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Patients' knowledge and attitudes regarding living with implantable electronic devices: results of a multicentre, multinational patient survey conducted by the European Heart Rhythm Association

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The purpose of this patient survey was to analyse the knowledge, experiences, and attitudes regarding cardiac implantable electronic devices (CIED) in patients with pacemakers, implantable cardioverter-defibrillators (ICDs), or cardiac resynchronization devices. Of the 1644 patients with CIEDs from seven European countries, 88% were over 50 years of age. Most patients (90%) knew what device they were implanted with and felt sufficiently informed about the indications for therapy. As many as 42% of patients needed additional information on the battery replacement and limitations in physical activity. The self-reported incidence of complications was 9%, and among these, a quarter of the respondents felt insufficiently informed about the possibility of complications and their management. The majority of patients (83%) were followed by face-to-face visits, which was the most commonly preferred follow-up strategy by the patients. Nearly 75% of the patients reported improved quality of life after device implantation, but about 40% had worries about their device. Less than 20% had discussed with their physician or thought about device handling in the end-of-life circumstances or end-stage disease. Notably, almost 20% of the ICD patients did not wish to answer the question regarding what they wanted to be done with their ICD in case of end-stage disease, indicating the challenges in approaching these issues.

Keywords Cardiac implantable electronic devices • Pacemaker • Implantable cardioverter-defibrillator • Cardiac resynchronization therapy • Patient preference • Patient knowledge • Complications • EHRA survey

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What's new?

- Cardiac implantable electronic devices (CIED), including pacemakers, implantable cardioverter defibrillators (ICD) and cardiac resynchronization therapy (CRT) are the standard of care in various cardiac conditions and are used in a growing number of patients.
- This patient survey analysed the knowledge, experiences and attitudes regarding CIED in 1644 patients with CIEDs from seven European countries.
- As many as 42% of patients, needed additional information on the battery replacement and limitations in physical activity and one quarter felt insufficiently informed about the possibility of complications and their management.
- Nearly 75% of patients reported improved quality of life after device implantation, but still about 40% had worries about their device.
- This study revealed that many patients with CIED in Europe still need more information about their device, possible complications and end of life questions.

Introduction

Cardiac implantable electronic devices (CIEDs), including pacemakers, implantable cardioverter-defibrillators (ICDs), and cardiac resynchronization therapy (CRT), are the standard of care in various cardiac conditions and are used in a growing number of patients. The CIEDs are effective in improving survival and quality of life. Although indications, implantation rates, and complications are well described among centres in Europe,[1] experiences of patients being implanted and living with CIED are less well explored. Being implanted with a device is a significant encounter for the individual, both physically and psychologically. Not only the diagnosis and implantation but also the function of the device may affect and worry the patient. Furthermore, important questions of how to live with the device and what to do with the device in a situation of severe or end-stage disease may arise. Patients' beliefs and knowledge about their illness are important determinants of their coping responses to their illness and their treatment.[2]

In the second patient survey performed by the European Heart Rhythm Association (EHRA),[3] we explored the knowledge, perception of information, and attitude towards the device among patients implanted with CIED.

Methods

The prospective, multicentre, multinational snapshot survey included patients with CIEDs, implanted either recently or in the past. The survey was designed and approved by the EHRA Scientific Initiatives Committee (SIC). Patients with CIEDs were offered to participate in the survey by anonymously answering the questionnaire posted on an electronic platform and available via the Internet or in the paper form. The questionnaire contained 18 questions in the patients' native language. The survey was sent to the EHRA Electrophysiology (EP) Research Network centres. The local ethics committee approval was obtained where needed according to the local policy. The EP Network centres were invited to participate on a voluntary basis. Patients were asked to submit their replies via the Internet or in the paper form, either without any help or with technical guidance from medical staff or family members. The paper forms were subsequently uploaded online by the SIC staff. Data were collected anonymously. The study was conducted from November 2016 to February 2017.

Results

Patient population

A total of 1644 patients (61% men) from seven European countries participated in the survey. The number of patients from each country was as follows: 812 (49%) from Poland, 435 (26%) from Italy, 175 (11%) from France, 86 (5%) from Denmark, 55 (3%) from Norway, 32 (2%) from Romania, 16 (1%) from Spain, and 33 (2%) were from other countries. There were 688 patients (42%) aged >75 years, 755 patients (46%) aged 50–75 years. and 199 patients (12%) aged <50 years. Most patients were living with a partner (77%), while 20% were living alone and 3% in a nursing home. Regarding the patients' education level, 37% of patients had a primary school education, 43% had graduated from secondary school, and 21% had a higher level of education. Almost half the patients filled the questionnaire by themselves (49%), 31% were helped by a health care professional, and 20% used help of a friend or a family member.

