‘Life with a device’: the octogenarians’ experiences with an implantable cardioverter-defibrillator—a qualitative study

Jenny Wising¹, Gustav Mattsson¹*, Komalsingh Rambaree², Mikaela Willmer³, Marita Wallhagen⁴, and Peter Magnusson¹,³,⁵

¹Centre for Research and Development, Region Gävleborg, Uppsala University, Lasarettsvägen 1, Gävle SE-80187, Sweden; ²Department of Social Work and Criminology, University of Gävle, Kungsbäcksvägen 47, Gävle SE-80176, Sweden; ³Department of Caring Sciences, University of Gävle, Kungsbäcksvägen 47, Gävle SE-80176, Sweden; ⁴Department of Building Engineering, Energy Systems and Sustainability Science, University of Gävle, Kungsbäcksvägen 47, Gävle SE-80176, Sweden; and ⁵Department of Medicine, Solna, Cardiology Research Unit, Karolinska Institutet, Karolinska University Hospital D1:04, Stockholm SE-171 76, Sweden

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Aims
Implantable cardioverter-defibrillator (ICD) treatment has expanded due to its effectiveness. However, there are concerns about complications, and use in the most elderly has been questioned. There is scarce data on qualitative aspects regarding experiences of living with an ICD among patients above the age of 80 years. The aim of this study was to explore octogenarians’ experience, knowledge, and attitude of living with an ICD.

Method and results
We used semi-structured interviews to collect data from 20 patients, aged 80–89 years (90% men). The data were then structured and analysed through deductive thematic analysis network approach using the ATLAS.ti v.8.4 software. The framework of the analysis was based on the Successful Aging Theory. Three main themes emerged regarding the patients’ experiences: Life goes on; Their Health, The Janus-Faced Device; Their attitudes, and Mind the gap; Their knowledge. None of the octogenarians regretted receiving their ICD, instead, they presented with feelings such as gratitude towards the device. However, a lack of knowledge about the devices was expressed, which can be a risk for potential complications, in turn causing suffering and unnecessary concerns.

Conclusion
Overall, the ICD did not pose a threat towards successful ageing. It was mainly considered a life-saving device. However, the lack of knowledge might hinder informed choices close to death and contribute to ethical dilemmas when deactivation of the ICD is a reasonable option.

Keywords
Heart failure • Implantable cardioverter-defibrillator • Octogenarians • Successful ageing theory • Qualitative method

Implications for practice
• Octogenarians are generally grateful towards their implantable cardioverter-defibrillator (ICD).
• Patient experiences of complications need to be recognized.
• Lack of knowledge.
• Deactivation of the ICD should continually be discussed.
• Healthcare providers need a holistic approach.

* Corresponding author. Tel: +46 (0)703 122296, Email: gustav.mattsson@regiongavleborg.se
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Introduction

The implantable cardioverter-defibrillator (ICD) is a cornerstone in the management of patients with increased risk of sudden cardiac death.1 The device effectively terminates potentially life-threatening ventricular arrhythmias, either by antitachycardia pacing or cardioversion, protects against bradycardia, and can be combined with a left ventricular lead in cardiac resynchronization therapy defibrillator (CRT-D). Nevertheless, inappropriate shocks do occur and complications requiring surgery are common.1 According to guidelines, an ICD is recommended for patients with ejection fraction ≤35% after at least 3 months of optimal medical therapy and a life expectancy of at least 1 year with a reasonable functional status and psychological well-being.1,2 The patient-reported lived experience among ICD patients is complex, with gratitude towards the treatment, but also distress and anxiety, mainly due to inappropriate shocks. There is a marked heterogeneity in the coping strategies, and diverse attitudes have been qualitatively explored.3,4

Current knowledge, both quantitative and qualitative, of ICD patients is mostly based on studies from cohorts at tertiary centres. Less is known about qualitative aspects of living with an ICD, especially in elderly patients.5 According to the Swedish ICD and Pacemaker Registry, the mean age of patients at ICD implant was 64 years (CRT-D 67 years) and the mean survival was 4.2 years.6 Furthermore, it has been questioned whether the implantation of an ICD, or an elective unit replacement, confers an actual survival benefit for octogenarians.7–9 The benefit of ICD in the elderly has been questioned in the era of optimal pharmacological management which includes CRT.10 A quantitative Swedish study focusing on octo- and nonagenarian ICD recipients revealed a considerable lack of knowledge regarding the ICD treatment11; these results regarding lack of knowledge are in accordance with other research.12–16

The overall aim of this study was to gather and explore octogenarians’ experiences, attitudes and knowledge of living with an ICD. Specifically, this article addresses the following research questions: (i) How do octogenarians describe their perspectives on overall health in relation to the ICD? (ii) What are their attitudes towards their ICD? (c) What knowledge do they have about ICD treatment?

