# The Experiences and Concerns of People With Cardiac Implantable Electronic Devices:

## A Qualitative Content Analysis of Reddit Posts

[redacted]

School of Psychology, The University of Adelaide

September 26, 2022

*This thesis is submitted in partial fulfilment of the Honours degree of Bachelor of Psychology (Advanced)(Honours)*

Word Count: 9306

# Table of Contents

## List of Figures

# List of Tables

# Abstract

Cardiac implantable electronic devices are used to treat a variety of cardiovascular diseases, such as cardiac arrhythmias. There are three common kinds of device: pacemakers, implantable cardioverter-defibrillators, and cardiac resynchronization therapy devices. While living with these devices presents a number of challenges, current literature has overwhelming focused on people with implantable cardioverter-defibrillators. Additionally, there is limited evaluation of how people living with these devices engage with online peer support. The present study, therefore, aimed to answer the research question "What questions, and information about their experiences, do people living with a cardiac implantable electronic device post to communities intended for them on the social media website Reddit?" The website Reddit was systematically searched for relevant communities, and posts made by those living with a device were collected. Conventional qualitative content analysis was employed to analyse posts made to the one subreddit found that met the inclusion criteria of the present study. From the 299 posts analysed, five overarching categories were established: Use of the Subreddit, Life with a Device, Healthcare Experiences, Psychological Experiences of Living with a Device, and Physical Sequelae of Device Implantation. Findings provide insight into how people living with these devices engage with online peer support and the challenges that they face. Novel findings regarding the age and health status of participants, and the impact of the COVID-19 pandemic, are presented. Further research is needed to explore the experiences of people living with a device and how to best improve healthcare communication, social support, and health literacy.

# Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

[redacted]

September 24, 2022

# Contribution Statement

In writing this thesis, my supervisors and I collaborated to generate research questions of interest, select the most appropriate one, and design the appropriate methodology for data collection and analysis. I conducted the literature search, completed the ethics application, collected and analysed the data, and wrote all aspects of the thesis. My supervisors provided feedback on my analysis and writing.

[redacted]

September 24, 2022

# The Experiences and Concerns of People With Cardiac Implantable Electronic Devices: A Qualitative Content Analysis of Reddit Posts

## The Burden of Cardiovascular Diseases

Cardiovascular diseases represent a wide range of potentially overlapping conditions, affecting the blood vessels and heart, that present significant burdens to both global health and the lives of individuals (Ávila et al., 2014; Boerschel & Schnabel, 2019; Dalen et al., 2014). Globally, cardiovascular diseases represent 32% of all mortalities (World Health Organization, 2021), with conditions such as heart failure and atrial fibrillation experienced by over 60 million (Lippi & Sanchis-Gomar, 2020) and 37 million (Lippi et al., 2021) people respectively. Over one million people in Australia live with heart disease (Australian Bureau of Statistics, 2018), and different cardiovascular diseases represent the most common, twelfth most common, and sixteenth most common causes of death nationally (Australian Bureau of Statistic, 2021). Alongside these mortality concerns, mental health conditions are a common comorbidity of cardiovascular diseases (Stein et al., 2019) and may be both a risk factor for, and consequence of, these conditions (Cohen et al., 2015; Kovacs et al., 2022). While many treatments are available for cardiovascular diseases, management of these conditions can carry a significant perceived treatment burden for patients (Gallacher et al., 2011; Potpara et al., 2020) and this may be worsened by limited health literacy (Friis et al., 2019). Cardiac implantable electronic devices are a growing treatment option for a range of cardiovascular diseases, such as cardiac arrhythmias and heart failure (Hussein & Wilkoff, 2019; Steffen et al., 2019), that present many unique challenges for patients.

## Cardiac Implantable Electronic Devices

There are three common types of cardiac implantable electronic device: pacemakers, implantable cardioverter-defibrillators, and cardiac resynchronization therapy devices (see Steffen et al., 2019, for a detailed review). These devices monitor the natural electrical conduction systems of the heart and, if not functioning correctly, apply an electrical charge in order to modify cardiac function. Generally, each device consists of a matchbox sized oval-shaped disk called the generator that contains the circuitry and battery of the device. The generator is implanted into a surgical pocket usually created in the upper chest and is connected to transvenous leads that, depending on the treatment required, enter the different chambers of the heart. Pacemakers are used to treat abnormal heart rhythms through a process of electrical stimulation known as “pacing.” Implantable cardioverter-defibrillators may provide similar functions to a pacemaker, but also have the ability to defibrillate the heart to prevent sudden cardiac arrest. Lastly, cardiac resynchronization therapy devices can have both the functions of a pacemaker and implantable cardioverter-defibrillator and are used to coordinate the two ventricles of the heart. Since the first implantation of a fully internal device in 1958, the technology has seen rapid advancements and growing use (Ward et al., 2013).

