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SPECIAL ARTICLE

Guidelines on the management of implantable cardioverter defibrillators at the end of life $^{\!\!\!\!\!/}$

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KEYWORDS

Implantable cardioverter defibrillator; Palliative care; Decision-making; Treatment retrieval Abstract This article is a joint document of the Spanish Society of Geriatrics and Gerontology, the Spanish Society of Palliative Care and the Section of Geriatric Cardiology of the Spanish Society of Cardiology. Its aim is to address the huge gap that exists in Spain with regard to the management of implantable cardioverter defibrillators (ICDs) in the final stages of life. It is increasingly common to find patients carrying these devices that are in the terminal stage of an advanced disease. This occurs in patients with advanced heart disease and subsequent heart failure refractory to treatment but also in a patient with an ICD who develops cancer disease, organ failure or other neurodegenerative diseases with poor short-term prognosis. The vast majority of these patients are over 65, so the paper focuses particularly on the elderly who are in this situation, but the decision-making process is similar in younger patients with ICDs who are in the final phase of their life.

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PALABRAS CLAVE

Desfibrilador automático implantable;

Guía sobre el manejo de desfibriladores automáticos implantables al final de la vida

Resumen El presente artículo es un documento conjunto de la Sociedad Española de Geriatría y Gerontología, la Sociedad Española de Cuidados Paliativos y la Sección de Cardiología Geriátrica de la Sociedad Española de Cardiología. Su objetivo es paliar la laguna que existe

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Cuidados paliativos; Toma de decisiones; Retirada de tratamiento en España en lo que respecta al manejo de los desfibriladores automáticos implantables (DAI) en las fases finales de la vida. Cada vez es más frecuente encontrarse enfermos portadores de DAI en fase terminal de una enfermedad avanzada, como insuficiencia cardíaca refractaria, enfermedades oncológicas, otras insuficiencias orgánicas o enfermedades neurodegenerativas con mal pronóstico a corto plazo. La enorme mayoría de estos pacientes tiene más de 65 años, por ello el documento se enfoca de forma particular a los ancianos que se encuentran en esta situación, aunque el proceso de toma de decisiones es similar en portadores de DAI más jóvenes que están en la fase final de su vida.

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Background. Ethical and legal principles

Implantable cardioverter defibrillators (ICDs) are devices that are indicated in patients with severe heart disease who have experienced sudden death by ventricular tachyarrhythmia or who are at high risk of experiencing it. The use of ICDs has increased, and more than 5000 ICDs are implanted every year in Spain, with a rate of 116 implants per million inhabitants, a figure well below the European average of 269 implants per million inhabitants. 1 It is increasingly frequent to find patients carrying ICDs in the final stages of disease, which has led a number of authors to recommend a screening routine in palliative care programs to detect ICD carriers and proceed accordingly.² In these patients, the permanence of these active devices can prolong unnecessary suffering, given that the patients frequently receive discharges from them, which are painful and decrease the quality of life.³ Furthermore, these patients are often treated by professionals who are not sufficiently prepared to address these conditions. The present document is aimed primarily at doctors but is also directed to nurses and healthcare professionals who interact with patients who carry these devices. Given that a large majority of these patients are over 65 years of age, 4 this document is focused on elderly patients; however, the decision-making process is similar in younger ICD carriers in end-stage situations.⁵

Previous studies have shown that patients receive little information related to the decision-making process and management of ICDs in the final stages of life. Specifically, few patients with ICDs receive information from their reference professionals on the benefits and dangers of these devices in the advanced stages of disease and, as a result, their deactivation is considered in only a few of these patients.^{3,6,7} The communication of sufficient information is not only a patient's right and an ethical obligation for the physician but it also allows for patient participation in the complex clinical decisions that are undertaken at the end of life. It also facilitates the adaptation and the perception of control by reducing uncertainty and allows for the possibility of planning with real objectives. It is not just a matter of reporting the diagnosis and prognosis of a specific disease but rather the discovery of patients' values and preferences, including patients in the decision-making process and making them active in the final process of life.8 From an ethical standpoint, the limitation of the therapeutic effort consists in not applying extraordinary and/or disproportionate measures for the established therapeutic goal in a patient with a poor vital prognosis and/or poor quality of life. In this context and given that ICD deactivation does not imply the immediate death of the patient, deactivation should be considered as a form of limiting the therapeutic effort. Advance directives encourage patient participation in decision making in situations where they cannot express their wishes themselves. A recent study showed that patients who had prepared advance directives received care associated with their preferences. The directives also represent an opportunity for dialog with patients, facilitating clinical decisions, promoting a feeling of control by the patient and improving the clinical care relationship.

In an effort to cover the gap in Spain in the management of ICDs in the final stages of life, the Spanish Society of Geriatric Medicine and Gerontology, the Spanish Society of Palliative Care and the Geriatric Cardiology Section of the Spanish Society of Cardiology have developed the present document. The objectives of this document are as follows: (1) To describe the ethical, legal and clinical issues related to the deactivation of ICDs in patients in terminal conditions. (2) To highlight the importance of communication and a multidisciplinary approach. (3) To provide decision-making schemes to guide clinicians in caring for these types of patients.

Methodology

The present consensus was developed in the meeting "Palliative Care in Cardiology", held in Madrid in November 2012. The meeting was not sponsored, registration was free and open to all professionals and had 120 attendees. Upon confirming the difficulty of managing these patients, a multidisciplinary workgroup was created to develop this document.

Patient evaluation integrated geriatric assessment

Geriatric assessment is a broad term used to describe the health evaluation of elderly patients, with an emphasis on components and results that differ from those of a standard medical assessment. This approach assumes that the health status of elderly patients depends on various influences beyond the manifestations of the disease itself. These influences include the social sphere, psychological and mental health and environmental factors. Principles similar to these can be used for patients in the final phases of life, regardless of age. The usefulness of the integrated geriatric assessment

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