The study was framed using the Successful Aging Theory (SAT), with the aim to explore if an ICD influences the chances of achieving successful ageing. In the last two decades, SAT has provided a reliable theoretical framework in ageing research investigating how individuals can achieve and attain a successful ageing condition and what role health and medical care plays in self-reported quality of life as ‘successful ageing’.17,18 SAT describes the connection between physical and mental activities and characteristics that simultaneously occur at the base of the coping processes with health and wellbeing, leading to successful ageing.19 In the earlier definitions of SAT, explained by Rowe and Khan, absence of disability/disease was a determinant.20 The process of ageing is, however, often characterized as a period of increased risk of diseases and decrease in physical and psychological functions. The disability paradox refers to elderly people who are suffering from physical and psychological losses, but still describe themselves as successful agers.21 The modern version of SAT has therefore been revised, and subjective perceptions of wellbeing such as positive spirituality have been added among the factors that enable successful ageing.22 While scoping the literature it became clear that the subjective perception of wellbeing is deemed to be one of the most important factors in achieving successful ageing, together with adaption, independence and physical wellbeing.23–26

Method

Design

This study was designed using a deductive exploratory qualitative methodology, and SAT was chosen as a theory before data collection began. A literature review on SAT was undertaken, and a theoretical framework was developed to facilitate the data collection and analysis, using ATLASTi v.8.4 software (Figure 1). In keeping with the aim and research questions, SAT was found to be coherent in terms of explanatory breadth and simplicity for framing this study and not excluding any collected data.

Unlike inductive approaches, themes are constructed in relation to a theoretical framework (constructed from literature review) when using a deductive approach. The main purpose of using a deductive approach in thematic network analysis is to explore the patterns and relationships between the themes in relation to the set research questions from a predefined theoretical framework. Such an approach therefore facilitates theoretical and research question-based coding.27

Setting and data collection

Medical records from all patients who underwent ICD implantation or exchange between January 2007 and January 2017 in Region Gävleborg were validated.26 Those included in the cohort were >80 years at the time of validation, were fluent in Swedish, and had a postal address in Region Gävleborg. After written informed consent, the interviews were performed in the respondents’ homes. The interviews were conducted by the first author (J.W.), with exception for five of the interviews, which were conducted by a trained research assistant, also a registered nurse.

We used maximum variation sampling to cover both gender, and a history of appropriate and inappropriate ICD therapy. Out of 44 candidates, 13 were excluded for various reasons (deceased, had changed their address, ICD removed or turned off, dementia) and 5 declined. Among the remaining, 20 participants completed the interviews as planned. The mean duration of the interviews was 33 min. They were conducted between February and May 2019.

Data analysis

deductive Thematic Network Analysis (TNA) methodology, as outlined in Attride-Stirling,27 was applied to analyse the data in six steps: Step 1: Coding the material; Step 2: Identify Themes; Step 3: Construct Thematic Networks; Step 4: Describe and Explore Thematic Networks; Step 5: Summarize Thematic Networks; and Step 6: Interpret Patterns (p.391). In the deductive approach of TNA, different levels: (i) lowest-order premises evident in the text (Basic Themes); (ii) categories of basic themes grouped together to summarize more abstract principles (Organizing Themes); and (iii) super-ordinate themes encapsulating the principal metaphors in the text as a whole (Global Themes) are identified, organized, analysed, and reported with reference to the main themes identified in literature review of a predetermined theoretical framework (in this case, SAT, refer to Figure 1).22–23 Figure 1 depicts the main themes that emerged in reviewing the literature on SAT. The central aspect within TNA is the identification, exploration and description of linkages between the themes for depicting network/s of relations between themes in the interpretation of the patterns.
The use of computer software in qualitative data analysis is gaining popularity and validity because of the many in-built technological features that allow for more rigorous and transparent data analysis. Working directly with recorded data in audio format allows researchers to listen and check important aspects of qualitative data analysis, such as the quotations, codes, and themes, in direct relation with the raw data in the computer software.

