor.”

Over time, this creation of a new vision occurs and reoccurs after each new illness episode or firing. It is ongoing and circular, including the possibility for continuing self-reflection and rethinking of life.

**Constitutive Pattern: Redefining Life While Forestalling Death**

A constitutive pattern links common themes and shows their relationship across texts. An SCD experience or discovery of lethal arrhythmia changed the lives of individuals who had an ICD implanted as death became a symptom to be treated by technology. Although each person’s story was different, the common meanings
reflected shared experiences. Their lives were now controlled by a machine, which required lifestyle changes. This lifesaving device now set new boundaries. Individuals with an ICD felt a loss of control and profound change in their lives, which were now threatened by death. As these individuals got on with living, they began to take measures to regain a tentative control and conditional acceptance. They considered “what mattered to them most” to help them decide how to redefine their lives.

They may have gathered information and support, given control over to God, or become paralyzed in fear. They needed to reshape and redefine their lives while living with uncertainty, enduring discomforts, and getting on with their lives. If they were unable to learn to manage their fear of death, they became paralyzed, isolated, and afraid to live, prisoners of their fear. During this time, they continued to create a new vision, whether transformative or restrictive, that considers life while forestalling death. Whether they have the device inserted, they must consider death as a symptom to be treated. The technology is a double-edged sword that cannot be considered all good or even neutral. At what cost do the benefits of technology come? As one person reflected,

Yes, I know it is saving my life, but when you have been shocked as many times as I have with no warning and at high energy then I wonder if it is not better to be dead. . . I am getting to the point where I am not about to tell them to remove it. I live in constant fear, yet, I know, without it I will die.

IMPLICATIONS

In discovering the shared experiences and common meanings of recipients of an ICD, we begin to understand the effect of technology on their lives. There is an emotional side to adjusting to an ICD that may not be apparent to medical providers. The intrusion of technology is at a cost. This study allows us to increase our understanding of the effect of technology on the lives of those who depend on it to forestall death. Heideggerian hermeneutics allows for interpretation of the contexts of the everyday involvement with living with an ICD. The understanding of the meaning of this technology was explicated along with possibilities and potentialities revealing what was important for these individuals. Hermeneutics offers an approach for considering these issues and examining the relationship technology has to our lives. Heidegger (1977) stated,

Everywhere we remain unfree and chained to technology . . . We are delivered over to it in the worst possible way when we regard it as something neutral: for this conception it makes us utterly blind to the essence of technology. (p. 4)

Technology is everywhere in our lives, and often we do not pay attention to its effects. We are very dependent on technology to prolong life and save us, postponing death if we develop a health problem. These individuals with ICDs highlight the influence of technology on their personal lives. It is a profound change that death is considered a symptom to be treated rather than the end of life.

Those who work in the health care system see the ICD as technology that saves lives, and only recently have the implications for end-of-life decisions been considered. Do-not-resuscitate orders do not imply a decision to deactivate the device because this is not explicit in the consent. The ICD is considered a biofixture, an
intrinsic part of the patient from an ontological perspective (Paola & Walker, 2000). Patients need counseling to understand and express their views on advanced directives.

In this study, I found that during the course of their experiences, the individuals begin to redefine their lives and manage their fear. Gathering information and integrating the new boundaries assist in redefining an acceptable meaning. People attempt to deal with the loss of control and place it into a manageable perspective. Seeing others with similar experiences empowers them. Support groups, whether online or face-to-face, create a bridge between those in this community. "The bridge swings over the stream ... not just connecting the banks that are already there, but emerge as banks only as the bridge crosses the stream ... the bridge gathers around, leads in many ways" (Heidegger, 1971, p. 152). The support groups connect and provide a gathering place for sharing stories, interpreting, and integrating the changes into their lives. They are a place to learn to manage fears.

As health care providers, we must be cognizant of the effect of technology on the lives of the individuals who live with it. The underlying assumption that technology is good must be weighed against the effects of technology—both good and bad. Reasonable decisions can then be made to support the quality of life desired by individuals who choose to live with the technology. We are only beginning to understand the full potentials of technology in our world, and we must continue to remain open to its possibilities and potentialities.

REFERENCES


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