



New old life of patients after implantation of implantable cardioverter defibrillator¹

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Abstract: The aim of this article is to provide a detailed description of patients' lives after implantation of an implantable cardioverter defibrillator (ICD). First, the basic function and mechanism of the device as well as the types of experienced shocks, including phantom shocks, are described. Then, the three most important dilemmas faced by patients are discussed: ICD implantation, battery replacement and device deactivation. Subsequently, the scientific literature on psychopathological symptoms in patients is reviewed. The latest results of research on anxiety and depression in patients with ICD are presented, and the relationship between anxiety and depression and experienced shocks is discussed in detail. The results of a few studies on the occurrence of stress and post-traumatic stress disorder in patients are also presented. In addition, the focus was on the perception of the implantation of a cardioverter defibrillator as a traumatic event. The aim of this article was also to discuss the quality of life of patients with a cardioverter defibrillator. The results of studies that indicate a deterioration, improvement or maintenance of the level of quality of life of patients comparable to those of healthy people are presented. In addition, a specific, important from the perspective of people with ICD aspect of the quality of life, which is the health-related quality of life, was discussed. The results of research in this area are also not unambiguous. In addition, predictors of health-related quality of life were indicated. The article also addresses the issue of changing the identity of patients after implantation of a cardioverter defibrillator. The results of research conducted in this field, which were most often of a qualitative nature, were discussed. In the discussion on the identity of people with ICD, changes in self-image were emphasized, but this issue was not a frequent subject of psychological research. Finally, the challenges faced by partners of patients with an implanted cardioverter defibrillator were characterized. Also in this area, most of the research was qualitative, and the data come from interviews with relatives of cardiac patients.

Keywords: identity, implantable cardioverter defibrillator, partner, psychopathology, quality of life

Introduction

An implantable cardioverter defibrillator (ICD) is a device surgically inserted under the skin, usually on the left side of the chest (Kazimierska, Suska-Bąk, Kowalik, Maciag & Smolis-Bąk, 2014). The device monitors cardiac activity and rapidly detects potentially fatal ventricular arrhythmias (Kuśmierz, Wleklik, Uchmanowicz, & Jaroch, 2016; Sobański, Brzezińska-Rajszyś, Grodzicki et al., 2020). On sensing an irregular heartbeat, the ICD sends a strong electrical impulse to restore normal heart rhythm (Kazimierska et al., 2014). This can be done via antitachycardia pacing, which is not painful and barely noticeable by some patients, or high-energy shocks, felt by patients and usually painful (Kuśmierz et al.,

2016; Sobański et al., 2020). Patients with an implantable cardioverter defibrillator sometimes report experiencing shocks despite the lack of evidence of their occurrence, which are referred to in the literature as phantom shocks (Bilanovic, Irvine, Kovacs et al., 2013; Ooi, He, Dong, & Wang, 2016). Depending on the methodology adopted, this phenomenon is reported to affect approximately 5–10% of patients (Amiaz et al., 2016; Starrenburg et al., 2014; Varghese, Geller & Ohlow, 2019).

Most patients with an ICD accept the need to use the device and the limitations associated with it (Januskiewicz et al., 2022; Wójcicka, Lewandowski, Smolis-Bąk & Szwed, 2008). One year after ICD im-

1 Article in Polish language: Nowe stare życie pacjentów po wszczepieniu kardiowertera defibrylatora <https://www.stowarzyszeniefidesetratio.pl/fer/2023-3Pale.pdf>

plantation, the patients' level of psychological functioning is similar to that before the procedure (Burke, Hallas, Clark-Carter, White, & Connelly, 2003; Pedersen, Hoogwegt, Jordaens, & Theuns, 2013). Some people, however, find it challenging to adapt to the novel situation (Wójcicka et al., 2008). These patients consider the implantation of the ICD an unnecessary procedure – they have a negative viewpoint on follow-up evaluations, fail to observe medical recommendations and contemplate the removal of the device. Patients may perceive the ICD in two alternative ways – as an indicator of imminent death or as a life-saving device (Humphreys, Lowe, Rance & Bennett, 2016a).