The gathered data was assigned in ATLAS.ti in audio format for analysis using the procedure outlined in ATLAS.ti Scientific Software Development GmbH (2019. ATLAS-ti.v.8.4. Available from https://atlasti.com/). Segments of the interviews in audio format were selected as free quotations. Within each of the selected quotation, the ‘edit comment’ feature was used to transcribe the quotation from audio to text. Each of the quotations was then assigned codes. The ‘coding by list’ feature and procedure in ATLAS.ti was mainly adopted. A coding list from the literature review on SAT was created in ATLAS.ti (based on the concepts shown in Figure 1). For instance, quotations such as ‘I cannot walk long distances anymore’ were coded under ‘Physical well-being’. The themes were then linked to the research questions.

For each of the central codes (those with high levels of ‘groundedness’—high frequency in connection with the quotations), three types of ‘Memos’ were created using the ‘Memos’ feature in ATLAS.ti. ‘Theoretical Memos’ were used to gather and link all theoretical explanations and discussion; ‘Analytical Memos’ were used to link analytical discussions created by the researchers with codes and quotations; and ‘Reflexive Memos’ were used to gather the reflexivity of the researchers in relation to the codes, quotations and the research process as part of the validity. An example of the process is shown in Figure 2. In order to test the intra-coder reliability, the main coder redid part of the coding and checked for differences. To test the inter-coder reliability, another researcher redid part of the coding, and again checked for differences. Given that the coding process was performed deductively with a pre-designed coding list, there were almost no differences between the initial and repeated coding. This was also true for the inter-coder reliability. All authors discussed and agreed on the coding and on the ‘themes’ capturing the coded data. The study was approved by the Regional Ethics Review Board in Uppsala, Sweden (Dnr 2018/418). The investigation conformed to the principles outlined in the Declaration of Helsinki.

Results

Out of the 20 participants, 18 were males (Table 1). Ages ranged from 80 to 89 years with a median of 82 years, and the time living with an ICD ranged from 2 to 21 years with a median of 5 years. Appropriate ICD therapy had occurred in seven participants, and three had experienced inappropriate shocks. Three main themes were identified.

Theme 1—Life goes on: their health

The octogenarians talked about declining physical health and functioning. They expressed their enjoyment of life and their desire to
Table 1  Characteristics of the 20 interviewed octogenarians with an ICD

| Sex, age | ICD indication | Time since ICD implantation | Appropriate therapy | Inappropriate therapy | Complication requiring surgery |
|---------|----------------|-----------------------------|---------------------|-----------------------|--------------------------------|
| M, 81 yr | Primary        | 4 yr                        | Cardioversion       | Yes                   | No                             |
| M, 85 yr | Secondary      | 9 yr                        | Cardioversion       | No                    | No                             |
| M, 86 yr | Secondary      | 21 yr                       | Cardioversion       | No                    | Yes                            |
| M, 81 yr | Secondary      | 10 yr                       | None                | Yes                   | Yes                            |
| F, 81 yr | Primary        | 3 yr                        | None                | No                    | No                             |
| F, 81 yr | Primary        | 7 yr                        | None                | No                    | Yes                            |
| M, 89 yr | Primary        | 3 yr                        | None                | No                    | No                             |
| M, 81 yr | Primary        | 3 yr                        | None                | No                    | Yes                            |
| M, 82 yr | Secondary      | 7 yr                        | None                | No                    | Yes                            |
| M, 82 yr | Secondary      | 5 yr                        | Cardioversion       | Yes                   | Yes                            |
| M, 82 yr | Secondary      | 15 yr                       | Cardioversion       | No                    | No                             |
| M, 82 yr | Primary        | 5 yr                        | ATP                 | No                    | No                             |
| M, 85 yr | Primary        | 5 yr                        | None                | No                    | No                             |
| M, 82 yr | Primary        | 3 yr                        | None                | No                    | No                             |
| M, 81 yr | Primary        | 5 yr                        | None                | No                    | No                             |
| M, 82 yr | Secondary      | 3 yr                        | None                | No                    | No                             |
| M, 86 yr | Primary        | 2 yr                        | None                | No                    | No                             |
| M, 82 yr | Secondary      | 5 yr                        | None                | No                    | No                             |
| M, 80 yr | Secondary      | 16 yr                       | Cardioversion       | No                    | No                             |

