

PERSON-CENTERED MEDICINE IN A PATIENT WITH IMPLANTABLE CARDIOVERTER DEFIBRILLATOR: THE IMPORTANCE OF COMMUNICATION AND EDUCATION

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Implantable cardioverter defibrillators (ICDs) are the most effective treatment for life-threatening ventricular arrhythmias, reducing mortality in patients at a high risk of sudden cardiac death (SCD). Although physical benefits of ICD are unquestionable, ICD implantation is a stressful event for patients. It may cause problems in adaptation to the device and deteriorate patient quality of life (QOL). At the same time QOL is influenced by cardiac disease, as well as by psychosocial adjustment to the changed life situation. ICD recipients commonly experience fear, anxiety and depression, which may occur as a result of concern about their health, lack of understanding how the ICD works, activates and feels, and unpredictability of receiving ICD shocks. ICD-related fears and concerns, especially about the often painful ICD discharges, have been identified as a major determinant of psychological distress and impaired QOL. Also, stress and anxiety can potentiate pathological processes that increase the risk of SCD. The objective of this paper is to present a peculiar case of a young woman having experienced frequent ICD activations, the impact of the device implantation on her psychological status, and how educating others helped her cope with the life with ICD.

Key words: defibrillators; chronic disease; communication; education, medical

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INTRODUCTION

Sudden cardiac death (SCD) is the leading cause of morbidity and mortality in Croatia and a major public health concern (1). Most SCDs are triggered by ventricular arrhythmia (2). Major clinical trials have consistently shown implantable cardioverter defibrillators (ICDs) to be superior to antiarrhythmic drugs in the treatment of life-threatening ventricular arrhythmias, reducing mortality in patients at high risk of SCD (3). Although medical benefits of ICD are unquestionable (4-7), many patients who receive an ICD shock develop some form of psychological distress in the aftermath (8). A typical ICD recipient faces the challenges of life with both cardiac disease and ICD therapy. These may include fear of recurrent arrhythmia,

sudden death, proper functioning of the device, and feeling of the loss of control over ICD discharge (9). Therefore, a number of ICD patients show psychosocial adjustment difficulties and at least 30% of them manifest clinically significant levels of anxiety and depressive symptoms (10). Our patient was one of those recipients. In this paper, we present how communicating with other patients, medical staff and students, and later educating them about life with chronic illness helped her cope with her psychosomatic condition. Additionally, by her case we present a good example of person-centered medicine applied in clinical practice, which emphasizes that health is not just the absence of the disease, but an interaction of biological, psychological, social and spiritual factors within the individual (Fig. 1) (11).

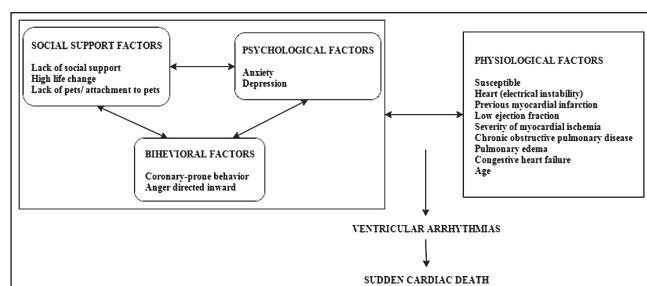


Fig. 1. *Holistic model of cardiovascular health* (based on Thomas et al. 2001).

CASE REPORT

A 29-year-old female patient was admitted to the hospital in poor general condition, highly febrile, tired and weak. She was diagnosed with interstitial pneumonia of unknown etiology. During follow-up examination 3 weeks later, the patient complained about malaise, dyspnea on exertion and occasional palpitations. Physical examination revealed abnormalities in her heart rhythm. Further cardiologic evaluation showed significantly reduced systolic function of the heart with the heart ejection fraction of 35%. Based on echocardiogram findings, dilated cardiomyopathy was diagnosed. The patient was prescribed a beta-blocker, an antiarrhythmic (amiodarone) and an angiotensin-converting enzyme (ACE) inhibitor (ramipril).

