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THE EXPERIENCE OF PATIENTS LIVING WITH AN IMPLANTABLE CARDIOVERTER DEFIBRILLATOR

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Abstract

Introduction: Different research presents the implantable cardioverter defibrillator (ICD) as an effective technology for patients with heart disease. In Kazakhstan ICD, implements last ten decades.

The aim of our research is to study the experience of patients after ICD implantation.

Materials and methods: We search documents related to the provision of care to patients with an implantable cardioverter defibrillator. Our cross sectional study included a survey of patients with ICD. The questionnaire consisted of the following parts: demographic data; availability and complexity of medical care in healthcare organizations; the attitude of medical professionals; satisfaction and preferences of respondents with the information received about the ICD. 63 respondents involved in online survey, which conducted in Russian and Kazakh languages, depending on the preferences of the respondents. The survey was conducted among patients who received an ICD in Almaty and Kyzylorda region in February - May 2021. Statistical analysis provided by using the SPSS 13. The variables are presented as the median Me [Q1, Q3]. The analysis of frequency characteristics of qualitative indicators was carried out using non-parametric methods using the Pearson criterion (χ^2). Differences in the data were considered statistically significant at $p < 0.05$.

Results: Positive dynamics that the clinical protocol has been developed for healthcare professionals. Outpatient difficulties were associated with an inconvenient system of registration, observation by a cardiologist on a paid basis 36.5%. The satisfaction of the respondents with the attitude of the medical specialists in outpatient and inpatient was high; with given information about ICD lower by respondents with higher education and satisfaction by age revealed that respondents under 60 had a high variation. One third of respondents does not prefer or do not know their preference for the exercise tolerance test and preferred the consultation of a psychologist during hospitalization for implantation.

Conclusion: There are needs to improve the provision of information on the positive and potential negative effects of ICD technology, and the provision of advice to patients at the primary care level, in order to improve the satisfaction and quality of life of patients with ICD

Key words: implantable cardioverter defibrillator, preference of the patient with ICD, patients with heart disease.

Резюме

ОПЫТ ЖИЗНИ ПАЦИЕНТОВ С ИМПЛАНТИРУЕМЫМ ДЕФИБРИЛЛЯТОРОМ КАРДИОВЕРТЕРА

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Введение. Различные исследования представляют опыт применения имплантируемого кардиовертер-дефибриллятора (ИКД) как эффективную технологию для пациентов с сердечными заболеваниями. В Республике Казахстан последнее десятилетие активно применяется технология ИКД.

Целью нашего исследования является изучение опыта жизни пациентов после имплантации ИКД.

Материалы и методы. Мы изучили существующие нормативные документы, связанные с оказанием помощи пациентам с имплантируемым кардиовертер-дефибриллятором. Наше кросс-секционное исследование предполагало проведение опроса пациентов с ИКД. Анкета состояла из следующих частей: демографические данные; доступность и сложность оказания медицинской помощи в организациях здравоохранения; отношение к пациенту сотрудников медицинской организации; удовлетворенность и предпочтения респондентов полученной информацией о ИКД. 63 респондента участвовали в онлайн-опросе, который проводился на русском и казахском языках в зависимости от предпочтений респондентов. Опрос проводился среди пациентов, получивших ИКД в г. Алматы и Кызылординской области в период февраль–май 2021г. Статистический анализ проведен с помощью SPSS 13. Переменные представлены в виде медианы Ме [Q1, Q3]. Анализ частотных характеристик качественных показателей проводился непараметрическими методами с использованием критерия Пирсона (χ^2). Различия данных считали статистически значимыми при $p < 0,05$.

Результаты: Положительной динамикой является наличие клинического протокола для врачей. Трудности на уровне первичного звена были связаны с неудобной системой регистрации, наблюдением кардиолога на платной основе - 36,5%. Удовлетворенность респондентов отношением специалистов-медиков в первичном звене и стационарных условиях была высокой; удовлетворенность по вопросу предоставления информации об ИКД ниже у респондентов с высшим образованием; и удовлетворенностью по возрасту, выяснилось, что респонденты до 60 лет имели высокий разброс. Треть респондентов не предпочитают или не знают, информацию о толерантности к физической нагрузке, а также треть предпочли консультацию психолога во время госпитализации для имплантации.