Device types and indications

As self-reported, 41% of the patients were implanted with an antibradycardia pacemaker, 33% with ICD, 8% with CRT, and 7% with cardiac resynchronization therapy defibrillator (CRT-D), while 10% of patients did not know the type of device they received. The device was implanted 0–1 year, 1–3 years, 4–6 years, or 7–15 years ago each in approximately 25% of the patients.

Among the self-reported indications for device implantation, slow heart rhythm was the most common reason (36%), followed by atrial fibrillation (23%), cardiac arrest or syncope (23%), prophylactic implantation due to high risk of cardiac arrest (20%), and heart failure (25%); 5% of patients did not know why they received the device.

Device monitoring and follow-up

Face-to-face regular hospital follow-up visits were the most common follow-up strategy (83%), while 17% were followed up remotely, with either less frequent on-site visits (11%) or on-site visits scheduled as needed (4%). Most patients (51%) preferred to be followed up by regular on-site visits, while 27% left the choice of a follow-up strategy to their physician; 15% of participants preferred to be monitored remotely, with less frequent face-to-face visits.

Complications-related information

Most patients (57%) reported that they were extensively informed about possible complications before CIED implantation, 29% received some information, and 14% reported that they had been supplied with insufficient information. The self-reported incidence of complications was 9% (91% of patients reported no complications). Infections constituted half of the complications (4%). If a complication occurred, 72% of the patients felt sufficiently informed about it, while

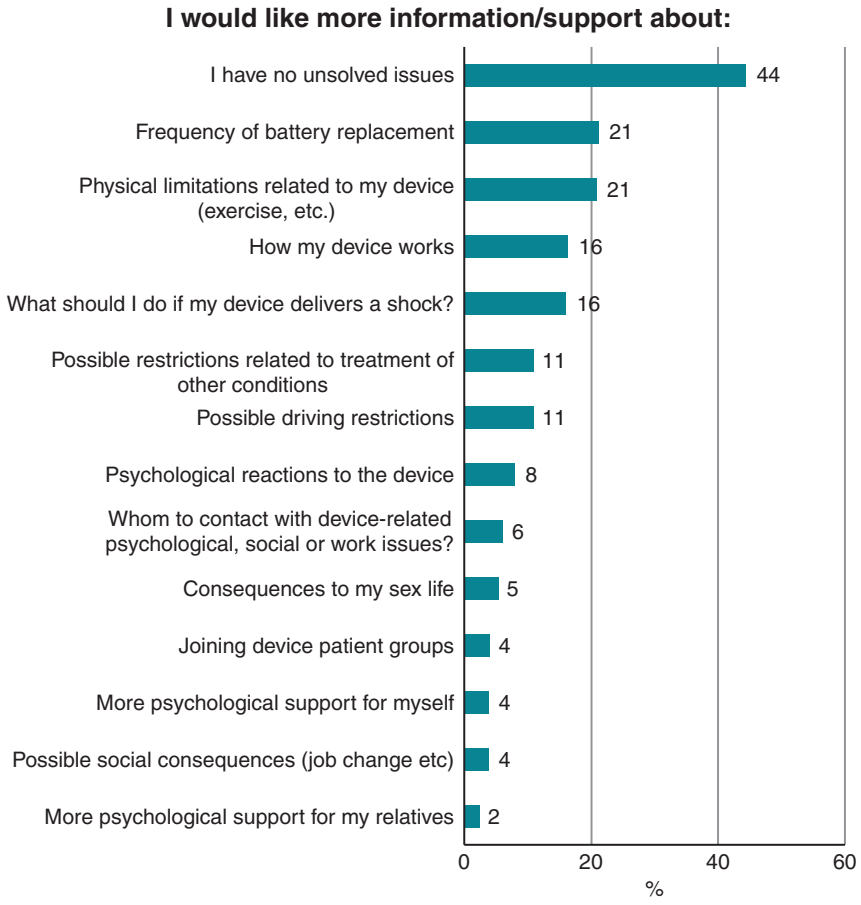

Figure 1 Bar graph showing the need for information or support among 1644 patients with implantable electronic devices (multiple answers possible).

the remaining 28% felt insufficiently informed about the complication and its management.

Overall, most patients (44%) felt sufficiently informed, while the device battery capacity and possible limitations in physical activity (21% each) were the issues that patients would like to be more informed about (*Figure 1*).

Quality of life

The majority of patients (69%) had never regretted receiving the device, while 24% of them had not given this question a second thought. A small proportion (7%) regretted or sometimes regretted to have been implanted with CIED, usually because of complications and insufficient information about daily life restrictions.

