

Introduction

An implantable cardioverter-defibrillator (ICD) is an established treatment for survivors of life-threatening ventricular arrhythmias. The ICD monitors cardiac rhythms and can deliver a variety of programmed functions, including defibrillation shock therapy in the presence of tachyarrhythmias or where a cardiac condition predisposes an individual to sudden cardiac death (Glikson et al., 2021, Dörner et al., 2023). The shock therapy comprises high-energy electrical currents that pass over and depolarise the myocardium converting lethal rhythms to life-sustaining or normal rhythms, thereby averting sudden cardiac death (Nichol et al., 2017).

The range of defibrillating devices include implantable cardioverter-defibrillators (ICDs) with or without cardiac resynchronization therapy (CRT), subcutaneous cardioverter-defibrillators (S-ICD), and wearable cardioverter-defibrillators (WCD) (Al-Khatib et al., 2016). The devices can be single-chamber, dual-chamber and biventricular. All include a right ventricular defibrillator lead, while the dual chamber device also has a right atrial pacing lead. In addition to the right ventricular defibrillator lead, the biventricular ICD also has a left ventricular pacing lead and is sometimes referred to as a cardiac resynchronisation therapy device.

The ICD may be used as a form of primary prevention in, for example, patients with left ventricular dysfunction who are at risk of SCD from ventricular tachyarrhythmia, while they are employed as secondary prevention for individuals with a prior episode of ventricular tachycardia or ventricular fibrillation (van Welsenes et al., 2011). The ICD is implanted using local anaesthetic in the subclavicular area, and it is programmed to detect the heart rhythm. If ventricular tachycardia is confirmed, the

device will deliver anti-tachycardia pacing or shock, as indicated (Al-Khatib et al., 2016).

The number of ICD recipients is increasing annually, and is expected to continue to rise, due to an aging population, expanding indications for ICDs and compelling evidence from several randomised controlled trials that resynchronisation therapy reduces mortality, while improving functionality, wellbeing, and quality of life (Al-Khatib et al., 2016, Fluor et al., 2013, Glikson et al., 2022).

However, despite the benefits of ICDs, patients' knowledge about ICD-related decisions can be lacking (Lewis et al., 2014, Mooney et al., 2019). The Working to Improve Discussions about Defibrillator Management trial identified that challenges exist in relation to communication about devices (Goldstein et al., 2008b).

Therefore, all available opportunities should be taken by healthcare professionals to have open discussions with patients about their ICDs (Glikson et al., 2022, Beattie, 2013). Such opportunities include pre-device insertion, hospital admission or readmission, the aftermath of ICD shocks, where a functional decline is noted, or on admission to a hospice (Brady, 2016).

While ICDs may prolong life, they also cause anxiety, stress, and uncertainty (Flanagan et al., 2010, Ghezzi et al., 2023, Humphreys et al., 2016). Furthermore, the pain related to shocks can be severe and distressing (Boriani et al., 2019, Strachan et al., 2011). Consequently, some ICD recipients develop coping strategies including lifestyle restrictions and avoidance behaviours to facilitate living with an ICD (Cutitta et al., 2014). While some research is available about how people manage life with an ICD, little is known about that period where ICD recipients' transition from life without an ICD to living with one. Therefore, the aim of this paper

was to explore how patients perceived the transition to life after the implantation of a cardioverter defibrillator.

Methods

Design and setting

This qualitative exploratory, descriptive study was undertaken in the republic of Ireland. The research site was a large tertiary hospital where ICDs are implanted. The catalyst for the study was based on a clinical encounter involving a male patient in his second decade who was preparing for discharge following insertion of an ICD. The man was well-educated and intellectually capable, yet his knowledge, understanding and preparation for the transition to life with an ICD was totally inadequate. This gave rise to the current study.

Theoretical underpinning

This study was understood in the context of transition theory, which is concerned with the passage from one stage in life to another; it occurs in phases, over time (Meleis et al., 1986, Schumacher and Meleis, 1994). The theory asserts that health and illness transitions are linked with nursing practice, that transition patterns are varied, and that that healthy transition is characterised by process and outcome. (Meleis et al., 1986). This theory was considered a good fit for our study.

Inclusion and exclusion criteria

Eligible patients had an ICD, or a cardiac resynchronisation therapy device (CRT-D) implanted for primary or secondary prevention of sudden cardiac death. In addition, they had to be at least 18 years of age, fluent in English and cognitively competent to give informed consent. Their device must have been implanted and activated for at

least 12 months prior to the study, to allow time for adjustment to their device. The exclusion criteria comprised those who resided in an extended or residential care setting, patients with left ventricular assist devices and those awaiting urgent heart transplantation. Using these criteria, a cardiology nurse distributed one letter of information to eligible patients inviting them to participate. Those who were interested contacted the researchers directly.

