

Psychological and clinical problems in young adults with implantable cardioverter-defibrillators

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Abstract

Background: Implantable cardioverter-defibrillators (ICD) are the most effective treatment in patients with the risk of sudden cardiac death. ICD improves patients' safety but is also the source of numerous inconveniences. Especially young people consider such ICD-related inconveniences as most unwelcome.

Aim: To assess the quality of life and main psychological problems encountered in young adults with an ICD.

Methods: We studied 45 subjects aged 14-29 years (mean 21.2±4.3). ICDs were used in primary prevention in 22 patients, and in secondary prevention in 23 patients. Time elapsed from implantation ranged from 5 months to 11 years (4.3±2.7 years). Since the problems affecting this group were rather specific, the patients' quality of life was assessed with a special questionnaire addressing important issues and problems associated with living with an ICD.

Results: ICD discharges were observed in 67.4% of patients (primary prevention – 45.5%, secondary prevention – 82.6%), multiple shocks in 47.2%, and phantom shocks in 21.4%. Anxiety associated with an ICD discharge was reported by 84.4% of patients. In order to prevent ICD discharges, 53.3% of patients decreased their activity. Problems with memory were observed in 42.2% of patients, with concentration in 47.6%, and with sleep in 42.2%. Almost half of those over 18 years of age were active drivers. None of the subjects experienced an ICD discharge during sexual intercourse. None of the men reported any sexual problems, while seven (41.2%) women did. Almost a quarter of the patients claimed to have had complications after the implantation. Young adult patients generally were compliant to have their ICD checked and accepted their limitations and disease. Fewer people assessed their health status as bad. Some patients in the group studied found it extremely difficult to accept their disease and/or ICD and to adapt to the situation. As many as nine patients believed the ICD implantation had been unnecessary, seven did not accept the ICD, three patients thought negatively of follow-up visits, three were not compliant, 13 did not accept the limitations, four refused to accept the fact that their disease existed, and seven refused to do anything. At least four patients talked or thought about having the ICD removed.

Conclusions: Patients with ICD have problems in different spheres of their activity (physical, psychological, and social). Such patients need to be informed appropriately about the ICD itself and its functioning. They should be granted psychological support from health professionals who are familiar with the specific problems of ICD recipients.

Key words: quality of life, sudden cardiac death, implantable cardioverter-defibrillator, psychological problems

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Introduction

Implantable cardioverter-defibrillators (ICD) are implanted in patients with the risk of sudden cardiac death (SCD). The ICD increases the safety of the patient (by limiting the risk of SCD) and reduces the possibility of neurological complications due to SCD [1, 2]; however, it causes numerous inconveniences and difficulties [3, 4]. The limitations that result from the heart disease together with the difficulties connected with the ICD are especially severe in young adults [5, 6]. The treatment of this group of patients is connected with many difficulties and requires

immense knowledge of the functioning of young people with ICD. The presented report is the first one in Poland, and also one of very few publications in world literature, to cover many aspects of the quality of life of young adults with ICD.

Methods

Fifty five subjects who had an ICD implanted in our department between the years 1995 and 2006 and who were younger than 21 years at the time of the implantation procedure (6-21 years, mean 16.7±3.5) were qualified for

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the study. The characteristics of the study group are presented in Table I. The questionnaire was sent via regular mail after an earlier phone call informing about the aim of the study and the request to complete the forms. It was not possible to establish the current addresses and telephone numbers of 5 patients. One patient died. Two female patients refused to participate in the study. Two patients did not return the questionnaire.

Considering the specificity of the problems of examined patients, in order to assess the quality of life, an individual questionnaire concerning important issues and problems of patients with ICDs was used. The first part of the questionnaire covered issues connected directly with the functioning of patients with ICDs: questions about ICD shocks, if they occurred, the number of ICD shocks, whether the patient suffered from a series of ICD shocks (>3 ICD shocks per 24 hours), phantom ICD shocks (the condition when the patient thought he had an ICD shock, but the ICD control did not reveal it), and whether the patient is afraid of the ICD shocks. The questions also referred to the test ICD shock performed as a standard procedure a few days after the implantation as well as the evaluation of the implantation site. The second part consisted of questions connected with various psychological problems: occurrence of aggressive behaviour, problems with sleeping, concentration, psychologist's and psychiatrist's care, and intake of sedative drugs. The third part applied to everyday activity of patients: education, work, driving and physical activity. The fourth part included questions about the advantages and disadvantages of life with an ICD and plans for the future. Some of the questions were closed questions, with suggested answers, i.e. yes or no, while some of the questions were open. Additionally, patients older than 18 years (n=35) received a separate anonymous questionnaire concerning the possible influence of the ICD on their sexual life.