In 68% of the patients, the device had never caused any problems; however, 12% reported difficulties regarding diagnostic procedures (e.g. cardiac magnetic resonance imaging), 7% regarding private life (e.g. travelling and relationship with partner), 4% of patients experienced professional problems (e.g. driving restrictions), 2% had insurance issues, and 0.4% reported difficulties regarding pregnancy.

While 64% of the patients had no device-related concerns, 36% were concerned about the delivery of shock, possible primary or daily activities induced malfunctioning of the device, or had other worries (*Figure 2*).

Only 6% of the patients reported that the device affected their daily life. Restrictions in physical activity and the possibility of sleeping on the left side were most commonly reported. The quality of life after device implantation was clearly or slightly improved in the majority of patients, while it was impaired in only 5% (*Figure 3*).

Information and attitude in the case of end-stage disease

The majority (84%) of patients had no discussion what to do with their device in the end-of-life situation, 12% briefly discussed the issue, and 5% reported they have been thoroughly informed about the possible alternatives by their physician. Among patients with ICD, 66% never thought about how they wanted their device to be handled in the case of terminal illness; 6% of the patients would prefer that their ICD remains active, 5% would consider asking for ICD deactivation, while 2% reported that they had thought about the issue but did not have a clear preference. Notably, 18% of the participants preferred not to answer this question.

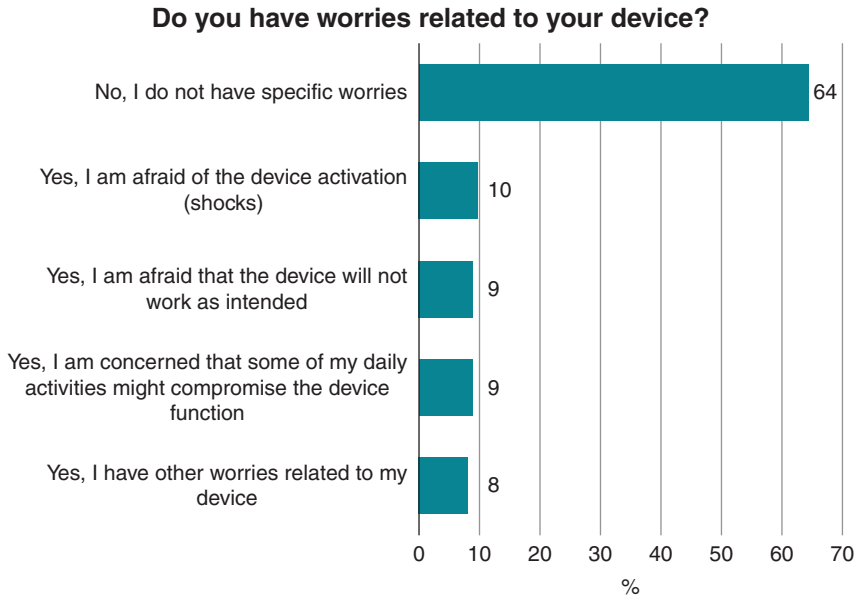

Figure 2 Bar graph showing device-related concerns among 1644 patients with implantable electronic devices.

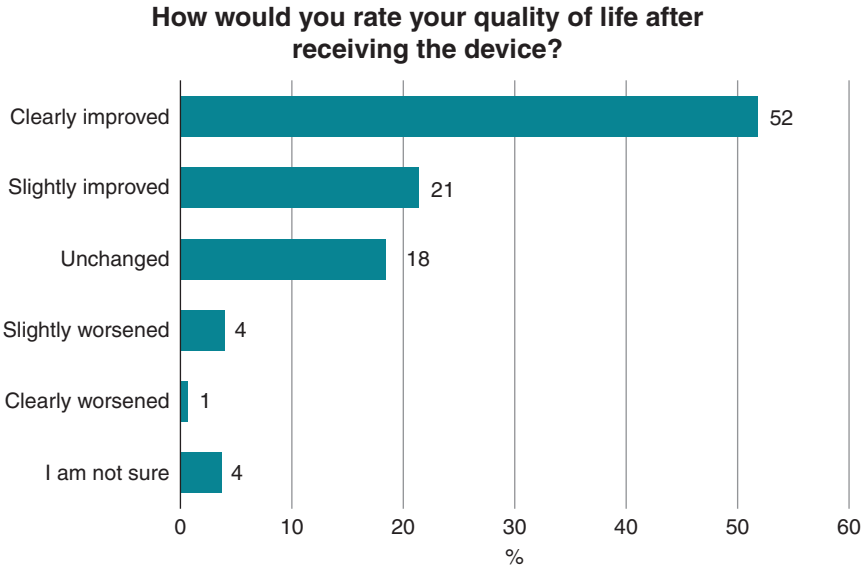

Figure 3 Bar graph showing quality of life after device implantation among 1644 patients with implantable electronic devices.