Выводы: Наблюдается потребность в улучшении предоставления информации о положительных и потенциальных отрицательных эффектах технологии ИКД, и предоставления рекомендации для пациентов на уровне первичного звена, чтобы повысить удовлетворенность и качество жизни пациентов с ИКД.

Ключевые слова: имплантируемый кардиовертер-дефибриллятор, предпочтение пациента с ИКД, пациенты с заболеваниями сердца.

Түйіндеме

ИМПЛАНТАЦИЯЛЫҚ КАРДИОВЕРТЕР ДЕФИБРИЛЛЯТОРЫ БАР НАУҚАСТАРДЫҢ ӨМІР СҮРУ ТӘЖІРИБЕСІ

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Кіріспе. Түрлі зерттеулер имплантацияланатын кардиовертер дефибрилляторын (ИКД) жүрек ауруы бар науқастар үшін тиімді технология ретінде ұсынады. ИКД технологиясы соңғы онжылдықта Қазақстан Республикасында белсенді түрде жүргізілуде.

Біздің зерттеуіміздің **мақсаты** - ИКД имплантациясынан кейінгі науқастардың өмір сүру тәжірибесін зерттеу.

Материалдар және әдістері. Біз имплантацияланатын кардиовертер дефибрилляторы бар науқастарды күтуге қатысты қолданыстағы ережелерді қарастырдық. Біздің кросс-секциялық зерттеуіміз ИКД бар науқастармен сауалнама жүргізуді қамтыды. Сауалнама келесі бөліктерден тұрды: демографиялық деректер; денсаулық сақтау ұйымдарында медициналық көмек көрсетудің қолжетімділігі мен күрделілігі; медициналық ұйым қызметкерлерінің науқасқа қатынасы; респонденттердің ИКД туралы алынған ақпаратқа қанағаттануы мен қалауы. Респонденттердің қалауына қарай орыс және қазақ тілдерінде жүргізілген онлайн сауалнамаға 63 респондент қатысты. Сауалнама 2021 жылдың ақпан - мамыр айларында Алматы және Қызылорда облысында ИКД алған науқастар арасында жүргізілді. Статистикалық талдау SPSS 13 көмегімен орындалды. Айнымалылар Ме медианасы [Q1, Q3] ретінде берілген. Сапалық көрсеткіштердің жиілік сипаттамаларын талдау Пирсон критерийін (χ^2) пайдалана отырып,

параметрлік емес әдістермен жүргізілді. Деректер айырмашылықтары $p < 0,05$ статистикалық маңызды деп саналды.

Нәтижелер: Дәрігерлер үшін клиникалық хаттаманың болуы оң үрдіс болып табылады. Алғашқы медициналық-санитарлық көмек деңгейіндегі қиындықтар тіркеу жүйесінің қолайсыздығымен, ақылы негізде кардиологтың бақылауымен байланысты болды, 36,5%. Респонденттердің алғашқы медициналық-санитарлық көмек пен стационарлық мекемелердегі медициналық мамандардың көзқарасына қанағаттануы жоғары болды; жоғары білімі бар респонденттердің арасында ИҚД туралы ақпаратты ұсынуға қанағаттанушылық төмен; және жасы бойынша қанағаттану, 60 жасқа дейінгі респонденттердің әртүрлілігі жоғары болды. Респонденттердің үштен бірі жаттығуларға төзімділік туралы ақпаратты ұнатпайды немесе білмейді, ал үштен бірі бөлігі имплантация үшін госпитализация кезінде психологтың кеңесін қалайды.

Қорытынды: ИҚД технологиясының оң және ықтимал теріс әсерлері туралы ақпаратпен қамтамасыз етуді жақсарту және ИҚД-ы бар науқастардың қанағаттануы мен өмір сүру сапасын жақсарту үшін алғашқы медициналық көмек деңгейінде науқастарға ұсыныстар беру бойынша қажеттілік байқалады.

Түйінді сөздер: имплантацияланатын кардиовертер дефибрилляторы, ИҚД бар науқастардың таңдауы, жүрек ауруы бар науқастар.

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Introduction

An implantable cardioverter defibrillator (ICD) is an effective treatment for patients with cardiomyopathy and heart failure symptoms and prevention of sudden cardiac death (SCD), which affected to survival rate [7, 8, 13, 23]. The frequency of patients who underwent ICD surgeries increases annually. This is due to the technical feasibility of the implant and the expansion of indications for patients requiring an ICD [18]. The age of patients receiving ICD increases, and accordingly they have several comorbidities [1]. However, patients with ICD may receive sudden shock or other complication death and cardiac arrest, system migration, infection [3, 12, 26].