Because not all responders answered all the questions, the description of the results includes the number of answers (n=x).

Results

ICD shocks

The characteristics of ICD shocks are presented in Table II. The frequency of occurrence of the fear of ICD shock and the intensity of the fear are displayed in Figure 1.

When describing the feelings accompanying ICD shocks 45.5% of subjects mentioned pain; 22.7% described it as a beat; 9.1% felt bad. The patients also described their feelings during ICD shocks as 'intense, unpleasant', 'strong shock', and 'decline of the visual field, loss of consciousness, hitch' (n=22).

In order to eliminate the number of ICD shocks 53.5% of subjects limited their activity, 42.2% did not limit their activity and 4.4% limited their activity at some times (n=45). In order to prevent ICD shocks the patients avoided running

– 58.3%, exertion – 45.8%, 4.8% – playing football, carrying weights, fast walking, swimming, hard work, rapid and intense movements, and 1 person avoided stress (n=24).

Table I. Characteristics of the study group

Number of subjects [n]	45
Age [years]	21.2±4.3 (14–29)
Female	20
Primary prevention	22
Secondary prevention	23
Time after ICD implantation [years]	4.3±2.7 (5 months – 11 years)
Aetiology:	
hypertrophic cardiomyopathy	19
long QT syndrome	6
idiopathic ventricular fibrillation	6
arrhythmogenic right ventricular dysplasia	5
dilated cardiomyopathy	3
polymorphic catecholaminergic	
ventricular tachycardia	3
others	3

Table II. Characteristics of ICD shocks

	Yes	No
Shocks (n=43)		
[n]	29	14
[%]	67.4	32.6
Series of shocks (n=36)		
[n]	17	19
[%]	47.2	52.8
Phantom ICD shocks (n=42)		
[n]	9	33
[%]	21.4	78.6
Fear of ICD shocks (n=45)		
[n]	38	7
[%]	84.4	15.6
Shocks after ICD implantation	primary prevention	secondary prevention
[%]	45.5	82.6
Number of ICD shocks per individual (n=25)	1–30 mean=7.1	
ICD shocks (n=20)	appropriate 14 subjects	inappropriate 10 subjects (only inappropriate – 6, appropriate and inappropriate – 4)
Number of series of ICD shocks (n=13)	10 subjects experienced 1 series of ICD shocks, individuals experienced 2, 3 and 10 series of ICD shocks	
Number of ICD shocks in one series	3–36 mean=8.6	

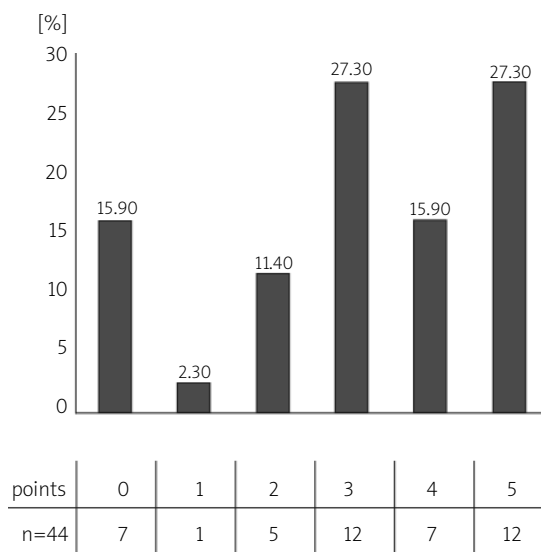


Figure 1. Fear of ICD shock – patient self-assessment (in points from 0 to 5)

None of the examined subjects reported problems with leaving home or staying home alone. Two subjects noted that they had not had such problems for a few months/years.

After ICD implantation (n=40) 6 subjects (15%) reported improvement in the quality of life, 2 subjects (5%) reported worsening, 3 patients reported anxiety as the major change, 2 patients reported stress, and 2 subjects reported decreased intensity of physical activity; patients also pointed out the necessity to follow doctor's recommendations, problems in interpersonal contacts, decreased self-esteem, changes in their plans for the future ('before implantation I was a healthy man, now I have to live the life of an invalid'); a lack of changes was reported by 9 patients (22.5%).

Answers to the question 'What did/do you give up doing because of the ICD implantation?' (n=37) included: physical exertion – 27%, sport – 27%, swimming – 8.1%, activities that can lead to damage of the ICD device – 8.1%, dancing – 5.4%, using the mobile phone in the right hand – 5.4%, single answers – carrying heavy things, going to the supermarket; 21.6% of the subjects did not give up doing anything.