Her condition worsened 5 years later by amiodarone-induced hyperthyroidism. The patient felt tightening pain on the left side of the chest, palpitations and shortness of breath at rest. The 24-hour ECG Holter monitoring showed paroxysmal ventricular tachycardia and ventricular extrasystoles, while echocardiography revealed her ejection fraction to be reduced to 30%, so the ICD implantation was indicated for primary prevention of SCD.

During postoperative hospitalization, ICD activated for the first time. The patient likened the feeling to "being hit in the chest by train" and described the pain as the most horrible she had ever experienced. A month after the implantation, ICD device activated 28 times throughout two evenings, each time delivering shock therapy to her heart.

In the next five years, she was hospitalized seven times for characteristic arrhythmia symptoms and numerous ICD activations with electric shocks, some of which made her lose consciousness and fall down.

The patient started feeling depressed and anxious about her health. When she first sought psychiatric help, she was afraid that ICD might suddenly activate, especially when she was alone. She reported feeling tired but too scared to sleep for fear that she would not wake up.

Also, any kind of stimulus on the left side of her chest, where the device was placed, would create the feeling of ICD activation. The patient started avoiding physical activity and situations that might cause ventricular tachycardia and consequently activate ICD. She expressed concern about the future and admitted being preoccupied with thinking about her illness.

The patient's psychological distress resulted in many unanswered questions she had about her new condition. Encouraged and supported by her psychotherapist, she decided to help other people coping with the same disease, facing the same problems, using information and sources that helped her. Learning how to give and receive feedback enabled her to explore and understand even better the experiences she had. Moreover, she started educating people by sharing her needs, concerns and priorities. She attended Fundamental of Medical Skills classes at the School of Medicine and talked to students about the importance of communication in medicine, honestly answering all of their questions. Further, as a guest lecturer she presented her case and experiences at several conferences. She also got involved in the work of different support groups, speaking openly about her fears and concerns, sharing information that helped her cope with everyday issues. The patient's role as an educator for other patients, their families, medical students, doctors and other medical staff had multiple benefits. It presented a unique opportunity to learn from an "expert by experience" about patient-provider communication, about the nature of suffering and loss. Also, it resulted in increasing awareness and empathy for the patient, while at the same time it reduced her psychological distress.

After the ICD battery replacement procedure, the patient's physical condition improved. Arrhythmic events became less frequent, resulting in fewer device activations. Consequently, the patient's psychological status improved, anxiolytic therapy was no longer needed and her QOL improved significantly.

DISCUSSION

Studies show that a significant proportion of ICD patients experience anxiety, depression, or both (12). This may result from a number of factors, such as exposure to mood-distabilizing experiences (surviving sudden cardiac arrest, undergoing long hospitalization and invasive procedures), concern about the severity of their cardiac condition, or apprehension of how the ICD works, looks and feels (13,14). Psychological recovery of those patients is significantly influenced by the experience of an ICD shock, which destroys their defense mechanisms, erodes confidence and creates uncertainty about the future. The unpredictability of

shock occurrence amplifies patient concerns of where another shock will happen and who will witness it (15). In addition, the fear of pain reduces patient physical and social functioning. Fear reinforces avoidance of activities such as exercise because physical symptoms (e.g., elevated heart rate) are perceived by patients as dangerous. Those patients also avoid shopping centers, public transport or any places where having a shock would be inconvenient or embarrassing (16). Young people find these ICD-related inconveniences especially difficult to deal with (17), as they bring into question many things they used to do or planned to do before ICD implantation. For example, their ability to have children, to drive, to have intimate contacts, to travel and pass through metal detectors, to use cell phones or different household appliances, all of which could seriously deteriorate their QOL.