ATP, antitachycardia pacing; F, female; ICD, implantable cardioverter-defibrillator; M, male; yr, years.
maintain their health. A recurring statement was that the participants enjoyed life and did not wish it to end, even though they were aware of their advanced age. A majority of the octogenarians stated that they exercised to the extent they were able to, as per the recommendations of their physicians. Furthermore, most of the participants viewed their loss of physical functioning as a result of infirmity of age and comorbidities, not their ICD. They did not consider the ICD a substantial part of the degenerative health process. They described the ICD as something ‘imperceptible’, ‘it is just there’, and expressed that the device had become a part of their body. For example, respondent 1 described it as follows:

‘I usually say to everyone who asks that I don’t have a problem with that thing (ICD) but you can help me with the other things. But those are ailments that one has with age and that are now coming in older days. Because you are… worn out’.

Only two participants mentioned that the actual device caused physical discomfort. One octogenarian said that the device stretched the skin because of its bulkiness, and another mentioned that the device rubbed when he used seatbelts, so he stopped travelling by car. Respondent 2 expressed social discomfort due to the ICD. Respondent 2 received an ICD shock when he was playing tennis, which scared his fellow player, and made him take up bowling instead. In addition, he enjoyed skiing, but did not consider the ICD to be a hindrance for his active lifestyle:

‘And the funny thing is that skiing, it is not the ICD that you think of in first place [as being an obstacle]. It’s my poor eyesight that affects the skiing’.

However, the ICD did remind him of his declining health:

‘When you shower and feel the lump here… It is obvious… Nonessential things. You get a little reminder. And then you take your drugs once a day and I go… the thoughts cross’.

A few of the octogenarians suffered from device-related complications that were described as ‘troublesome’. The most severe complication was infection, which required explant of the whole system. For instance, Respondent 3 had experienced several complications, both infections requiring re-implantation but also lead dysfunction. Once, his ICD alarm went off during his breakfast due to a fractured lead. When asked how he perceived the experience of receiving an ICD, he used the term ‘bloody tough’.

**Theme 2—‘The Janus-faced device’: their attitudes**

The Janus-face is a metaphor used to describe polarities and contrasting aspects, chosen to emphasize the octogenarians’ view of their ICD as a two-edged sword. The ICD has two important sides; one side as a source of concern for life, and on the other a source of concern for death. None of the octogenarians regretted receiving their ICD. Their attitudes towards their ICD were those of gratitude, trust, and a sense of security. They had a strong trust in the ICD treatment, and to receive an ICD was equivalent to life. As Respondent 4 stated:

‘And then when they decided on the ICD, it was all natural, I said… So I want… I want to live’.

The treatment gave the participants a sense that they could relax, and that they did not need to be scared that something would happen to them. Respondent 5 received two appropriate shocks. He talked about the shocks he had received without any fear of the device; instead, he felt grateful to still be alive:

‘You could say… I’m alive… There is only a bat to the head at the back of my neck that can take me now, because this starts me off’.

To some octogenarians, turning off the ICD was considered equivalent to euthanasia or even physician-assisted suicide. The majority of the participants did not mention that they had been informed about the possibility of deactivating the device with their physician. However, one participant, Respondent 6, mentioned having a discussion with his physician about deactivation of his device. Respondent 6 was the participant who had been an ICD carrier the longest, 21 years. Even though he had talked to his physician about deactivation, he doubted that his physician would go through with it:

‘I don’t think he will do it… Strange, well… Well I mean it is… In the situation in Sweden today you’re not allowed to take someone away really…’

The participants who had received ICD shocks did not doubt the treatment. On the contrary, a few of them expressed that the shock made them feel more secure, because it was proof that the device functioned and saved their lives. Respondent 7 had received both appropriate and inappropriate shocks. He explained that he felt the shock through his entire body, but he was not worried about receiving another shock. Instead, he felt gratitude towards the device:

‘Well, I know that it works… he (the physician) said that it is not confirmed but it might have been that my heart stopped… It might be. Well, I said… If that is right then I am forever grateful that I had this implanted’.