Table III. Evaluation of subjects' health

Health n=44	Good	Average	Bad
Prior to implantation			
[n]	22	16	6
[%]	50	36.4	13.6
Currently			
[n]	24	19	1
[%]	54.5	43.2	2.3

Answers about advantages of life with an ICD included: security – 66.7%, life protection – 13.3%, serenity – 10%, increased activity – 6.7%, fewer hospitalisations – 6.7%, normal life – 6.7%, single answers – more serious attitude to life, breaking habits, positive life attitude, better quality of sleep; 16.7% of the subjects did not notice any positive aspects of life with an ICD (n=30).

The disadvantages of life with an ICD in patients' opinion (n=31) included: ICD shocks (anxiety, unnecessary) – 22.6% of subjects, 22.6% – the appearance of the implantation area (scar – 4, convexity – 3), limitations (i.e. when deciding on a profession, inability to carry heavy things, do gymnastics, work out, dance, use some electrical devices) – 16.1% of subjects, 9.7% – the extraneous body, 9.7% – pain in the ICD implantation area, 6.5% – taking care of the ICD, 6.5% – exchanges of the device. 9.7% of subjects reported no negative consequences.

As answers to the open question 'After ICD implantation I am afraid of...' 57.5% of the patients indicated ICD shocks (inappropriate moment, the presence of other people who are not aware of the ICD, in situations when other people may get hurt, i.e. when driving a car; inappropriate discharges), 7.5% of the patients indicated the possibility of ICD damage (e.g. getting smashed), 5% – effort, 5% – exchanges of the device, 5% – passing through the gate in a supermarket, single answers – the future, thunderstorms, swimming in a lake (n=40).

Seventy seven percent of the subjects believed that the implantation was necessary; 23.1% reported otherwise (n=39). The ICD was accepted by 82.9% of the patients, and not accepted by 17.1%. At least 4 subjects (9%) of the studied group spoke/thought of ICD removal.

The defibrillation test (DFT) following ICD implantation

Twenty-four subjects (57.1%) were anaesthetised for DFT; 18 (42.9%) were fully conscious (n=42). When asked about the feelings accompanying DFT (n=16), out of 13 patients who were not anaesthetised, 7 had unpleasant memories ('one of the worst moments in my life', 'something awful', 'horrific'); those who were anaesthetised (3 patients) did not remember DFT or described it positively.

Nine patients (22%) reported post-DFT, whereas 32 (78%) did not (n=41).

Evaluation of the implantation site (scar)

The appearance of the implantation site was accepted by 77.3% of the patients and was not accepted by 22.7%, including 5 females and 5 males (n=44). Three patients (6.7%) did not have any stipulations concerning the implantation site, 25 (55.6%) described it as a scar, 17 (37.8%) as a keloid. Twenty patients (55.8%) admitted to exposing the wound, 19 (44.2%) to covering it (n=43). When asked about the look of the scar, 16 patients (48.5%)

Table IV. Characteristics of physical activity (number of patients)

	Walking	Running	Cycling	Swimming	Dancing	Working out
Before the heart disease	25	25	30	23	16	19
Before the ICD implantation	33	18	29	23	22	12
Currently	38	5	28	17	16	2

had no stipulations, 15 patients (44.5%) had negative opinions (n=33). At least one subject, who was ashamed of the appearance of the implantation site, had problems with intimate contacts; another patient reported that he had stopped going to the swimming pool.

Consequences of the disease

Because of the disease patients had given up the following: physical effort – 47.4% of subjects, sport – 34.2%, education – 7.9%, dancing – 7.9%, stress – 5.3%, (n=38). The disease was accepted by 75% of patients, 15.9% of the subjects resisted it and 9.1% denied the disease. The evaluation of the subjects' health condition is displayed in Table III.

Forty one (93.2%) patients followed doctor's recommendations, whereas 3 (6.8%) did not. 68.3% of the patients accepted the limitations, 31.7% did not (n=41).

Table V. Psychological aspects of functioning with ICD

	Yes	No
Psychological care n=45 [%]	6 13.3	39 86.7
Psychiatrist care n=44 [%]	2 4.5	42 95.5
Sedative drugs n=41 [%]	6 14.6	35 85.4
Memory problems n=45 [%]	19 42.2	26 57.8
Concentration problems n=42 [%]	20 47.6	22 52.4
Sleeping problems n=45 [%]	19 42.2	26 57.8

Table VI. Characteristics of aggressive behaviour

	Occurrence of aggressive behaviour (n=45)				The frequency of aggressive behaviour before implantation (n=42)			Type of aggression (n=44)	
	often	sometimes	rarely	never	the same	less	more	physical	verbal
[n]	3	15	20	7	25	15	2	11	33
[%]	6.7	33.3	44.4	15.6	59.5	35.7	4.8	25	75

Life activity

Decreased life activity was noted by 22 subjects (50%), unchanged by 18 patients (40.9%), increased by 4 subjects (9.1%) (n=44). The characteristics of the physical activity are displayed in Table IV.