A systematic review found a lack of evidence for improved quality of life in patients with ICD [5]. Complexity and adverse events may be associated with inappropriate therapy, or incorrect selection of impulses. Thus, the role of healthcare professionals in preparation patient ICD is very important. Patient with ICD education strategies can include online or offline methods [6, 19, 24]. There are a number of issues that need to be discussed by healthcare providers with patients, as a matter of end-of-life deactivation [16], patient goals and values, collaborative decision support interventions for patients [25, 4]. The review shows the importance of having guidelines for healthcare providers which provided information for patients which needed ICD is crucial [20, 9, 25]. In Kazakhstan last ten decades provided ICD for patient with heart disease.

The aim of this work is to study the experience of patients after ICD implantation.

Materials and methods: An appraisal was conducted of documents related to the provision of care to patients with an ICD. Inspection of the documents focused on the

existing guidelines, strategic programs, and the benefits for patients.

Our cross-sectional study design involved a survey of patients with ICD. The questionnaire consisted of the following parts: demographic data; availability and complexity of medical care in healthcare organizations; the attitude of medical professionals; satisfaction and preferences of respondents with the information received about the ICD. The attitudes of medical specialists were assessed by respondents from very satisfied - 5 points to not satisfied -1. The survey questions were adapted from Pedersen and coauthors [16].

The survey involved 63 patients and conducted by telephone. Before starting the survey, we familiarized patients with the purpose of the study and obtained voluntary consent to participate. The survey was conducted in Russian and Kazakh languages, depending on the preferences of the respondents. The survey was conducted among patients who received an ICD in Almaty and Kyzylorda region between February - May 2021.

Statistical analysis provided by using the SPSS 13 software (IBM, USA). The variables are presented as the median Me [Q1, Q3]. The analysis of frequency characteristics of qualitative indicators was carried out using non-parametric methods using the Pearson criterion (χ^2). Differences in the data were considered statistically significant at $p < 0.05$.

The Local Ethics Committee of Kazakhstan's Medical University «KSPH» (Almaty, Kazakhstan) approved the study. (№ 04-09-44 - IRB-A130 from 03-02-2021).

Results

Regulatory documents on ICD in Kazakhstan:

Clinical protocol "Implantation of a magnetic resonance imaging compatible cardioverter-defibrillator with cardioresynchronization function and remote monitoring" was developed and recommended by the Expert Council of the Republican Center development of health care of the Ministry of Health and social development of the Republic of Kazakhstan dated September 30, 2015 Protocol No. 10. The protocol was supposed to be revised 3 years after its publication and from the date of its entry into force or in the presence of new methods with a level of evidence that has not yet been revised (<http://www.rcrz.kz/index.php/ru/2017-03-12-10-51-13/klinicheskie-protokoly>). Reimbursement of expenses is carried out at the benefit package for all groups of population. No ICD patient guidelines in Kazakhstan were found in the search.

Baseline characteristics:

The largest number of respondents was male and had a secondary specialized education. There were no difference in the age group between over and under 60 years. One third of the respondents had the status of unemployed and the remaining 54,0% were pensioners. A deviation from the norm of body mass index is observed among 22,2% of the state of pre-obesity, 20,6% of obesity of the 1st degree (Table 1).

Availability and complexity of medical care in healthcare organizations

When receiving medical care in outpatient difficulties

were associated with an inconvenient system of registration with narrow specialists was indicated by 17,5%, especially for respondents under 60 years old ($P<0,031$), as well as observation by a cardiologist on a paid basis 36,5%, especially in the age younger than 60 years 48,5% ($P<0,038$) (table 2).

Table 1.

Baseline characteristics for included patients (n =63).

Demographics/ Characteristics		% (n) a
Sex	Female	15 (23,8%)
	Male	48 (76,2%)
Educational level	High	15 (23,8%)
	College	30 (47,6%)
	School	18 (28,6%)
Age, mean+SD	60+	30 (47,5%)
	60-	33 (52,4%)
Social status	Worker	5 (7,9%)
	A housewife	3 (4,8%)
	Retiree	34 (54,0%)
	Unemployed	21 (33,3%)
Single/ partner	Single	15 (23,8%)
	partner	48 (76,2%)
BMI, mean+SD	Yes, Normal	48 (76,2%)
	I am obese	15 (23,8%)
	Obesity 1 degree	31 (49,2%)
	No	14 (22,2%)

Table 2.