Because of the complexity of these devices, there is a tendency to focus mainly on their technical aspects. Person-centered medicine has emerged as a response to the organ-specific, technical, fragmented medical treatment and care (18). This movement is growing toward the formulation of a medicine of the person (of the totality of the person's health, including the ill and positive aspects), for the person (to assist the fulfillment of the person's life project), by the person (with clinicians as full human beings, professionally competent, and with high ethical aspirations), and with the person (19). It insists on the collaborative partnership when working with patients and their families, both in diagnostic and therapeutic processes, and views the patient as a person with biological, psychological, social and spiritual needs (20). Fulfillment of these needs depends on communication skills, since communication is an integral part of any relationship with patients and their families, and as such represents the key to the success of a medical team. It has an impact on patient experience of care, improves patient adherence to treatment regimens, clinical outcomes, quality of care, and their safety, contributes to teamwork and cultural sensitivity, and reduces medical malpractice risk. Patient experience of their illness, knowledge about it, and nature of the illness are all intertwined in medical decisions and outcomes (21). Considering that patients are experts in their own lived experiences, they need to be included in health professional education. In fact, their role has been acknowledged throughout history, with Sir William Osler stating that "the best teaching is that taught by the patient himself" (22). Patient-centered practice and education needs to progress from the patient's passive bedside or office role. It should include a direct and active engagement of patients in the teaching process, thus enabling open and explicit sharing of wishes and values, needs and preferences that reflect patient centeredness. There is good evidence that such approaches lead to actual improvements in patient outcomes (23).

CONCLUSIONS

The core of the medical profession has always been the relationship between the health professional and the person seeking assistance. Education is the critical component in this process, for it is the intervening variable in development of the culture of health and medicine as a culture of life.

Appropriate education and support should necessarily be provided for ICD patients, both before and after the implantation. This can be done at facilities where ICDs are placed, by web-based programs, informative leaflets and support groups. Also, continued psychological monitoring and support may be needed in patients who have received shock, to reduce mood disturbances, fears and concerns, and to promote better QOL.

Moreover, medical education requires a revised approach to the teaching of clinical and communication skills, and inclusion of person-centered medicine. It must emphasize chronic illness care, interprofessional teamwork, and working in partnership with patients and their families. One way to address these needs is to involve patients as teachers in longitudinal interprofessional educational programs grounded in the principles of patient-professional partnerships and shared decision-making.

R E F E R E N C E S

1. Croatian National Institute of Public Health. Croatian Health Service Yearbook 2016. Zagreb: web edition 2017. Available at URL: https://www.hzjz.hr/wp-content/uploads/2017/10/Ljetopis_2016_IX.pdf
2. Wallace RL, Sears SF Jr, Lewis TS, Griffis JT, Curtis A, Conti JB. Predictors of quality of life in long-term recipients of implantable cardioverter defibrillators. *J Cardiopulm Rehabil* 2002; 22: 278-81.
3. AVID Investigators. A comparison of antiarrhythmic-drug therapy with implantable defibrillators in patients resuscitated from near-fatal ventricular arrhythmias. *N Engl J Med* 1997; 337: 1576-83.
4. Kuck KH, Cappato R, Siebels J, Ruppel R. Randomized comparison of antiarrhythmic drug therapy with implantable defibrillators in patients resuscitated from cardiac arrest: the Cardiac Arrest Study Hamburg (CASH). *Circulation* 2000; 102: 748-54.
5. Connolly SJ, Gent M, Roberts RS *et al.* Canadian Implantable Defibrillator Study (CIDS): a randomized trial of the implantable cardioverter defibrillator against amiodarone. *Circulation* 2000; 101: 1297-302.
6. Moss AJ, Zareba W, Hall WJ *et al.* Prophylactic implantation of a defibrillator in patients with myocardial infarction and reduced ejection fraction. Multicenter Automatic Defibrillator Implantation Trial II Investigators. *N Engl J Med* 2002; 346: 877-83.