Forty and half percent of the patients lived their life exactly as their peers, 30.1% lived a worse life, none of the subjects functioned better, 28.1% lived differently (slower – 4, more carefully – 5, 1 – 'without sport or recreation, avoiding meeting other people', 'feeling sorry when seeing somebody running, dancing and I cannot because fibrillation or ICD shock is possible – such simple life situations'). The sum of the answers 'worse' or 'differently' was 25 (59.5%) (n=42).

Sixteen subjects drove a car (45.7% of people older than 18 years), 23 did not (19 – 54.3% of people older than 18 years).

Psychological problems

The characteristics of some psychological aspects of functioning of young adults with ICD are presented in Table V. Some of the patients reported having sleep problems after ICD implantation. Twelve subjects (26.7%) had problems with both memory and concentration. According to the patients, the problems with memory and concentration occurred or increased after sudden cardiac arrest, ICD implantation, or ICD testing, or resulted from the intake of medications.

The characteristics of patients' aggressive behaviour are displayed in Table VI.

Sexual area

The questionnaire concerning sexual life was completed by 28 out of 35 subjects older than 18 years, 11 males and 17 females. None of the studied subjects experienced ICD shock during intercourse. None of the studied male subjects encountered difficulties in the sexual area. Seven female subjects (41.2%) had problems: 4 patients felt anxiety about sexual contacts, 4 limited intimate contacts, 3 did not have

intercourse. Two female patients added their own comment: one felt anxiety about sexual contacts shortly after ICD implantation, but not at the moment; the other explained that she felt ashamed of the scar.

Plans for the future

Most of the subjects mentioned work, family, 'living happily with the disease that they have and that they got used to', 3 patients do not have plans for the future ('lack of long-term plans because of the disease', 'I live for the present day'), 1 – 'it is difficult to change the plans you had that are now unattainable', 'remove the ICD' (n=34).

Discussion

In the years 1995-2006 in our department an ICD was implanted in 598 patients; 10% of them were young adults (<21 years of age) [7]. Long-term observation of such a large group of patients results in vast experience, especially in terms of the treatment of young adults with ICDs in Poland [8].

During the observation period most of the subjects experienced ICD shocks. Similar results are presented by Sears et al. [9]. According to their study the percentage of patients experiencing ICD shocks during the first two years after the implantation varies between 50 and 70%. Maron et al. observed appropriate ICD interventions in 20% of subjects (in secondary prevention – 42%, in primary – 13%) (mean 3.7±2.8 years) [10].

Another issue concerning that group of patients are inappropriate ICD shocks. Lewandowski et al. observed 46 young adults (mean follow-up of 4.3 years). No significant differences in the number of appropriate discharges were noted between children and adults, but more inappropriate discharges were observed in younger patients (30% single or multiple unnecessary interventions) [8]. Credner et al. observed a series of ICD shocks in fewer patients than in the presented study (10-30%) [11]. ICD shock is a very traumatic and painful experience; its consequences might include serious psychological disorders such as post-traumatic syndrome [4].

The feelings accompanying ICD shocks are very unpleasant, which is one of the reasons for the fear of their occurrence. Sears et al. reported a lower percentage of patients presenting with a fear of ICD shocks compared with our study (33-46%) [12]. ICD shock tends to be such a strong experience that even an indifferent impulse (e.g. slight physical effort) can result in anxiety or a panic attack. The studies of Godemann et al. indicate that 19.4% of subjects present with agoraphobia and/or panic attacks [13]. It is especially difficult for patients to accept inappropriate shocks (especially in the primary prevention, and when there is a lack of appropriate shocks) and series of ICD shocks.

In extreme situations a patient limits his activity, not only physical but also life activity, in a considerable and unwarranted way [13]. Our observations suggest that the problems in the studied group are even greater than the questionnaire would suggest. It should be emphasised that the ICD implantation procedure reduces patients' physical activity more than the heart disease (Table IV). The fear of ICD shocks seems to be more important for patients than the threat connected with the disease. Sixty percent of patients claim that they live worse or a different life than their peers. Dyga et al. in a study of a group of young patients with pacemakers found that the way of life of one third of them differed significantly from the way of life of their peers [6]. The most severe limitations (reported most often) that result from the disease and the presence of device are connected with physical activity. Young subjects examined by Dyga et al., similarly to our group of patients, complained of decreased physical activity, limitations in working out, not attending gymnastics at school, taking care not to damage the device, stress, and 'not being able to do things that others do'. It is especially difficult for young patients since the need for physical activity is strong during developmental age [6]. Repeated ICD interventions most often result in decreased physical activity. The study of Duru et al. [14] confirms that patients with ICD shocks more often present with restriction of their physical activity more greater fear.