Although living with an ICD brings a variety of challenges, patients describe different strategies for adapting to their new situation (Humphreys et al., 2016a). One such strategy is avoiding or limiting activities that they believe would cause a shock, such as sex or physical activity (Flemme, Hallberg, Johansson, & Strömberg, 2011; Humphreys et al., 2016a). Secondly, patients limit the sources which could provide them with information about the ICD to avoid inconsistent information and reduce anxiety (Humphreys et al., 2016a). Other tactics include: diverting their attention away from everyday problems, accepting their condition, determining new and achievable goals, and modifying previously set objectives (Flemme et al., 2011).

1. Making the decision

Making the decision to have an ICD implanted is a difficult time for patients. As found by Barisone et al. (2022), one of the most important motives quoted by cardiac patients when agreeing to such an intervention is the willingness to protect themselves against sudden death. Moreover, they express a sense of duty towards their family. At the same time, they are convinced that they practically have no other choice due to the risk to their lives. It should be noted that sometimes both patients and their relatives do not fully understand the mechanism and function of the ICD (Hill, McIlpatrick, Taylor, Dixon & Fitzsimons, 2022). This makes it difficult to make any device-related decisions (Lewis, Stacey & Matlock, 2014).

The second major decision facing patients is the aspect of battery replacement (Lewis et al., 2014). This particular issue has not been the subject of extensive research. Thylén et al. (2013) established that fewer than half of patients discuss battery replacement with their doctor. Those with a higher quality of life, under 65 years of age, carrying an ICD for a longer period of time, and those who have experienced a battery replacement before are more likely to do so.

ICD deactivation is an issue that raises a particularly large number of uncertainties and reflections, and many people are not even aware that such an option exists (Lewis et al., 2014). This is the third difficult decision that patients must face. This dilemma most often arises in relation to people nearing the end of their life who are receiving palliative care (Picco, 2020). According to expert opinion and clinical guidelines, ICD deactivation should be considered and discussed with the patient in an advanced disease stadium (Grądalski & Smyczyńska, 2015; Hill et al., 2022). The procedure is justified by the need to prevent pain and suffering associated with high-energy therapy (Sobanski et al., 2020). As heart failure progresses, the frequency of arrhythmias and, consequently, the frequency of device discharges increases, leading to the question of the balance of gains and losses associated with the ICD (Grądalski & Smyczyńska, 2015). The patients' final decision is dependent on numerous factors, including those linked to medical, ethical, medicolegal, religious and world outlook aspects (Sobański et al., 2020). According to patients, the potential deactivation of the ICD should be discussed before the device is implanted, which is rarely the case (Hill et al., 2022; Lee et al., 2017). This particular procedure is a relatively infrequent topic of discussion between doctors and patients. Goldstein, Lampert, Bradley, Lynn & Krumholz (2004) found that 30% of patients took part in such conversations, usually in the last days of their life. In a study by Herman, Stros, Curily, Kebzy & Osmancik (2013), almost half of the respondents indicated that they had never considered deactivating the device in an end-of-life situation. As many as 8% of people discussed the topic with their doctor, 40% wanted to take part in such a conversation, and around 40% of primary prevention patients and around 22% of

secondary prevention patients refused to raise the topic. Picco (2020) points out that patients should be aware, among others, that deactivating the ICD does not cause death and does not make it more painful, whereas defibrillation at the end of life can be painful, ineffective and stressful for the patient.

2. Anxiety and depression

Anxiety symptoms are frequently felt by both children (Eicken et al., 2006) and adults (Wójcicka et al., 2008) with an ICD. Matchett et al. (2008) point out that the feeling of anxiety is the strongest psychological symptom in patients, and it is most pronounced immediately after the implantation of the cardioverter defibrillator (van den Heuvel et al., 2022). Van der Lingen et al. (2023), in the process of carrying out the PSYCHE-ICD project, assessed the severity of anxiety symptoms in patients the day before device implantation. They found that almost a third of them presented mild to severe symptoms of anxiety. Such symptoms may continue for one (Pedersen et al., 2011) or even two years after ICD implantation (Frydensberg et al., 2020). Such anxiety, therefore, may develop into chronic anxiety. Furthermore, on occasion, relevant symptoms may develop over the subsequent years after the procedure (Pedersen et al., 2021). For this reason, patients should receive psychological support not only during the ICD implantation period but also in the following months and years. The source of patient anxiety may be the shocks (Tripp, Huber, Kuhl & Sears, 2019) and the device itself. Patients worry that the ICD may fail or stop working completely (Humphreys et al., 2016a; Moradi et al., 2022; Tagney, James & Albarran, 2003). Furthermore, they express concern about feeling pain during a shock (Humphreys et al., 2016a) and suffering an injury to the implantation site (Moradi et al., 2022). The fear of having to reduce sexual activity also plays a vital role (Dubin, Batsford, Lewis & Rosenfeld, 1996; Tagney et al., 2003).

