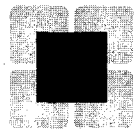

Patient and spouse acceptance and adaptation to implantable cardioverter defibrillators

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■ Although electrophysiologic devices have been available since 1932 for managing sudden cardiac death, it was not until 1980 that the predecessor to the automatic implantable cardioverter defibrillator was introduced. Subsequently, questions about psychosocial adaptation have prevented wide acceptance of these devices. To study this issue, 69 patients with treatment-resistant ventricular arrhythmias were sent a questionnaire following cardioverter implantation; spouses also received questionnaires. Of these, 42 patients and 38 spouses completed and returned questionnaires. The questionnaire was designed to elucidate psychosocial adaptation. Results suggest that patients and couples adapt to the automatic implantable cardioverter defibrillators adequately, but not without some specific reservations.

□INDEX TERMS: CARDIOVERSION, VENTRICULAR ARRHYTHMIA □CLEVE CLIN J MED 1990, 57:441–444

DESPITE THE ever-increasing number of antiarrhythmic drugs, as well as standard surgical interventions, sudden cardiac death remains a leading cause of death in the Western world. These malignant ventricular arrhythmias have 1-year mortality rates of 30%.

Newer implantable cardioverter technology significantly improves morbidity and mortality when high-risk patients are properly selected, but until recently, the psychosocial consequences of implantation have not been adequately studied.

To further elucidate the relationship between the implantation of a cardioverter defibrillator and psychosocial adjustment, we retrospectively assessed quality of life, patient and spouse attitudes, and prevalence of depression and anxiety. The data were gathered through self-administered questionnaires.

A device for managing sudden cardiac death was first introduced in 1932, by Albert Hyman, the father of cardiac pacing.[1] He was chastised for his aggressive intervention, and had reservations about publishing his results because of skepticism in the medical community.

It was not until the early 1970s that Mirowski introduced the concept of automatic implantable defibrillators, and Winkle and associates continued with the development of the automatic implantable cardioverter defibrillator (AICD).[2–4] The first human implant took place at Johns Hopkins Hospital in 1980,[2] and in recent years this mode of treatment has received growing acceptance.

METHODS

After receiving implantable cardioverter defibrillators for treatment of refractory ventricular arrhythmias, 69 patients (and their spouses) were asked to complete a

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TABLE 1
DEMOGRAPHIC DATA

Variables (42 subjects)	%
Sex	
Men (38)	90
Women (4)	10
Employed	
Yes (8)	19.1
No (34)	80.9
Completely disabled	75
Age (yr)	
34–39 (4)	9.5
40–49 (3)	7.1
50–59 (12)	28.5
60–69 (19)	45.4
70–76 (4)	9.5
Years of education	
≤12	78.6
>12	21.4
Annual income	
$10– 20,000 (15)	35.7
$21– 30,000 (11)	26.1
$31– 45,000 (5)	11.9
$46–100,000 (11)	26.3

battery of psychometric tests to clarify psychosocial adaptation and device-specific concerns. All patients had failed conventional as well as novel pharmacotherapies before implantation. At the time the psychometric battery was completed, the mean duration of implantation was 17.6 (range 1 to 52) months and device discharges per patient ranged from 0 to 45. The frequency distribution of discharges was as follows: 24 patients with 0 to 1 discharge, 8 patients with 2 to 5 discharges, 3 patients with 6 to 10, 1 patient with 11 to 15, and 4 patients with more than 16 discharges (ie, 17, 19, 30, and 45).

The psychometric battery consisted of self-assessed ratings of mood (the Beck Depression Inventory, or BDI);[5] ratings of anxiety (the Self-Assessment Anxiety Scale, or SAS, by Zung);[6] and the Cleveland Clinic AICD Psychosocial Inventory. Scores on the BDI of 10 to 19 reflect depression of mild severity; 20 to 29, moderate severity; and 29 and above, clinical depression requiring immediate intervention. Scores on the SAS lower than 45 reflect normal degrees of anxiety; 45 to 59, minimal to moderate; 60 to 74, marked; and above 74, extreme.