When asked if they had thought about death, most of the octogenarians answered that they avoided thinking about it and focused on the present moment. However, a few of them expressed concern that the ICD might hinder a peaceful death:

‘Because it’s a horrible pain when it kicks in. It’s a diabolical pain they say… those whom it has happened to. And you want to be able to have a calm death if nothing else…’

The worst concern for Respondent 7 was losing his memory or becoming hospitalized, and he feared that the ICD might prolong time before death:

‘… the risk of becoming a vegetable might be greater when you have an ICD than when you do not because then you might die immediately’.
Theme 3—Mind the gap: their knowledge

When deciding on an ICD, the majority of the participants described themselves as being mostly passive in the decision-making process. They trusted that the physician with their medical knowledge was more suited to make the decision for them. For instance, Respondent 6 received his ICD as secondary prevention after a heart arrest and the ICD started to deliver shocks. Initially, he had doubts about the device, but decided to trust the physician who persuaded him by saying that the ICD treatment acted as a safety mechanism:

‘It was bloody tough... However, I thought... Well, there is no other option? You knew that it was... according to what they said it was a... a... at the same time a... well... a safety’.

The information given by healthcare personnel about the ICD treatment was described in positive terms. Several participants mentioned that the information was provided both orally and in writing, and that they gave their consent before the implant. A few of the octogenarians had saved all their papers in folders and wanted to show the folders during the interviews. None of the participants felt uninformed about their device. There was, however, a distinct lack of knowledge about how and when an ICD could be deactivated, and about the difference between an ICD and a pacemaker.

During the interviews, many of the participants reflected about the deactivation of their ICD for the first time, revealing certain knowledge gaps. For instance, Respondent 8, a well-educated man, showed tremendous knowledge about his congestive heart failure. When it came to his ICD, however, he had not given it much thought. When asked if he knew how to deactivate the device, he answered:

‘I guess you push a button somewhere. It is my wife who keeps track of all the buttons’.

During the interviews, many of the octogenarians started to guess how to deactivate the device. They also expressed logistical concerns regarding their ICD. Respondent 9 became anxious that the ambulance might not be able to deactivate the ICD, which might make the transport to the hospital painful due to ICD shocks. Another participant had recently lost his wife due to cardiac arrest, and had been living by himself since then. While sharing this traumatic memory, he also expressed concerns regarding his own death and ICD treatment. When his wife had her cardiac arrest, he called the emergency operator and was then asked to open the front door, so that the paramedics could get in. Since then, he had been struggling to figure out how the paramedics would get through the front door if he had a cardiac arrest and the ICD started to deliver shocks.

Besides knowledge gaps about deactivation and the difference between an ICD and a pacemaker, one participant wanted more information on the procedure and how the electrodes were attached to the heart. Overall, the octogenarians were able to recall why they received the ICD, at least making the connection that it had to do with their heart condition. They tended to regard the ICD as a minor intervention and had trouble remembering information about the device, since other health problems appeared more pressing. For example, Respondent 10 received his ICD around the same time as he also underwent open-heart surgery and perceived the heart valve replacement as much more traumatic than the ICD procedure. The indication for the ICD was not comprehended:

‘... and where they have got heart rushes from as a big problem... That I do not understand. That is to me mind-boggling’.

The participants often gained their knowledge from other patients with an ICD, hearsay about ICD shocks from people without medical training, or from media. Only a few of the participants mentioned discussions about ICD shocks and deactivation with their physician. It was expressed that trust was an important factor in the relationship with healthcare professionals. Furthermore, the language used by the physician when informing the participants was crucial for the participants’ interpretation of their current health condition. Respondent 11 was a man of few words during the interview, but became emotional talking about his implantation procedure, which had been challenging. During the implantation, the operator had problems connecting the leads to his heart, which he explained as follows:

‘There was nowhere to attach it to... And that made me quite broken... I perceived it as if my heart was like a sponge...’