7. Bardy GH, Lee KL, Mark DB *et al.* Amiodarone or an implantable cardioverter-defibrillator for congestive heart failure. *N Engl J Med* 2005; 352: 225-37.
8. Sears SF, Kirian K. Shock and patient-centered outcomes research: is an ICD shock still a critical event? *Pacing Clin Electrophysiol* 2010; 33: 1437-41.
9. Fricchione GL, Olson LC, Vlay SC. Psychiatric syndromes in patients with the automatic implantable cardioverter defibrillator: anxiety, psychological dependence, abuse, and withdrawal. *Am Heart J* 1989; 117: 1411-4.
10. Sears SF Jr, Todaro JF, Lewis TS, Sotile W, Conti JB. Examining the psychosocial impact of implantable cardioverter defibrillators: a literature review. *Clin Cardiol* 1999; 22: 481-9.
11. Thomas SA, Friedmann E, Kelley FJ. Living with an implantable cardioverter defibrillator: a review of the current literature related to psychosocial factors. *AACN Clin Issues* 2001; 12: 156-63.
12. Sola CL, Bostwick JM. Implantable cardioverter-defibrillators, induced anxiety, and quality of life. *Mayo Clin Proc* 2005; 80: 232-7.
13. Vlay SC. Psychosocial aspects of surviving sudden cardiac death. *Clin Cardiol* 1984; 8: 237-43.
14. Sears SF, Lewis TS, Kuhl EA, Conti JB. Predictors of quality of life in patients with implantable cardioverter defibrillators. *Psychosomatics* 2005; 46: 451-7.
15. Schuster PM, Phillips S, Dillon SL, Tomich PL. The psychological and physiological experiences of patients with an implantable cardioverter defibrillator. *Rehabil Nurs* 1998; 23: 30-7.
16. Lemon J, Edelman S, Kirkness A. Avoidance behaviors in patients with implantable cardioverter defibrillators. *Heart Lung* 2004; 33: 176-82.
17. Sears SF Jr, Burns JL, Handberg E, Sotile WM, Conti JB. Young at heart: understanding the unique psychosocial adjustment of young implantable cardioverter defibrillators recipients. *PACE* 2001; 24: 1113-7.
18. Snaedal J. Components of person-centered medicine in medical treatment and care. *Int J Pers Cent Med* 2012; 21: 29-32.
19. Mezzich JE. Building person-centered medicine through dialogue and partnerships: perspective from the international network for person-centered medicine. *Int J Pers Cent Med* 2011; 1: 10-3.
20. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000; 51: 1087-110.
21. Đorđević V, Braš M, Brajković L. Person-centered medical interview. *Croat Med J* 2012; 53: 310-3.
22. Osler W. The hospital as college. In: *Aequanimitas with other addresses to medical students, nurses and practitioners of medicine*. Chapter XVI. London: HK Lewis, 1904.
23. Fiddes PJ, Brooks PM, Komesaroff P. The patient is the teacher: ambulatory patient-centred student-based interprofessional education where the patient is the teacher who improves patient care outcomes. *Intern Med J* 2013; 43: 747-50.

SAŽETAK

MEDICINA USMJERENA OSOBI KOD PACIJENTA S IMPLANTABILNIM KARDIOVERTER DEFIBRILATOROM: VAŽNOST KOMUNIKACIJE I EDUKACIJE

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Implantabilni kardioverter defibrilatori (ICD) danas su najučinkovitija metoda liječenja životno ugrožavajućih ventrikulskih aritmija, čime smanjuju pojavu nagle srčane smrti u visoko rizičnih bolesnika. Iako je korist ICD u poboljšanju tjelesnog zdravlja neosporna, implantacija je za bolesnika stresan događaj. Može doći do poteškoća u procesu psihosocijalne prilagodbe bolesnika na život s uređajem te pogoršanja kvalitete života. U tih su osoba česti strah, anksioznost i depresija. Nastaju kao posljedica zabrinutosti za vlastito zdravstveno stanje, nedovoljne obaviještenosti o kirurškom postupku i načinu rada ICD, ograničenjima u svakodnevnom životu te nepredvidljivosti aktivacije uređaja. Upravo ta strahovanja i zabrinutosti, osobito nakon iskustva bolnog ICD elektrošoka, najviše uzrokuju psihološki nemir kod bolesnika. Dodatno, stres i anksioznost mogu potencirati patološke procese koji povećavaju vjerojatnost iznenadnog srčanog aresta. Cilj je ovoga rada prikazati slučaj mlade žene koja je nakon implantacije ICD doživjela brojne i učestale aktivacije uređaja, često praćene elektrošokom, naglasiti utjecaj koji je to iskustvo imalo na njeno psihološko stanje te pokazati na koji joj je način poduka pomogla nositi se s novonastalom životnom situacijom.

Ključne riječi: defibrilatori implantabilni, kronična bolest, komunikacija, izobrazba medicinska