Discussion

This prospective, international, multicentre patient survey conducted in seven European countries provided important insights into the contemporary patients' knowledge, information, and attitudes regarding living with CIED. The survey revealed the unmet need for more information with respect to battery replacement and physical activity. Nevertheless, the survey showed that European patients implanted with CIED were well informed of the device indications and the type of device they were implanted with. In most patients, quality of life increased or remained unchanged after device implantation, and only few patients regretted device implantation. Only a minority of patients discussed with their physician what to do with the device in the case of end-stage disease or end-of-life situation, and there was a tendency among patients to avoid this question.

Patients' knowledge, need for information, and quality of life after device implantation

Patients participating in this survey were generally well informed about their type of device and the indication for the implantation, with less than 10% of them not being able to answer these questions. Of note, almost half the patients were >75 years of age, indicating a good knowledge in the elderly. However, the need for information about the device has not been met, because only 40% of patients felt they had no unresolved questions and 40% had worries regarding their device.

Patient information is of uppermost importance, as it reduces stress of living with CIED and the disappointment in the case of complications. Information on the device should ideally be given during the face-to-face conversation and in the written form, with the possibility of discussing further questions with an appropriate health care provider. This survey showed that patients felt well informed about the complications related to the implantation procedure. However, among those who reported to have had complications, as many as one-quarter felt insufficiently informed about the potential complications and their management. Furthermore, even questions concerning the way of living with the device during follow-up were less well answered. The need for further information was most often related to device functioning (e.g. battery replacement) and physical activity.

Physical activity is an important question to address when living with CIED, and, of course, it has to be individualized in accordance with the type of device and underlying disease. Current international recommendations only suggest moderate leisure-time physical activity for patients with ICD.[4,5] Recent studies have indicated that the device *per se* should not restrict physical activity. In patients used to an active lifestyle, restrictions in activity are particularly limiting. A multinational registry has shown that many athletes with ICD engage in competitive sports, without physical injury, or failure to terminate the arrhythmia.[6] Physicians should carefully consider the patients' need for activity, when choosing leads, devices programming, preventive bradycardic medication, physical rehabilitation, and psychological counselling to allow the maximum benefit and the minimum harm for physically active ICD patients.[7]

Interestingly, 73% of the patients reported improved quality of life after device implantation. Considering that 56% of our population received a pacemaker (pacemaker 41% and CRT 15%), a substantial proportion of ICD patients also reported an improvement in their quality of life. This may be explained by optimal medical therapy, regular follow-up visits, and psychological effects. However, patients worried about their devices, and 40% reported concerns about technical problems. In particular, 10% of the respondents were frightened to receive a shock from ICD. Although the attention has been paid to reduce appropriate and inappropriate shocks, this problem still appears considerable.

Only a small minority of patients regretted device implantation. The reasons given by these patients were most frequently associated with device complications and restrictions of physical activity.

Monitoring during follow-up

Most patients were followed on regular on-site visits and only few patients were followed up remotely. Remote follow-up of CIEDs allows for fewer in-office visits in combination with earlier detection of the relevant findings.[8,9] However, most patients preferred to continue regular on-site visits, and only 15% wanted more extensive remote monitoring with fewer on-site visits. This result may reflect a lack of awareness about potential benefits of remote monitoring. The cost–benefit ratio of remote follow-up is actively debated, and the reimbursement issue is one of the significant barriers to its practical implementation.[8,9]

Information and attitude in the case of patients' end-stage disease

Although nearly half of the patients were >75 years of age, only the minority discussed with their physician or even thought about what to do at the end of life. Physicians and patients may be reluctant to discuss these problems, particularly when the probability seems remote. Most physicians have experienced the dilemma of turning off a pacemaker or ICD in terminally ill patients. For many years, the ethical debate about pacemakers has focused on whether and under what circumstances they may be turned off in the end-of-life care.[10] Of note, almost 20% of the ICD patients in this survey did not want to answer the question about what they wanted to do with their device in such a situation. This may reflect an unwillingness to approach the argument. The current guidelines on prevention of sudden cardiac death give a Class IIa recommendation regarding the discussion of end-of-life issues with patients, both before ICD implantation and at significant points along the illness trajectory.[11] Furthermore, recommendations state that ICD deactivation should be considered when clinical conditions deteriorate.[11] This issue remains difficult and requires attention and awareness among physicians and health care personnel. Incorporation of patients' values and preferences in these questions should be considered as an integral part of the decision-making process.[2]

Conclusion

Patients were generally well informed about their device and indications. However, there is a need for further information, mainly regarding device functioning, battery replacement, and physical activity. Quality of life improved in the majority of patients, including patients with ICD. Questions about what to do with the device at the patient's end of life were rarely discussed by patients and physicians.

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