Discussion

This study explored several aspects of the lived experience among octogenarians. In this study, all the participants experienced a decline in health with advancing age. However, it is important to acknowledge that the majority of the octogenarians expressed contentment with their current health status, despite comorbidities. Early definitions of SAT established that SA meant being free from disabilities/diseases; however, such a conceptualization excluded the majority of elderly individuals. The current discussion has shifted focus to the degree of health required to achieve SA.20 Physical wellbeing needs to be minimally fulfilled, which includes a pain-free life, maintained basic physical functioning, well-managed chronic diseases, and avoidance of potential complications.30

ICD treatment is efficacious in preventing sudden arrhythmic death1 and it can therefore be an important part of a well-managed treatment plan for SA. However, the implantation of an ICD brings risks of complications. A literature review shows that the rate of complications after ICD implantation is 9.1%,31 the most common being lead dysfunction, followed by infection. In addition, the recipients might experience inappropriate shocks at a 5-year cumulative incidence of 9.1%.26 Furthermore, studies have shown that those receiving inappropriate shocks have an increased risk of all-cause mortality.32,33

This study’s findings, however, suggest that octogenarians consider the ICD to have marginal negative impact on their physical wellbeing. Instead, patients expressed their gratitude towards the device which protect them from life-threatening arrhythmias. Even those who experienced complications did not regret receiving an ICD, grading
the benefit of the treatment as greater than the complications. The octogenarians in the study saw the ICD as a part of SA. This conclusion is in accordance with a Swedish quantitative study stating that 97% of the octo- and nonagenarians rated their general experience of living with an ICD as good/very good.10

Moreover, the participants in the present study seemed to adapt well to their ICD and their current overall health. Previous research has shown that elderly individuals view the ability to adapt as being crucial for SA (as a process, rather than a state of being).34 While the octogenarians’ younger counterparts have been found to describe the ICD implantation as painful,15 and expressed awareness of or even physical encumbrance by their ICD,4 the results of the present study show that the majority of the participants did not pay much attention to the device. Octogenarians are less likely to complain than younger individuals,36 and maybe this is due to the octogenarians’ greater ability to adapt and accept a worsening health status.

Overall, the results show that the participants experienced positive emotions in connections with their ICD, such as gratitude, trust and safety, causing a positive effect on their subjective wellbeing. Positive emotions towards the ICD are in line with previous studies.4,35 According to SAT, high levels of wellbeing significantly lower the risk of mortality and disability when controlling for other risk factors, and it has even been suggested that the ultimate criterion of SA is the subjective perception of wellbeing.30

However, as expected, the ICD treatment did also have a negative impact, such as concern regarding their upcoming death and the potential harm in an ICD shock. Sometimes the concerns were a result of insufficient knowledge. Lack of knowledge among ICD carriers is a known problem ranging over all age groups,11–14,37 and for those above the age of 65, the knowledge level is significantly lower.38 Furthermore, this insufficient knowledge led the octogenarians to believe that the ICD made them virtually immortal. This over-estimation of the ICD’s abilities to keep them alive has also been found in earlier research.39

Our sample comprised patients of an advanced age, with short life expectancy per se. Nevertheless, the patients reported spirit of life and regarded the device as a companion in daily life. Although limited by physical health issues, the ICD was appreciated. Importantly, the concerns about end-of-life matters, especially ICD deactivation, were seldom addressed at follow-up. Some of them even perceived deactivation as euthanasia or physician-assisted suicide, which might imply ethical dilemmas closer to end of life. In fact, in another study, 28% of the participants thought that deactivation was equivalent to euthanasia,15 and another study found that 17% of the participants considered deactivation physician-assisted suicide.16 Hence, discussion about life-and-death issues should be continuously addressed during the life course with ICD carriers at advanced age. Furthermore, the lack of knowledge could be managed with structured follow-up and promotion of patient–patient interaction such as organizations and support groups. The shared decision-making process should be enhanced, and a holistic view of the patients and their concerns should be adopted during follow-up during the entire life span.30

Limitations

This study is limited by geographical and ethnic selection, which may hinder generalization of findings. Moreover, participants were predominantly males, reflecting a bias in the indication decision-making of ICD therapy.

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Conflict of interest:
G.M. has received speaker’s fees from Alnylam, MSD, and Intermetmedic. P.M. has received speaker’s fees or grants from Abbott, Alnylam, Amicus Therapeutics, AstraZeneca, Bayer, Boehringer-Ingelheim, Coala Life, Intermetmedic, Lilly, MSD, Novo Nordisk, Octopus Medical, Orion Pharma, Pfizer, Vifor Pharma, and Zoll. All other authors have declared no conflict of interest.

Data availability

Data available upon reasonable request.

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