The possibility of emotional disorders increases proportionally to the number and frequency of ICD shocks [15]. In the CIDS study the quality of life deteriorated in those patients who had experienced five or more ICD shocks during the last 12 months [4]. Contrary results were obtained from the NSIRSO study, where no correlation was found between the ICD shocks and the quality of life [16].

There are many possible complications of ICD implantation [7, 8]. Lewandowski et al. indicate that surgical complications in young patients occur often (12%), whereas in adult patients only in 3% of cases [8]. Our observations indicate that the complications affect more subjects, not just those who mentioned it in the questionnaire. Due to the complications one patient died. The study of Gepner et al. confirms that surgical complications in patients with ICD are frequent [7].

Another issue concerning the studied group is DFT. An important question is whether the procedure should be performed under general or local anaesthesia. It is thought that when the patient experiences the ICD shock in controlled conditions he gains knowledge of how to behave during the ICD shock in everyday life; however, the patients' reports do not confirm that; the test ICD intervention and real ICD shocks differ significantly and the test does not prepare the subject for real shock. Attention should be paid to the very unpleasant sensations and high levels of stress that accompany DFT testing performed without general anaesthesia. From the psychological point of view such experiences should be limited.

Currently in our department DFT is performed during the implantation procedure (in general anaesthesia); it is not routinely performed after the procedure.

Patients with ICDs are at high risk of experiencing anxiety disorders and depression. Sears et al. demonstrated that the level of anxiety increases in 24-87% of patients after ICD implantation, and 13-38% of subjects present with anxiety disorders [12]. According to Eicken et al. almost 50% of young patients suffer from depression and/or increased level of anxiety [17]. Younger patients are more stressed and present with worse quality of life [18].

Examined subjects experience many psychological problems (Tables V, VI). According to Sears et al. memory problems affect 64% of patients, sleeping disorders 56% of ICD patients (this is compatible with the results of the present study), and irritation level increases in 18% of subjects [13].

Another important problem in the studied group is the appearance of the implantation site. In the majority of young patients with an ICD the scar does not objectively look good. The scar can be the cause of difficulties in self-acceptance and numerous limitations. In Dyga et al.'s study two patients presented with keloid, and 27% of patients presented with scarring (9 girls and 7 boys) [6]. Specific problems of this age – group connected with self-esteem, problems with accepting one's body, scars on the skin and the importance of physical appearance are quite common.

Sears et al. demonstrated that 33% of patients experienced problems in their sexual life [12]. Eicken et al. reported that 43% of patients with ICDs reduced their sexual activity after ICD implantation [17]. In our study 41% of females had problems with their sex life.

In our study almost 50% of subjects continued driving a car. Lüderitz et al. reported that almost 1/3 of subjects continued to drive a car. According to their study the risk of a road accident due to arrhythmia or ICD shock is relatively low [4]. Also the latest study of Epstein et al. (2007) demonstrates that the risk of a car accident in patients with ICDs, including numerous factors, is 3.4%, which is lower than in the general population (7.1%) [19]. Moreover, driving a car can reduce stress and limitations in everyday life. Lüderitz et al. also point out the significant negative correlation between quality of life and the limitations in driving a car [4]. Some patients consider a ban on driving a car as a major difficulty, huge infirmity and stigmatisation (for some young adults it is almost a tragedy).

Young adults usually regularly attend ICD controls, and accept the limitations and the disease. They notice positive aspects of life with an ICD; moreover, after implantation of the ICD they reported an improvement in their health (Table III). In the NSIRSO study, 91% of patients with an ICD described their quality of life as satisfactory, 45% of them described it as better than prior to the ICD implantation procedure, whereas 46% did not notice any change in the quality of life [16]. Some patients do not accept the disease

or the limitations connected with it. Another thing that makes life with an ICD hard to accept is ICD implantation as primary prevention, which may result in the low motivation for this type of treatment. Many patients wonder whether the implantation procedure was necessary considering the lack of appropriate, life-saving ICD shocks and the complications that occur. Patients face various problems; it depends on how important are physical activity, sport, physical appearance, and future plans, including professional plans, and to what extent the disease disturbs all these things. If the disease impedes or prevents the realisation of future plans, including simple activities (e.g. playing football, running), the need to change plans for the future occurs. What is crucial is the acceptance and awareness of the disease, the threat that it carries, the will to live, self-acceptance despite the infirmity, having important plans (e.g. planning a family) and the ability to fulfil them, and family support. Adaptation to the new situation results in fewer ICD shocks and complications. The majority of patients with an ICD, who experienced sudden cardiac arrest or symptomatic ventricular fibrillation prior to the ICD implantation procedure, consciously agree to the procedure, being aware of the high risk of sudden cardiac death [4].