Much attention has been paid by researchers to depression in ICD patients. Its symptoms can be observed at every stage of treatment. Van der Lingen et al. (2023) evaluated depression symptoms in patients

the day before the implantation procedure. It emerged that a third of the patients presented symptoms of mild, moderate or severe depression. These data are significant given that initial symptom severity is correlated with symptom severity in subsequent months (Andersen et al., 2023; Freedenberg, Thomas & Friedmann, 2011). Moreover, depression symptoms may develop within the two years following the procedure (Pedersen et al., 2021). Oshvandi, Khatiban, Ghanei Gheshlagh & Razavi (2020) reviewed the available publications to assess the prevalence of depression in ICD patients. The researchers established that almost one in four patients experience this disorder. In an earlier review of the literature (Magyar-Russell et al., 2011), the indicators provided were slightly lower and pointed to depression symptoms in one in five people with an ICD.

As found by Zormpass et al. (2022), the severity of depression is associated with smoking, obesity and reduced quality of life. The researchers, therefore, advocate that the evaluation of depressive symptoms and lifestyle factors should form part of the treatment plan. Similar conclusions are put forward by Frydensberg et al. (2020), who recommend systematic screening for anxiety and depression not only immediately after ICD implantation but especially after 2-3 months, with a view of identifying high-risk patients.

Considering the features of the ICD, one of the key issues is the relation between the incidence of depression and anxiety in patients and the shocks they receive. Many researchers indicate that patients experience most strongly anxiety linked to the discharge of the device (Humphreys et al., 2016a; Mańkowska- Załuska et al., 2015; Maryniak, Szumowski, Orczykowski, Przybylski & Wälczak, 2009; Schulz et al., 2013), which is a sudden and unexpected phenomenon (Barisone et al., 2022). Patients are apprehensive of not only the first shock but also every subsequent shock (Humphreys et al., 2016a). This is because a discharge of the ICD generates a conviction that the heart is not functioning properly, which further heightens anxiety (Barisone et al., 2022) and reminds patients of their mortality (Humphreys et al., 2016a). The research conducted by Pedersen, Hoogwegt, Jordaens & Theuns (2013) established that shocks significantly deteriorated the functioning of patients, as manifested in their anxiety

and depression. Ghezi et al. (2023) reviewed articles published up to August 2022 and concluded that the prevalence of anxiety and depression is particularly high in patients experiencing shocks. Rottmann, Skov, Andersen, Theuns & Pedersen (2018) came to a similar conclusion that shocks hinder adaptation to new situations, which can lead to undesirable symptomatology. It has to be emphasised, however, that this dependency is not confirmed by all researchers. The disparate concerns that patients have in relation to the ICD may be connected to their anxiety and depressive symptoms, regardless of the shocks experienced (Pedersen, van Domburg, Theuns, Jordaens, & Erdman, 2005). According to Kamphuis, De Leeuw, Derksen, Hauer & Winnubst (2003), manifestations of anxiety and depression are a response to perceived physical and psychological difficulties, independent of the ICD discharges. Lindekilde and her team (2022) found that baseline anxiety is, similarly to depression, associated with a higher risk of death, but not with the occurrence of ICD discharges. The lack of such a relationship is also pointed out by Dougherty & Hunziker (2009). Prudente (2005) indicates that phantom shocks can be a manifestation of anxiety and depression. Although the researcher emphasises the significant role of patients' awareness of this phenomenon, she highlights that there is no direct link between psychopathology and the occurrence of phantom shocks.

3. Stress and post-traumatic stress disorder

As many as 10-15% of ICD patients experience stress, and its symptoms can even be observed more than twenty years after device implantation (Thylén et al., 2014). Despite the above, researchers pay far less attention to stress and post-traumatic stress disorder in people with an implantable cardioverter defibrillator than to other psychological consequences of living with an ICD. An aspect frequently addressed in the literature is the role of the shocks patients experience in the aetiology of stress. However, it is impossible to unequivocally define this role based on the research performed to date. Thomas & Friedmann (2011)

found that discharges of the ICD play a crucial role in generating stress in patients. By comparison, Thylén, Moser, Strömberg, Dekker & Chung (2016) indicate that stress in patients is much more strongly triggered by their anxieties connected to the ICD than by shocks themselves.