The Psychosocial Inventory was designed to elicit information on demographics, medical history, patient attitudes towards the device, body image distortions, lifestyle alterations, impact on family and marriage, general quality of life, and device-specific concerns. The data derived from the Psychosocial Inventory was gathered through multiple-choice questions.

RESULTS

Of the 69 patients who were asked, 42 agreed to be involved in the study and returned completed questionnaires. The 38 spouses of the married patients also completed questionnaires. The questionnaires of 38 couples and four single patients were statistically analyzed. The mean age of the 42 patients was 57.7 years (range, 34 to 76 years). *Table 1* summarizes additional patient demographics.

Complications

Complications of implantation included premature battery depletion in seven patients, lead displacement requiring surgery in six, AICD failure requiring premature device replacement in five, ventricular tachycardia falling below the detection rate in three, inappropriate discharge in three, and infection requiring surgery in one. In all, more than half exhibited significant medical complications.

Psychometric battery

The Beck Depression Inventory was completed by 40 patients (mean ±SD, 9.2 ± 7.4, range 0 to 27) and 37 spouses (mean ±SD, 7.4 ± 6.2, range 0 to 22). The Self-Assessment Anxiety Scale was completed by 40 patients (mean ±SD, 36.5 ±8.3, range 12 to 53) and 33 spouses (mean ±SD, 34.8 ± 9.0, range 17 to 57).

Although 35% of patients received a BDI total score that suggested depression, standardized psychiatric interviews were not conducted and for this reason DSM IIIR diagnoses are not available. See *Table 2* for a breakdown of the ratings data. The Cleveland Clinic AICD Psychosocial Inventory was completed by all patients (n=42) and spouses (n=38). Of the 42 patients, concerns of resuscitation, shock, and death were either lessened or nonexistent in 78.5%.

The following results were obtained from the returned questionnaires:

Perception about device

The AICD was perceived as being a "life extender" by 76.2% of the patients, a "source of security" by 73.8%, a "source of anxiety" by 4.8%, and "best friend" by 4.8%. Among spouses, 81.6% perceived of the AICD as a "life extender," 65.8% as a "source of security," and 18.4% as a "source of anxiety." None perceived of it as "best friend."

Perception about discharge

The AICD discharge was viewed as being "not so bad" by 21.4% of the patients, painful by 16.7%,

lightning-like by 45.2%, and terrifying by 14.3%.

The patient's mood following the discharge was either reassured or unchanged in 52.4% and nervous or tired in 73.8%.

Integration into body image

The device was reported as successfully incorporated into body image by 83.3% of the patients, but altered body perceptions were frequently reported. More than half (57.1%) viewed the size of the device as excessive, 35.7% felt self-conscious, and 7.1% had difficulty looking at themselves or touching the area of implantation.

Lifestyle alterations

The device caused no lifestyle changes, according to the reports of 45.2% of patients. Increased independence was reported by 64.2%. At the time of administration of the Psychosocial Inventory, 24 of 32 (75%) reported they had been forced to retire because of heart problems. Although 17 of 40 (43%) reported they would now like to return to work, only 12 (30%) believed they could. Data are not available on the number of patients who successfully returned to work.

Among the patients, 42.5% reported concerns that sexual activity would trigger the device; 46.4% of the spouses had similar concerns. This prompted many to abstain from sexual relations altogether.

Patient and family perceptions

The implantation of the AICD reduced patient perception of family worry from pre-implant levels of 50% to post-implant levels of 16.7%. Patient perception of family overprotectiveness decreased from 31% to 16.7%.

The implantation of the AICD reduced family perception of patient worry from pre-implant levels of 55.3% to post-implant levels of 21.1%. Family perception of patient overprotectiveness decreased from 44.7% to 31.6%.

Home-going concerns

The major concern of patients was local availability of experienced emergency room care (64.7%). Almost half of the patients had additional concerns about where they might be when the device discharged (47.6%), the timing of the discharges (45.2%), and whether the device could successfully defibrillate their hearts (42.8%). Additional concerns were cost (42.8%), discharge-related pain (40.4%), frequency of follow-up visits (33.3%), and concern over the device's energy reserves (26.1%).