It seems that psychological factors play an important role in adapting to life with the ICD, and significantly modify the quality of life in the studied group. Some of the studied subjects in our group experience significant difficulties in accepting the disease and/or ICD as well as adapting to the situation: 9 patients consider the ICD implantation as unnecessary, 7 do not accept the ICD, 3 patients present with a negative attitude towards routine check-ups, 3 patients do not follow medical recommendations, 13 patients do not accept limitations, 4 patients deny the disease, 7 patients resist. At least 4 patients from the studied group talk or think about removal of the ICD. This problem is not assessed since for ethical reasons a question concerning this issue was not included in the questionnaire.

Multiple British studies demonstrate that over 30% of children under the age of 15 years with chronic disease present with many adaptive problems (neurosis disorders, impaired educational motivation, problematic social behaviours) [20]. Adolescence is the least favourable age to cope with the disease. It was found that time positively influenced adaptation to life with an ICD [6]. The majority of patients from the studied group do not use the psychologist's or psychiatrist's care, or take sedative drugs (Table V). The question still remains unanswered whether they cope with the problem themselves or they are left alone with it. Some of the patients do not use psychological therapy even though it was suggested [8]. It should be remembered that access to psychological therapy in Poland is limited, especially considering psychologists who would be familiar with the problems of this group of patients. However, for many of the difficulties that the patients encounter, psychological help is essential. The necessity of psychological help in young

subjects was emphasised by Eicken et al. [17]. The problems may also arise some time after ICD implantation, during the exacerbation of the disease, during ICD shocks and other complications. Psychological care is especially essential during hospitalisation or when numerous complications occur. In order to improve the quality of life of patients with an ICD and to avoid numerous psychological problems the following are necessary: forming an appropriate attitude towards ICD shocks, explaining the mechanisms of its functioning, answering patients' questions and prevention of improper behaviour. Support should also be given to members of the families of patients with an ICD, in order not to share their own fear with patients. The studies of Kohn et al. [21] demonstrated that psychological support might result in a reduction of anxiety and depression. Sears et al., however, claim that the cardiologist might be able to provide sufficient psychological help [9]. There are numerous arguments supporting the idea of the psychologist being a member of the team that takes part in the treatment of the patient. Physicians usually do not have enough time and very often lack the psychological skills. Sometimes the doctor wants to hear that the patient feels fine. Sometimes there is a specific bond between the patient and the doctor and the patient does not want to worry the doctor who takes care of him.

Patients with ICDs have ambivalent feelings. The ICD device is the source of the fear of ICD shocks and the feeling of being dependent, but also the guarantee of safety. Depending on which is stronger, the patients returns to everyday activities, or, conversely, the ICD results in anxiety disorders, post-traumatic syndrome, loss of the will to live, and a sense of misery and helplessness [22]. The presented study confirms this thesis. It becomes crucial whether the patients focuses on what they have lost or on what they may gain despite the limitations they encounter. As one of the female patients wrote in her questionnaire, 'you must appreciate what you have and not look back on what you have lost'.

Study limitations

The study was limited by the fact that the questionnaires were completed by the patients in different periods after the implantation, which might have influenced the results. However, the observations made demonstrate that the time that has passed since the procedure is not crucial for the patients' opinion. The number of ICD shocks, complications, the occurrence of inappropriate ICD shocks, series of ICD shocks seemed to be more crucial. Another limitation of this study was the fact that patients did not complete a similar questionnaire before the ICD implantation. However, many of the questions could only be answered after the implantation, i.e. about the fear of ICD shocks or sex life.

Conclusions

1. Patients with an ICD experience numerous, various difficulties in different areas of their life (physical, psychological, social).

2. ICD patients require support with information (appropriate knowledge about the ICD and ways of functioning with it) as well as psychological care of specialists familiar with the specific problems of this group of patients.