Difficulties in obtaining medical services.

difficulties		- 60 - years	Up to 60 years	Total	P <
		N (%)	N (%)	N (%)	
System of appointment to narrow specialists inconvenient PHC	Yes	9 (27,3%)	2 (6,7%)	11 (17,5%)	0,031
	No	24 (72,7%)	28 (93,3%)	52 (82,5%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Long waiting in line for an appointment with a primary care doctor	Yes	7 (21,2%)	2 (6,7%)	9 (14,3%)	0,099
	No	26 (78,8%)	28 (93,3%)	54 (85,7%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Long waiting time for an appointment with narrow PHC specialists	Yes	10 (30,3%)	3 (10,0%)	13 (20,6%)	0,047
	No	23 (69,7%)	27 (90,0%)	50 (79,4%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Long waiting time for hospitalization in PHC hospital	Yes	8 (24,2%)	6 (20,0%)	14 (22,2%)	0,686
	No	25 (75,8%)	24 (80,0%)	49 (77,8%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Long waiting time for an ambulance in PHC	Yes	1 (3,0%)		1 (1,6%)	0,336
	No	32 (97,0%)	30 (100,0%)	62 (98,4%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Long waiting time for functional and diagnostic examinations of PHC	Yes	2 (6,1%)	2 (6,7%)	4 (6,3%)	0,922
	No	31 (93,9%)	28 (93,3%)	59 (93,7%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Long waiting times for laboratory tests in PHC	Yes	2 (6,1%)	2 (6,7%)	4 (6,3%)	0,922
	No	31 (93,9%)	28 (93,3%)	59 (93,7%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Insufficient diagnostic examination	Yes	12 (36,4%)	3 (10,0%)	15 (23,8%)	0,014
	No	21 (63,6%)	27 (90,0%)	48 (76,2%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Long waiting times for subsidized medicines	Yes	5 (15,2%)	2 (6,7%)	7 (11,1%)	0,285
	No	28 (84,8%)	28 (93,3%)	56 (88,9%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	

Table 2 continue.

Reception of a cardiologist in a private clinic	Yes	16 (48,5%)	7 (23,3%)	23 (36,5%)	0,038
	No	17 (51,5%)	23 (76,7%)	40 (63,5%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Purchase of medicines at your own expense	Yes	24 (72,7%)	21 (70,0%)	45 (71,4%)	0,811
	No	9 (27,3%)	9 (30,0%)	18 (28,6%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Laboratory examinations	Yes	5 (15,2%)	3 (10,0%)	8 (12,7%)	0,54
	No	28 (84,8%)	27 (90,0%)	55 (87,3%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	
Instrumental examinations (ultrasound, MRI, CT)	Yes	13 (39,4%)	10 (33,3%)	23 (36,5%)	0,528
	No	19 (57,6%)	20 (66,7%)	39 (61,9%)	
	others	1 (3,0%)		1 (1,6%)	
	Total	33 (100,0%)	30 (100,0%)	63 (100,0%)	

The attitude of the medical specialists of the outpatient and inpatient

The satisfaction of the respondents with the attitude of the medical specialists in outpatient and inpatient was determined by including 12 questions. The results showed that, depending on the level of education, the attitude of the medical specialists in outpatient was assessed by the respondents with higher education median 4,46 [3,67; 4,67],

college 3,17 [3,67; 4,67] and secondary school 4,58 [3,67; 4,67], in inpatient with higher education 5,00 [4,00; 5,00], college 5,00 [4,00; 5,00], and secondary school 5,00 [5,00; 5,00]. The analysis of satisfaction attitude in the outpatient was under 60 years old 4,67 [3,67; 4,67], over 60 years 3,96 [3,67; 4,67] and in the inpatient was under 60 years 5,00 [5,00; 5,00], over 60 years old 5,00 [4,00; 5,00] (figure 1 and figure 2).

Figure 1. The attitude of the medical specialists of the outpatient.