The sample

Forty-five patients were written to, and 15 contacted the researchers to express an interest in participating. Of these, three females and seven males pursued the invitation. The sample age range was 30 years to 74 years. The devices had been implanted a minimum of three years and a maximum of 17 years previously. Four participants had CRT devices, of whom one person had received a shock. Four of the six with non-CRT devices had received shocks.

Data Collection

The framework for the interview guide was based on the work of Kallio et al., (2016) who provide a five-step framework to support the development of an interview guide for use by qualitative researchers. The questions were derived from a review of the literature and the guide was linked to the overall trustworthiness of the study. The interviews took place in a private room near the coronary care unit of the hospital. Data collection comprised semi-structured interviews which were undertaken after questions were answered, and consent forms signed. The interviews lasted 45-68 minutes. The sensitivity of the topic was acknowledged, and reassurance given that, on request and without implications, the interview could be stopped, and withdrawal

facilitated. Note-taking during interviews was kept to a minimum, but detailed notes were recorded afterwards. Data saturation was not expected or achieved with ten participants. Notwithstanding this, the data were rich, meaningful, and contextual. All participants were invited to review their interview transcripts, and two participants did so, thereby adding to the trustworthiness of the study.

Ethics

The study was ethically approved by the Joint Research Ethics Committee, which jointly reviews applications for the hospital and University. The approval number was 201503-CA-14.

Rigor

The framework chosen for ensuring the quality of this study was based on the work of Lincoln and Guba (1985). This quality framework comprises credibility (truth), dependability (consistency), transferability (applicability), and confirmability (neutrality) and authenticity. These were achieved through, for example, the rigorous development of the interview schedule, prolonged participant engagement, the use of a reflective diary, verbatim transcriptions, member checking and the inclusion of original quotations to support the analysis, to mention a few.

Data analysis

Thematic data analysis was divided into 6 phases using Braun and Clarke guidance (Braun and Clarke, 2006). Analysis began with researcher familiarisation. This was followed by the generating initial codes, searching, reviewing defining and naming themes and finally producing the report. To achieve this, all records were used,

including initial interviews, raw data, process notes, the research instrument, and a reflective diary. Transcribing of verbatim data began immediately after the first interview, while analysis began during the interviews. Key phrases came directly from the data, to prevent superimposing our analysis on them. Initial codes (N=183) were generated by identifying meaningful key phrases that told the recipients' stories. Ongoing analysis resulted in theme development and refinement. Using paper and cut-outs, these were then linked with their corresponding excerpts and divided into relevant categories.

Findings

While the origin of the study was based exclusively on a clinical experience, the findings that emerged were centred on the components of the transition model, including the device implantation process, connectedness and disconnectedness, the lived perception of the change and the adjustment response patterns.

Collectively these were rooted in transition to life after ICD insertion and the comparison between life with and without an ICD. Two themes were derived from the data as follows: 1. Moving forward while looking back, 2. Shocked or lying in wait.

Excerpts from the study are included under each theme below, with additional exemplars provided in Table 1.

Moving forward while looking back

This theme titled moving forward while looking back described the journey from the initial days post ICD insertion to the present day. Participants reflected on how their perspectives on living with an ICD changed over time and how life with an ICD meant physical, psychological and lifestyle adjustments. From a physical

perspective, the discontinuation of contact sports and extreme exertional physical activities were referred to, in addition to changes in sexual relationships and lifestyle. Negative emotions included anger and anxiety, which stemmed from the realisation of living with a serious and life-threatening illness. This was associated with feelings of uncertainty about the future and a requirement for life-long changes. Each recipient had a different story to tell, but collectively they were affected by their need to transition to a new life, one that included an ICD.

“So now adrenaline is our worst enemy...and that’s what I have to manage. I think with exercise, I need to be careful. It’s not exercise per-se; it’s the adrenaline around it... I can’t take part in competitive sports; I would never take part in a race now.” (P1).

“It took me about six months to get used to it; I was always afraid I was going to die.” (P9).

For older participants, the need to physically adjust to the device was less problematic, as due to their age and underlying cardiac conditions many were already unable to partake in sports or strenuous physical activity prior to ICD insertion. They discussed the things they had previously taken for granted, such as climbing up ladders and using electric drills.

“It doesn’t really affect me, but you don’t do what you used to. I used to use drills and all that kind of stuff and I don’t really do that anymore, because I’d be afraid it would do something to it (the ICD).” (P9)

For some, physical adjustments included changes in sexual relationships after the ICD insertion. Alterations to sexual relationships were attributed to fear by one or both parties of delivering or receiving an inadvertent shock. While other aspects of

relationships were positively reported, it was the sexual activity that was significantly altered; a situation that was not considered to be transient and was expressed more openly by those who were younger.