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References

1. Przybylski A, Kurowski A, Lewandowski M, et al. Rola implantowalnych kardiowerterów-defibrylatorów w leczeniu komorowych zaburzeń rytmu serca. *Postępy Nauk Medycznych* 2002; 15: 99-103.
2. Przybylski A, Małeczka L, Pytkowski M, et al. Kardiowertery-defibrylatory u chorych z kardiomiopatią przerostową – dylematy i trudności. *Kardiologia Polska* 2005; 63: 391-7.
3. Kochańska A, Zarzycka B, Świętecka G. Jakość życia, problemy psychologiczne i adaptacyjne po implantacji automatycznego kardiowertera-defibrylatora serca. *Terapia* 2006; 2: 21-3.
4. Kochańska A, Lewicka-Nowak E, Zarzycka B. Czynniki wpływające na jakość życia u pacjentów z kardiowerterem-defibrylatorem serca. *Folia Cardiologica* 2006; 13: 171-7.
5. Sears SF, Burns JL, Handberg E, et al. Young at heart: Understanding the unique psychosocial adjustment of young implantable cardioverter defibrillator recipients. *PACE* 2001; 24: 1113-7.
6. Dyga-Konarska M, Bieganowska K. Jakość życia dzieci i młodzieży ze stymulatorem serca w ocenie pacjentów. *Folia Cardiologica* 2003; 10: 809-16.
7. Gepner K, Przybylski A, Maciąg A, et al. Przyczyny reoperacji u chorych z wszczepionym automatycznym kardiowerterem-defibrylatorem – obserwacja odległa. *Kardiologia Polska* 2007; 65: 893-8.
8. Lewandowski M, Przybylski A, Sterliński M, et al. Implantowalny kardiowerter-defibrylator u dzieci i młodzieży. Technika wszczepienia, opieka nad pacjentem, powikłania, holterowska analiza rytmu serca – doświadczenia własne. *Via Medica* 2005; 12: 842-51.
9. Sears FS, Conti JB. Understanding implantable cardioverter defibrillator shocks and storms: medical and psychosocial considerations for research and clinical care. *Clinical Cardiology* 2003; 26: 107-11.
10. Maron BJ, Spirito P, Shen WK, et al. Implantable cardioverter-defibrillators and prevention of sudden cardiac death in hypertrophic cardiomyopathy. *JAMA* 2007; 298: 405-12.
11. Credner SC, Klingenhoben T, Mauss O, et al. Electrical storm patients with transvenous implantable cardioverter-defibrillators: incidence, management and prognostic implications. *J Am Coll Cardiol* 1998; 32: 1909-15.
12. Sears SF Jr, Todaro JF, Lewis TS, et al. Examining the psychosocial impact of implantable cardioverter defibrillators: a literature review. *Clinical Cardiology* 1999; 22: 481-9.
13. Godemann F, Ahrens B, Behrens S, et al. Classic conditioning and dysfunctional cognitions in patients with panic disorder and agoraphobia treated with an implantable cardioverter/defibrillator. *Psychosomatic Medicine* 2001; 63: 231-8.
<http://www.psychosomaticmedicine.org/cgi/content/full/63/2/231>
14. Duru F, Buchi S, Klaghofer R, et al. How different from pacemaker patients are recipients of implantable cardioverter-defibrillators

- with respect to psychosocial adaptations, affective disorders, and quality of life? *Heart* 2001; 85: 375-9.
15. Maryniak A, Szumowski Ł, Walczak F, et al. Zespół stresu pourazowego u pacjenta z licznymi wyładowaniami ICD. Rola ablacji. *Kardiol Pol* 2006; 64: 910-2.
 16. Sears SF, Eads A, Marhefka S, et al. The U.S. national survey of ICD recipients: examining the global and specific aspects of quality of life. *Eur Heart J* 1999; 20: 232.
 17. Eicken A, Kolb C, Lange S, et al. Implantable cardioverter defibrillator (ICD) in children. *Int J Cardiol* 2006; 107: 30-5.
 18. Thomas SA, Friedmann E, Kao CW, et al. Quality of life and psychological status of patients with implantable cardioverter defibrillators. *Am J Crit Care* 2006; 15: 389-98.
 19. Epstein AE, Baessler CA, Curtis AB, et al. Addendum to 'Personal and Public Safety Issues Related to Arrhythmias That May Affect Consciousness: Implications for Regulation and Physician Recommendations: A Medical/ Scientific Statement From the American Heart Association and the North American Society of Pacing and Electrophysiology' Public Safety Issues in Patients With Implantable Defibrillators A Scientific Statement From the American Heart Association and the Heart Rhythm Society. *Circulation* 2007;115: 1170-6.
 20. Pilecka W. Przewlekła choroba somatyczna w życiu i rozwoju dziecka. *Wyd. UJ Kraków* 2002.
 21. Kohn CS, Petrucci RJ, Baessler C, et al. The effect of psychological intervention on patients' long-term adjustment to the ICD: a prospective study. *Pacing Clin Electrophysiol* 2000; 23: 450-6.
 22. Eckert M, Jones T. How does an implantable cardioverter defibrillator (ICD) affect the lives of patients and their families? *Internat J Nurs Pract* 2002; 8: 152-7.