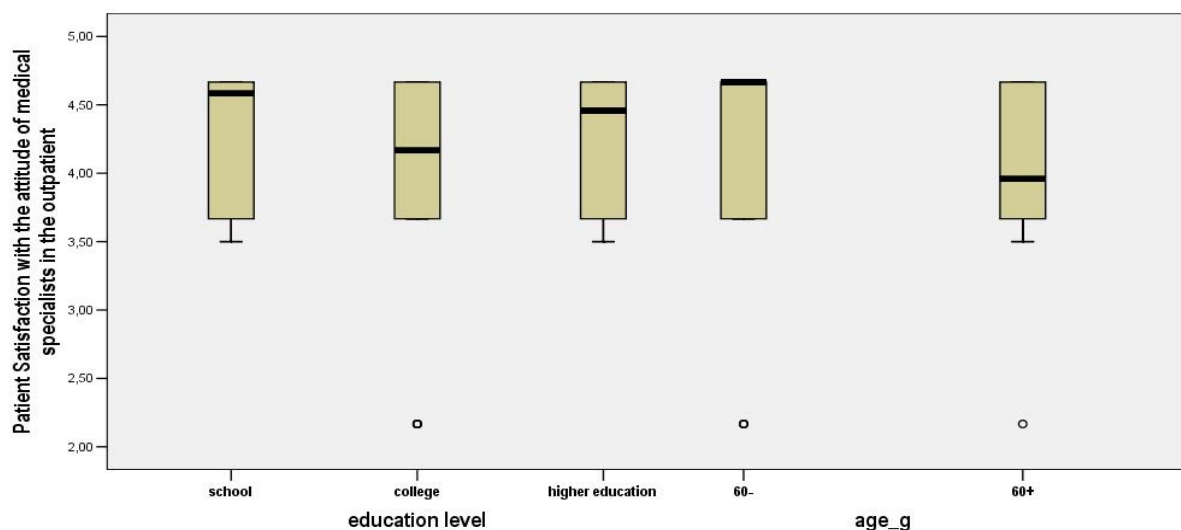
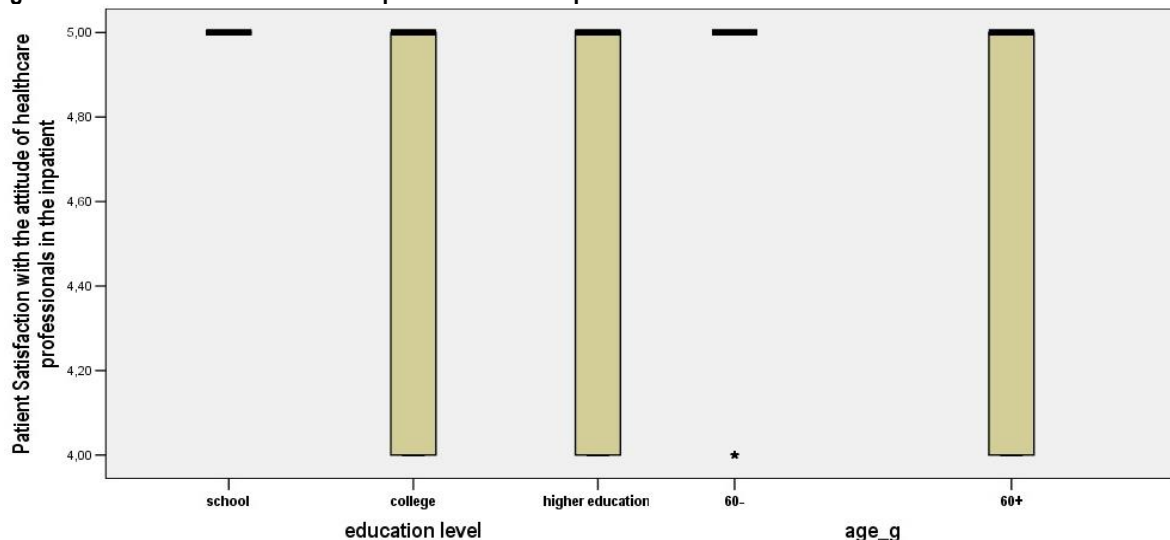