In addition to having concerns similar to those of the patients, one-third of the spouses expressed concern about whether they might unintentionally provoke device discharge by the candid expression of such feelings as anger.

TABLE 2
RATING DATA

	Patients (%)	Spouses (%)
Beck Depression Inventory		
	n = 40 mean (SD) = 9.2 (±7.4)	n = 37 mean (SD) = 7.4 (±6.2)
Mild (10–19)	65	90
Moderate (20–29)	35	5.4
Severe (>29)	0	0
Self-Assessment Anxiety Scale		
	n = 40 mean (SD) = 36.5 (±8.3)	n = 33 mean (SD) = 34.8 (±9.0)
Minimal to moderate (45–59)	15	12
Marked to severe (60–74)	0	0
Extreme (>74)	0	0

DISCUSSION

From this retrospective study of 42 patients, we report a low incidence of depression and anxiety and good general psychosocial adaptation to the implanted cardioverter defibrillator. The device was well accepted by patients, and most perceived themselves as adapting successfully. Patients viewed the device as an effective "life extender" and a "source of security," despite anxiety and fear associated with the unpredictable nature and timing of its discharge.

These findings replicate our previous clinical observations on psychosocial adaptation in this population.[7] Patients have concerns about where they will be when the device discharges, whether it will restore normal sinus rhythm, and the pain experienced at the time of discharge. Of less concern, overall, were issues of resuscitation, shock, and death.

Although the patients expressed positive perceptions about the device, most (94%) reported increased preoccupation with their heart condition since implantation. This somatic preoccupation reflects the ever-present risk of a terminal event. In addition, patients were concerned about frequency of follow-up visits and lack of community awareness. Many expressed concerns over the lack of familiarity with the device among primary care physicians. Spouses had similar concerns and expressed moderate anxiety over whether or not the expression of heightened emotion would cause the device to discharge. Patient and

spouse concerns about whether sexual activity might trigger the device prompted many to consider discontinuing sexual relations.

Among the limitations of the study are its retrospective design; lack of validation of the Psychosocial Inventory; lack of formal, semi-standardized, semi-structured psychiatric research interviews; and lack of information about why nonrespondents chose not to participate in the study.

In a recent study of the psychosocial consequences of implantation of the AICD, 17 patients were interviewed. They reported concerns about unpredictability of the discharge, premature battery depletion, and decreased physical and sexual activity.[8]

Most AICD wearers live with fear of embarrassment and pain if the device discharges, and with loss of self-esteem. Sixty percent of the patients expressed a fear of losing control during a discharge, 34% felt hopeless, and 40% shared the concern that their caretaker would be overburdened.

Another relevant issue is the cost of the device and related medical and surgical expenses, conservatively estimated to be between $45,000 and $55,000.[9] According to Vlay and associates,[10] this is a reasonable investment, considering the positive impact on the patient and family with regard to return to work and an active lifestyle. Although nearly half of our patients and their spouses (42.8% and 44.7% respectively) indicated significant concerns about cost and their ability to afford the AICD (73.8% reported they were having problems with their bills), they all reported that the device allowed return to an active lifestyle.

Several researchers have identified the potential problems these patients face and recommended a multidimensional approach to management, with a psychiatrist or clinical psychologist as part of the patient care team for all who receive the device.[8,10–12] The potential benefits of a shared group experience have also been demonstrated.[11] Nearly half of our patients and their spouses (43.6% and 54% respectively) expressed a desire for a support group; therefore, such a group was formed.

Patients with AICDs adjust and adapt well, despite realistic psychosocial concerns that are potentially fear- and anxiety-provoking. Future clinical and research recommendations include: (1) a prospective, longitudinal research design that includes serial, semi-structured, standardized, psychiatric interviews; (2) a psychiatrist or clinical psychologist as part of the treatment team, to be involved in pre- and postoperative semistructured, semistandardized, research interviews and to provide diagnoses and supportive counseling to patients and families; (3) a structured assessment of the impact of such premorbid factors as Axis II pathology, previous psychiatric history, and previous coping style; and (4) the development of support groups and other outreach and educational efforts to enhance community-wide knowledge and understanding of the device, including how to intervene if the device discharges appropriately or inappropriately.

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