“I think she is more afraid of something happening, like she would wake up and I would be dead in the bed beside her. We get on great, there’s nothing other than that (absence of sexual relations). I reckon though, I’ve never said it to her, but she was more afraid.” (P2).

There were vivid descriptions from participants of psychological adjustments, which were a necessity for all. Younger participants talked about their anger; not necessarily about having the ICD, but about their diagnosis and the prospect of having a life-threatening illness. They questioned why it had happened to them and some lived with a fear of dying and leaving loved ones behind.

“.... So, I walked home from the Hospital up to my home and I was angry, very angry. I was angry with the fact that I’m normal. I am normal in that I have never taken a drug in my life; I don’t behave ridiculously stupid like a lot of other people. So, there was a lot of anger, and I got home, and I was thinking about it and it just wouldn’t leave my head...and I keep saying why me? when I’m trying to do something with my life. That’s the annoying part.” (P6)

Psychologically, the transition to living with an ICD took several weeks for some, and years for others. Younger participants reported a longer processing and adjustment period. Most agreed that once they adjusted to the ICD (outcome), they relaxed more and became somewhat comfortable with their device.

“...But, it’s no longer a hindrance to me anyway. It’s like, you know it’s there, but it doesn’t bother me.” (P4)

The participants were prohibited from driving, although some continued to drive. The threat of being prohibited from driving, and the possible permanent loss of their driving licence was feared.

“My biggest thing at the time was, purely selfish reasons, I didn’t want somebody coming along and saying ‘oh you’re driving? You shouldn’t have a driving licence’ or ‘oh you can’t be insured’... but I thought ‘if my independence is taken from me, well that is the end of my life.’” (Participant 1)

“Like waiting on people to bring me here, there and everywhere was... I didn’t like that at all. I’ve always looked after myself.” (Participant 10).

Those whose driving licences were suspended at the time of the interviews described their discomfort with having to rely on others. The loss was not only related to the physical act of driving, but also concerned with reduced independence, role change, and, for some, a feeling of erosion of masculinity.

Shocked or lying in wait.

This theme related to the receipt or non-receipt of a shock from the device and how both altered the way they lived their lives since ICD implantation. For those who received a shock, albeit unpleasant, they knew and understood how it felt. Meanwhile, among those who had never received a shock, an image of a device “lying in wait” was conjured up.

The participants that had previously received shocks reported mixed accounts of this experience.

“I didn’t know what hit me, there was just this white flash: “boom!” I’m sitting here by the window and next thing; I was sitting over there...” (P5).

Knowing when a shock was imminent allotted for greater control and took less recovery time.

“I was prepared for it, because I could feel it coming on; so, you get yourself ready. I didn’t know what was happening to me the very first time it happened. But I prepared myself the second time; I sat myself down” (P6).

Receipt of a shock was described as a ‘terrible experience’, like being electrocuted. Those that received multiple shocks, described the experience as “horrific”, and had considered asking for the ICD to be removed or “turned off.”

“Yes, 1.2.3. BANG! They all happened within an hour. So, then I said, ‘I want it out, I want it out’ (P7).

Receiving a shock in public rendered participants embarrassed, vulnerable and feeling exposed. This led to unease about resuming activities outside the home.

And I was in the pub, which was worse. That’s embarrassing” (P5)

The shock experience was negatively associated with fear and vulnerability and was a reminder of mortality. Participants were relieved that the ICD had saved their lives, and for this they felt secure and grateful.

“So, the ICD saved my life – again!! I was over the three hundred (heart rate) and I know without it I would be dead twice already; that is a huge comfort... psychologically having it is fantastic” (P1).

It was important for participants to ascertain the reason for receiving a shock. They recounted events that preceded a shock in an attempt to identify and isolate what had triggered it. Where a trigger for the shock was isolated, they avoided this activity in future as part of the transition to an altered way of life.

Discussion

Transition theory principles guided this study where rich descriptions of adaptation, reconciliation, acceptance, and appreciation were provided by participants. The process of developing confidence and coping was also articulated. Our participants and those of other researchers (Flanagan et al., 2010, Humphreys et al., 2016, Mert et al., 2012, Palacios-Ceña et al., 2011) reported a need for physical and psychological lifestyle adaptations with an ICD particularly in the early stages of ICD insertion.

There were no familiar reference points for participants in the early stages of ICD insertion. This meant that feelings of insecurity replaced those of security, manifesting in psychological distress for many. This has been reported elsewhere with respect to ICD implantation (Flemme et al., 2012, Mert et al., 2012, Glikson et al., 2022, Humphreys et al., 2016). Fear and anxiety associated with defibrillation, uncertainty about the defibrillation experience and when and where defibrillation will happen, all contribute to psychological distress (Pasyar et al., 2015). It is therefore incumbent on health care professionals to identify ICD recipients' psychological needs, so that tailored, and time-appropriate education, support and psychological intervention can be offered (Beattie, 2013, Flemme et al., 2012, Humphreys et al., 2016).