Experiencing cardiovascular disease and the need for an implantable cardioverter defibrillator can be a traumatic event for many patients (Ladwig et al., 2008), causing them to develop post-traumatic stress disorder (PTSD), characterised by repeated reliving of the trauma, avoidance of related stimuli and overstimulation (World Health Organization, 1992). This results from the fact that the shocks experienced can be traumatic stressors, reminding patients of their life-threatening illness (Neel, 2000). Important predictors of PTSD in ICD patients include younger age, the severity of depressive symptoms and type D personality (Habibović, Denollet & Pedersen, 2017). It was established that one in five patients develops full-blown post-traumatic stress disorder between two and six years after the implantation of an ICD (von Känel, Baumert, Kolb, Cho & Ladwig, 2011). Versteeg, Theuns, Erdman, Jordaens & Pedersen (2011) analysed PTSD symptoms in patients on two occasions – first three and then six months after ICD implantation. Three months after the procedure, almost 12% of the subjects met the diagnostic criteria for PTSD, and 60% of these patients still met the same criteria six months after the implantation. Furthermore, six months after the surgery, 4% of patients who previously did not meet the criteria for PTSD now did. Similar indicators were arrived at by Ghezzi et al. (2023) by diagnosing post-traumatic stress disorder in almost 13% of their study subjects. With regard to paediatric ICD patients, it was established that parents of these patients are more likely to meet the diagnostic criteria for PTSD than the children (Schneider et al., 2022). Versteeg et al. (2011) also found that the strongest predictor of PTSD during the first evaluation were the shocks experienced, but type D personality and high levels of anxiety before the procedure also played an important role. Feelings of anxiety and fear associated with the implantation of the ICD (but not shocks) were significant predictors of PTSD six months after surgery.

4. Quality of life

Having to live with an ICD and the prospect of potential shocks are factors with a negative impact on patients' quality of life. However, this particular dependency is not easy to describe. Some researchers point to a reduction in the quality of life in ICD patients (Lévesque et al., 2020; Thomas et al., 2006). The predictors of a decrease in the quality of life include female gender, not having a job outside the home, experiencing shocks, negative experiences with the ICD, higher levels of ICD anxiety and the presence of anxiety, depression and type D personality (Groeneveld, Matta, Suh, Heidenreich, & Shea, 2006; Miller et al., 2019; Sears, Lewis, Kuhl, & Conti, 2005). Anxiety and depression are also significant predictors of the quality of life in paediatric patients (DeMaso et al., 2004). In contrast, some researchers point to an improved quality of life after device implantation (Januszkiewicz et al., 2022; Januszkiewicz et al., 2023; Kindermann et al., 2021). As established by Bednarek et al. (2014), this is made possible by educating patients about the design and operating mechanism of the ICD, the method of its implantation and the basic recommendations for the time before and after the procedure. In contrast with the research discussed above, Da Silva et al. (2018) point to the lack of dependency of the quality of life on ICD discharges. They reviewed seven studies comprising almost six thousand participants.

A large share of researchers choose to focus on a specific aspect of the quality of life, i.e. health-related quality of life (HRQoL). Some studies indicate that health-related quality of life in ICD patients is lower than in healthy individuals (Magnusson, Mattsson, Wallhagen & Karlsson, 2021; Noyes et al., 2007). Health-related quality of life in children and adolescents was also found to be reduced and similar to that of cardiac patients (Pyngottu, Werner, Lehmann, & Balmer, 2019). Other researchers indicate that the level of health-related quality of life in ICD patients is similar to the level observed in the general population (van den Heuvel et al., 2022) and the population of cardiac patients treated using different methods (Bundgaard et al., 2019; Leosdottir et al., 2006), and that it increases over time (van den Heuvel et al., 2022).

In a study by Israelsson, Thylén, Strömberg, Bremer & Årestedt (2018), most ICD patients with a history of cardiac arrest rated their health-related quality of life as acceptable and at a similar level to that of healthy individuals. When explaining these positive results, researchers point to regular follow-up visits and a heightened sense of control. In contrast, lower health-related quality of life compared to the general population was associated with being unemployed, having comorbidities, perceiving a decrease in control and having a type D personality. Other studies found that female gender (Israelsson et al., 2018; van den Heuvel et al., 2022), lower education (van den Heuvel et al., 2022) and high levels of anxiety and depression (Hammash et al., 2019) are important risk factors for reduced health-related quality of life.