Problemy kliniczne i psychologiczne młodych osób z implantowanym kardiowerterem-defibrylatorem

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Streszczenie

Wstęp: Kardiowerter-defibrylator serca (ICD) implantuje się chorym z ryzykiem nagłego zgonu sercowego. Urządzenie to zwiększa bezpieczeństwo, ale jest też źródłem niedogodności (wyładowania, wymiany urządzenia, powiktania, konieczność regularnych kontroli lekarskich, przestrzeganie zaleceń lekarskich). Trudności związane z funkcjonowaniem z ICD są szczególnie dotkliwe dla ludzi młodych.

Cel: Ocena głównych psychologicznych i klinicznych problemów młodych osób z implantowanym ICD.

Metodyka: Zbadano 45 osób w wieku 14–29 lat ($21,2 \pm 4,3$). W ramach profilaktyki pierwotnej ICD wszczepiono 22 chorym, w ramach profilaktyki wtórnej nagłego zatrzymania krążenia (NZK) – 23. Czas od wszczepienia (czas obserwacji) wynosił od 5 miesięcy do 11 lat ($4,3 \pm 2,7$ roku). Ze względu na specyfikę problemów tej grupy chorych, do badania jakości życia wykorzystano ankietę własną, dotyczącą ważnych zagadnień i problemów związanych z życiem z ICD.

Wyniki: Wyładowania miało 67,4% chorych (w tym 45,5% chorych z ICD wszczepionym w ramach profilaktyki pierwotnej i 82,6% z urządzeniem wszczepionym w ramach profilaktyki wtórnej), serię wyładowań miało 47,2% osób, wyładowania fantomowe – 21,4%. Lęk przed wyładowaniami odczuwało 84,4% badanych (skala 0–5, $x=3,1 \pm 1,7$). Aby uniknąć wyładowań, 53,3% chorych ograniczało aktywność. Aktywność po wszczepieniu u 50% chorych była mniejsza, u 40,9% taka sama, a u 9,1% chorych większa. Tak samo jak rówieśnicy funkcjonowało 40,5% osób, 30,1% – gorzej, 28,1% uważało, że funkcjonuje inaczej, nikt nie ocenił swojego funkcjonowania jako lepszego niż rówieśników. Problemy z pamięcią miało 42,2% chorych, problemy z koncentracją – 47,6%, problemy ze snem – 42,2%. Samochód prowadziło 45,7% osób powyżej 18. roku życia. Żadna z badanych osób nie miała wyładowania w trakcie współżycia. Trudności w sferze seksualnej nie zgłosił żaden z badanych mężczyzn, miało je 7 (41,2%) kobiet. Jako plusey życia z ICD 66,7% osób wymieniło bezpieczeństwo, 13,3% – ochronę życia, 10% – spokój, 16,7% uważało, że nie ma pozytywnych następstw wszczepienia ICD. Wśród minusów życia z ICD 22,6% chorych wymieniło wyładowania (w tym lęk z ich powodu i wyładowania niepotrzebne), taki sam odsetek badanych wskazał na wygląd (blizna, wypukłość), dla 16,1% były to ograniczenia wynikające z posiadania ICD: dla 9,7% – obce ciało, dla 9,7% – ból w okolicach ICD, dla 6,5% – uważanie na ICD, 6,5% jako minus wymieniło wymianę urządzenia, 9,7% nie widziało żadnych negatywnych następstw wszczepienia ICD. Powiktania po zabiegu miało 22% chorych. Młodzi chorzy ogólnie chodzili regularnie na kontrole ICD, akceptowali ograniczenia i chorobę. Po wszczepieniu odczuli poprawę swojego stanu zdrowia. Jednak niektórzy chorzy z badanej grupy doświadczali poważnych trudności w akceptacji choroby i/lub ICD i adaptacji do sytuacji – aż 9 osób uważało, że wszczepienie nie było niezbędne, 7 nie akceptowało ICD, 3 osoby miały negatywny stosunek do kontroli lekarskich, 3 nie przestrzegały zaleceń, 13 nie akceptowało ograniczeń, 4 osoby zaprzeczały chorobie, a buntowało się 7 chorych. Co najmniej 4 osoby z badanej grupy mówiły lub myślały o usunięciu ICD.

Wnioski: Osoby z wszczepionym ICD doświadczają wielu różnorodnych trudności w różnych sferach swojego funkcjonowania (fizycznej, psychologicznej, społecznej). Chorzy ci wymagają wsparcia informacyjnego (odpowiedniego przekazania wiedzy o ICD i zasadach funkcjonowania z ICD), jak również opieki psychologicznej osób znających specyfikę problemów tej grupy chorych.

Słowa kluczowe: jakość życia, nagły zgon sercowy, kardiowerter-defibrylator, problemy psychologiczne

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