The threat of prohibition from driving and the associated loss of independence was articulated among the participants in this study. This topic has been the subject of discourse in the literature. In European countries, driving is restricted for ICD recipients, although the guidelines tend to be inconsistent (Imberti et al., 2020). Restrictions range from 2-12 months for secondary prevention, and between 1-4 weeks for primary prevention or lead revision (Cruns and Vernoooy 2021, Imberti et al., 2020). However, the European Heart Rhythm Association have provided guidance, differentiating restrictions for private and professional driving (Vijgen et al., 2010). In summary, the recommendation is a permanent restriction from professional driving, but a resumption of driving for private use on receipt of an ICD (Vijgen et al., 2010). While the negative effects of driving restrictions are widely acknowledged, it is incumbent on healthcare professionals to convey current and accurate information to patients for their own safety and that of others.

Our participants reported the experience of an ICD shock as a negative event, leading to heightened fear and restrictive behaviours. This restriction of activities in response to ICD insertion has been reported elsewhere (Goldstein et al., 2008a, Humphreys et al., 2016, Pasyar et al., 2015). Those who received multiple shocks, or an electrical storm had additional psychological and physical adjustments. In these cases, assessment, family involvement and counselling about ICD have been recommended (O'Brien et al., 2005), and deactivation may be considered (Dickerson, 2002). There is little doubt that among individuals, transition events differ, with the potential for multiple co-existing non-linear transitions (Meleis et al., 1986).

Participants in this study described the broader effect of ICD implantation and how it affected relationships, including sexual relationships. While reduced sexual activity

due to fear of defibrillation was raised as a concern among the younger participants in this study, it is a potential concern for people of all ages. This is an unnecessary burden for patients, and a worry for healthcare providers that this is the situation for ICD recipients (Flanagan et al., 2010, Mert et al., 2012, Morken et al., 2010, Palacios-Ceña et al., 2011). Recipients' opinions can be shaped by their knowledge (Hill et al., 2015), which strengthens the need for education and counselling. Goldstein et al. (2008a) concluded that by assuring conversations occur for all ICD recipients, we can guarantee the highest quality of care.

Healthcare professionals can open the way for discussions about matters of importance to patients and are generally keen to do so. However, the timing of conversations is important. Patients may be overwhelmed by the experience of device implantation, with a resulting lack of retention of in-hospital education (Ferrick et al., 2023). The literature also suggests that lack of time and confusion can cause missed discussion opportunities between healthcare professionals and patients (Goldstein et al., 2008b, Sherazi et al., 2008). However, the avoidance of conversation culminates in lack of patient knowledge, misunderstanding and disempowerment. This highlights the requirement for optimal timing of education and discussion with the inclusion of information that is personalised and tailored to the person's capacity and lifestyle (Bolse et al., 2013).

Conclusion

We explored ICD recipients' experiences of transition to living with an ICD. The participants were at least one-year post ICD insertion. As expected, transition varied across the participants, and consequently a variety of patterns of responses

emerged from the data. The descriptions of the physical and psychological adjustments to life with an ICD were rich and unanimous. Physical adjustments involved modifying or ceasing activities, while psychologically, mixed emotions about the device, its necessity, its benefits, and its challenges were voiced. Receipt or the potential receipt of a shock was an on-going challenge, resulting in pain, fear, and uncertainty. The threat of being prohibited from driving was a significant worry for some and was associated with a perceived loss of independence.

We conclude that there is a need to support and educate all ICD recipients before and following device implantation. The need to recognise and support transition as a non-linear process is important, and a core component of nursing practice.

Discharge information should include partner or spouses and comprise information on driving restrictions, maintenance of physical activity, sexual activity and any other questions that arise during the education process. Opportune moments or triggers should be used to elucidate individual preferences, provide tailored support and counselling, while offering open fora for discussions. A guide for timing and topics is available from the European Society of Cardiologists and the British Heart Foundation. The implementation of these guidelines in clinical practice would help support ICD recipients.

Key points

- The provision of tailored education, information and support can help to dispel patients' concerns before and after ICD insertion.

- Nurses are ideally placed to assess patients' transition and offer support as their patients negotiate the path to coping and adjustment.
- The findings from this study have been used by the Irish Heart Foundation to support their work in devising support for patients who receive an ICD.

CPD reflective questions

- Why is it important to assess patients' coping strategies before and after ICD insertion?
- How might you assess the transition your patient and their recovery trajectory?
- Which guidelines are used in your workplace to support ICD recipients with decision making?
- What sort of information is provided to patients in your workplace before ICD insertion?
- What sort of information is provided to patients in your workplace following ICD insertion?
- Through your clinical practice, how can you positively impact the lives of ICD recipients?

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