5. New identity

One of the key topics that emerge in the narratives of patients with an ICD when they discuss changes in their lives is the change in their identity (Pasyar, Sharif, Rakhshan, Hossein Nikoo & Nava, 2017). This issue was primarily explored by means of qualitative research. Patients place particular emphasis on their reduced ability or inability to return to the roles they previously held, particularly their professional roles (Humphreys et al., 2016a; Moradi et al., 2022). Moreover, their attempts to reclaim their former self often generate feelings of disappointment (Humphreys et al., 2016a). Patients recognise themselves as disabled (Moradi et al., 2022) and emphasise their feelings of dependency, worthlessness and humiliation compared to how they felt in the past (Pasyar et al., 2017). According to research by Barisone et al. (2022), patients feel that their lives have changed dramatically, and the suggestions directed towards them about the need to lead a 'normal life' make them feel misunderstood. For this reason, ICD patients find support groups to be particularly useful. Such groups allow them to share their feelings with people with similar experiences.

After ICD implantation, patients have a different perception of their body, and their self-image also changes as a result. The sense of having a foreign

object inside their body makes it difficult for them to adapt to the new situation (Moradi et al., 2022; Pasyar et al., 2017). Patients are often surprised to find that the device is larger than they expected, that it protrudes from the body, its shape is clearly visible under the skin, and that the incision is under the collarbone instead of close to the heart (Humphreys et al., 2016a). Such a protrusion at the site of the device implantation or scarring evokes feelings of embarrassment (Frydensberg, Skovbakke, Pedersen & Kok, 2018). Furthermore, patients feel that their life is supported by a machine (Moradi et al., 2022). The device itself can be a source of physical discomfort. It is reported particularly by those patients who present difficulties in adapting to the new situation or those who were not convinced of the decision to have an ICD implanted (Humphreys et al., 2016a).

6. Partners of ICD patients

When discussing the lives of ICD patients, it is also important to mention how the implantation of the device affects the lives of their partners. They manifest similar levels of depressive symptoms (Pedersen et al., 2009; Rottmann et al., 2018), similar levels of stress (Van den Broek, Habibović & Pedersen, 2010) and higher levels of anxiety than the patients themselves (Pedersen et al., 2009; Rottmann et al., 2018). Van den Broek et al. (2010) established that the greatest concerns were raised by partners with regard to the care over ICD patients and potential overprotection, the change in roles previously performed, the feeling of helplessness and uncertainty resulting from shocks, the resumption of sexual activity the potential of shocks during sexual activity, and the patients' ability to drive. As part of their research, Humphreys et al. (2016b) conducted semi-structured interviews with eighteen partners of ICD patients. The respondents mentioned concerns linked to the risk of cardiac problems in the future; however, they did not always share these concerns with their partners. A considerable challenge for them was the

change from a parallel relation to a relation between the carer and the person receiving care. For many respondents, the most important objective was the return to normality, understood as a return to the state before their loved ones fell ill.

Conclusion

Patients living with an implantable cardioverter defibrillator are faced with a variety of challenges – starting with the implantation decision and ending with the dilemma of having to decide about the deactivation of the device. Some studies show that following ICD implantation, patients adapt well to their new life. It should be remembered, however, that some patients find the adaptation process difficult. Patients may experience severe anxiety and present symptoms of depression. A large share of researchers link both anxiety and depression with the discharge of the device. That being said, research findings in this area are not consistent. Some researchers validate such a correlation, while some point to alternative grounds for the psychopathological symptoms. Most researchers agree that these symptoms can occur at any stage of an ICD patient's life – from implantation until the death of the patient. The implantation of the implantable cardioverter defibrillator is also a source of stress for the patient, with some patients meeting the diagnostic criteria for post-traumatic stress disorder. The difficulty in adapting to a new life with an ICD, as well as the emerging psychopathological symptoms, also have an effect on patients' quality of life. Some patients consider the ICD as a life-saving device, while others regard it as a tool that restricts and hinders their functioning. Moreover, ICD patients point to the changes taking place in their selfhood and their self-image. It is also important to mention that the implantation of the ICD has an effect on the life of partners of patients with an ICD. Finding the situation demanding, they also may experience symptoms of anxiety or depression.

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