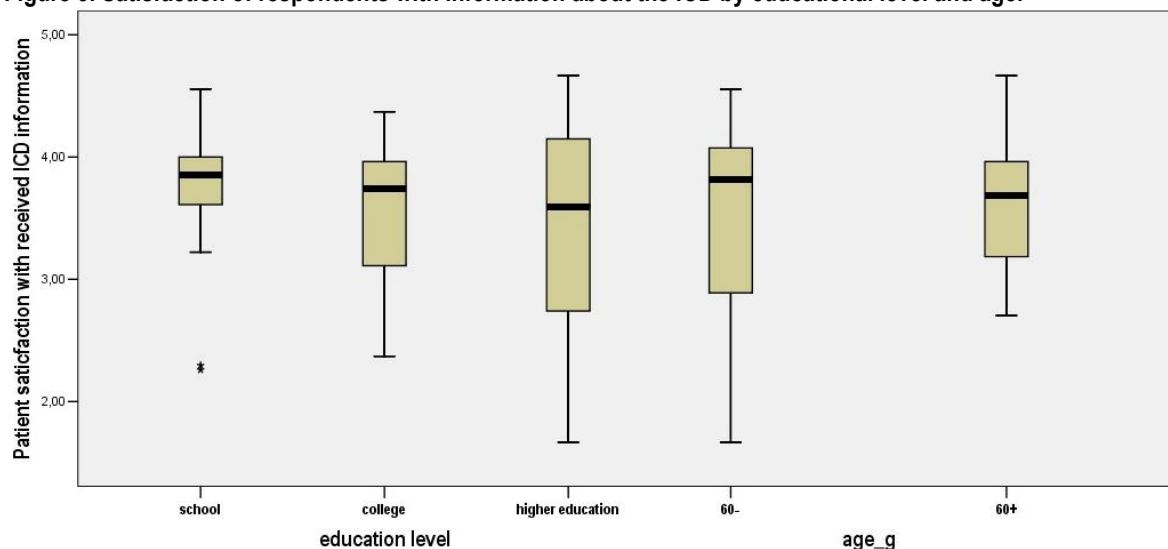
Figure 2. The attitude of the medical specialists of the inpatient.



Satisfaction of respondents with information about ICD The results for 27 items, showed satisfaction with the information received about the ICD, the median was 3,70 [3,11; 4,07], depending on the level of education, the median was estimated by respondents with higher education 3,59 [2,73; 4,16], college 3,74 [3,11; 3,99] and secondary school 3,85 [3,56; 4,11]. Consequently, respondents with secondary education further gave higher satisfaction ratings compared to other groups (Figure 3). An analysis of satisfaction by age revealed that respondents under 60 had a high variation. Thus, the median was 3,81 [2,70; 4,11], over 60 3,69 [3,17; 4,00].

Patient preferences for treatment options When studying patient preferences for treatment options that were not part of standard clinical practice, a personal conversation with a doctor / nurse 2-3 weeks after implantation was of interest to the largest number of respondents, 87,3%, as well as interest in the patient's well-being during hospitalization 92,1%. 90,5% of respondents would like the same doctor or nurse to call the patient to clarify the state of health after discharge. Almost a third of respondents 27,0% do not prefer or do not know their preference for the exercise tolerance test (which I can do physically), and preference for constant feedback through a remote monitoring system.

Figure 3. Satisfaction of respondents with information about the ICD by educational level and age.



60,3% of respondents would like to have the opportunity to meet other ICD patients. 42,9% did not want to have the opportunity to attend a ICD workshop with their family, especially those under 60 years old 51,5%. A third of respondents preferred the consultation of a psychologist during hospitalization for implantation (30,2% of respondents prevailed by 19,4% in comparison with those older than 60, $P < 0,252$), while the other third of 30,2% had the opposite opinion. Only a third of respondents, 30,2%,

prefer psychological counseling after discharge (the prevalence of participants under 60 years old was 19,4% compared to those over 60 years old), as well as 23,8% for families. The largest number of respondents, 79,4%, preferred receiving information about ICD several times, the largest number of respondents over 60 years old 93,3% compared to those under 60 years old 66,7% ($P < 0,009$), statistically significant (Table 3).

Table 3.

Patient preferences for treatment options that were not part of standard clinical practice.

		Under 60 age	Up 60 age	Total	P <
Personal conversation with doctor / nurse 2-3 weeks after implantation	Yes	30(90,9%)	25(83,3%)	55(87,3%)	0,367
	No	3(9,1%)	5(16,7%)	8(12,7%)	
Doctors / nurses ask how I feel during hospitalization	Yes	30(90,9%)	28(93,3%)	58(92,1%)	0,722
	No	3(9,1%)	2(6,7%)	5(7,9%)	
Doctor / nurse will call me after discharge	Yes	30(90,9%)	27(90,0%)	57(90,5%)	0,902
	No	3(9,1%)	3(10,0%)	6(9,5%)	
Exercise Tolerance Test (What Can I Do Physically)	Yes	26(78,8%)	20(66,7%)	46(73,0%)	0,346
	No	5(15,2%)	9(30,0%)	14(22,2%)	
	Do not know	2(6,1%)	1(3,3%)	3(4,8%)	
Cardiological rehabilitation	Yes	32(97,0%)	29(96,7%)	61(96,8%)	0,945
	No	1(3,0%)	1(3,3%)	2(3,2%)	
Constant feedback through the remote monitoring system	Yes	24(72,7%)	21(70,0%)	45(71,4%)	0,572
	No	8(24,2%)	9(30,0%)	17(27,0%)	
	Do not know	1(3,0%)		1(1,6%)	
Opportunity to meet other ICD patients	Yes	23(69,7%)	15(50,0%)	38(60,3%)	0,200
	No	10(30,3%)	14(46,7%)	24(38,1%)	
	Do not know		1(3,3%)	1(1,6%)	

Table 3 continue.

Opportunity to attend a seminar on ICD treatment with your family	Yes	16(48,5%)	20(66,7%)	36(57,1%)	0,145
	No	17(51,5%)	10(33,3%)	27(42,9%)	
Psychological consultation during hospitalization for implantation	Yes	13(39,4%)	6(20,0%)	19(30,2%)	0,252
	No	8(24,2%)	11(36,7%)	19(30,2%)	
	Do not know	1(3,0%)		1(1,6%)	
	Others	11(33,3%)	13(43,3%)	24(38,1%)	
Psychological consultation after discharge for me	Yes	13(39,4%)	6(20,0%)	19(30,2%)	0,134
	No	19(57,6%)	24(80,0%)	43(68,3%)	
	Do not know	1(3,0%)		1(1,6%)	
Psychological counseling for my family	Yes	8(24,2%)	7(23,3%)	15(23,8%)	0,623
	No	24(72,7%)	23(76,7%)	47(74,6%)	
	Do not know	1(3,0%)		1(1,6%)	
Retrieving ICD Information Multiple Times	Yes	22(66,7%)	28(93,3%)	50(79,4%)	0,009
	Do not know	11(33,3%)	2(6,7%)	13(20,6%)	

Discussion

In our review, we identified the need for guidelines for ICD patients in Kazakhstan. The importance of printed materials is that they include both positive and potential negative effects and help patients make ICD decisions [22].

Research notes the importance of communication between patients with ICD and physicians, as well as psychological support. Our study identified the needs of an average of one third of patients on this issue [22, 16,17].

In addition, our results show that 27,0% respondents do not know issues about physical activity, however systematic reviews identified positive result [2, 15] of physical activities for health condition of patients with ICD and patient education on this issue is very important. The attitude of physicians towards patients with ICD is one of the important aspects in the provision of care [11]. Our respondents gave a good assessment of the work of the employees of the medical organization, especially in the inpatient care in comparison with the outpatient care. Patient dissatisfaction with outpatient care services may be related to the attitude of medical service providers, registration officers, and pharmaceutical counters [14], patient waiting time and bureaucracy [21].

Investigating patient satisfaction with ICD information in general, there is an awareness of key aspects of the technology. However, highly educated respondents rated it at 3,7 out of 5,0, which indicates the need for additional information. Similar studies note the lack of information provided on ICD, especially on psychological, social and sexual consequences [10].

The limitations of this study include low sample size and study provide during COVID19, we have to provide online survey.

Conclusion

ICD is effective technologies, however to increase the satisfaction of patients there are need to improve in providing information regarding positive and potential negative effects of technology, and provide guidelines for patient, improve access to outpatient care.

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Contribution of the authors: All authors have made an equal contribution to the writing of the article.

Begisbayev T., Kosherbayeva L., Nazgul Akhtaeva - data collection, analysis, methodology, writing original draft.

Marzhan Brimzhanova, Valikhan Akhmetov, Dmitry Khvan - scientific management of the study, writing - review & editing.

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