The commonality of cardiac implantable electronic devices is evident from a global survey of 61 countries conducted in 2009 that found over one million devices, the vast majority of which were pacemakers, implanted that year (Mond & Proclemer, 2011). In Australia, the rate of pacemaker implantations has steadily increased between 2008 and 2017 with people over 80 years of age being the largest group to receive a device (Westaway et al., 2021). Furthermore, recent advancements in technology have seen the development of new devices including leadless pacemakers that are inserted directly into the heart to provide single chamber ventricle pacing (Steffen et al., 2019). These leadless pacemakers may reduce the treatment burdens faced by patients as they are associated with a lower risk of complications than traditional devices (Ngo et al., 2021). Subcutaneous implantable cardioverter-defibrillators, that do not require the insertion of transvenous leads, have also been developed for people who are only at risk of sudden cardiac arrest (Bögeholz et al., 2019). Even with the proliferation of these devices, and technological advancements, there is limited research assessing their impacts on patient experiences, and the evidence that does exist has overwhelmingly focused on those with implantable cardioverter-defibrillators (Tagney, 2010).

## The Impacts of Living With a Cardiac Implantable Electronic Device

Living with a cardiac implantable electronic device presents a number of unique and challenging experiences. Many people living with a device depend on it for their continued survival, and thus, these devices may act as reminders of their own mortality (Locsin et al., 2010). People implanted with a device may also face real and potentially life-threatening complications including: infections, hematoma formation within the device pocket, displacement or damage to the generator, failures of the leads, and inappropriate therapies being administered by the device (Atreya et al., 2016). Post-surgical infections can be particularly impactful for patients and represent one of the greatest contributors to patient mortality requiring significant medical intervention (Han et al., 2021). Furthermore, living with a device requires a commitment to regular contact with healthcare professionals, and even with the ability to remotely monitor the device, attending routine in-person evaluations is recommended (Slotwiner et al., 2015). For those nearing the end of their life, ceasing life-sustaining therapies must be considered (Gura, 2015) and there is a body of literature evaluating device deactivation decisions for people with implantable cardioverter-defibrillators (Lewis et al., 2014).

These devices may additionally impart a number of restrictions on the types of activities in which people may participate. To prevent damage to the device, the displacement of components, failures of the leads, or the device functioning incorrectly, patients may have to restrict or discontinue their physical and sporting activities (Sciarra et al., 2021). The physical presence of the device may also naturally restrict physical activities as implantation can cause persistent pain in the upper extremities and limit their range of motion (Surendran et al., 2021). To prevent damage to the device during recovery, and to protect others, many jurisdictions require patients to desist from driving for a prespecified period of time (Imberti et al., 2020). People living with a device must also avoid strong electromagnetic fields, for example those produced by induction cooktops, as these may interfere with the functioning of some devices (Driessen et al., 2019). Qualitative research methodologies have been particularly useful for elucidating the impacts of device implantation.

Current qualitative research has focused largely on the experiences of people living with an implantable cardioverter-defibrillator. A systematic review by Barisone et al. (2022), of 24 studies, found that people living with implantable cardioverter-defibrillator faced a number of challenges with both psychological and physical adaptation. Additionally, their review indicates that many people expressed fears and anxiety about their implantable cardioverter-defibrillator administering inappropriate defibrillation that could result in painful electrical shocks. An earlier review of qualitative studies conducted by Pike et al. (2020) highlighted comparable difficulties. Pike et al., however, also highlighted that many people actively strive to accept their implantable cardioverter-defibrillator and work towards positively evaluating their future with a device.

Similar experiences have been observed in the limited qualitative literature that has assessed people living with other types of cardiac implantable electronic device. Two studies of Iranian patients indicated that while some adapted positively, pacemaker implantation was a significant event that led to many lifestyle changes and could be a source of stress (Ghojazadeh et al., 2015; Rakhshan et al., 2017). Alongside lifestyle changes, a study of female patients indicated that living with a pacemaker may lead them to grapple with issues of identity and body image (Beery et al., 2002). People with pacemakers, Malm and Hallberg (2006) found, may experience disruptions to both their social participation and emotional state. They argue that based on how these disruptions are managed, people with pacemakers shift between different ways of living, with some being able to regain their desired way of life. People with subcutaneous implantable cardioverter-defibrators also experience a range of physical, psychological, and adaptational challenges (Forman et al., 2018; van der Stuijt et al., 2020). Yet overall, there is a dearth of qualitative literature that explores the experiences of people with cardiac implantable electronic devices other than implantable cardioverter-defibrillators. This trend of privileging the experiences of those with implantable cardioverter-defibrillators may be attributed to the perception that the shocks caused by these devices are more impactful and the health status of patients more dire (Tagney, 2010). A similar trend is seen in literature that evaluates the psychological correlates of implantation.

## The Psychological Correlates of Device Implantation

People with implantable cardioverter-defibrillators may experience similar rates of mental ill-health as those with other chronic and cardiac illnesses (Magyar-Russell et al., 2011; Oshvandi et al., 2020). While varying greatly on a number of methodological factors, a systematic review of 45 studies found that rates of diagnosable depression and anxiety among implantable cardioverter-defibrillator patients were 11% to 28% and 11% to 26% of patients respectively (Magyar-Russell et al., 2011). A later meta-analysis and systematic review found that middle aged people with an implantable cardioverter-defibrillator experienced depression at greater rates than the elderly (Oshvandi et al., 2020). For paediatric patients, as indicated by a systematic review of 14 studies conducted by Pyngottu et al. (2019), pacemakers and implantable cardioverter-defibrillators are associated with lower quality of life when compared to healthy controls. While paediatric patients generally adapt to living with an implantable cardioverter-defibrillator, anxiety may be particularly problematic for some (Pyngottu et al., 2019; Sears et al., 2009). In addition to diagnosable anxiety disorders, the fear associated with anticipating the electric shocks produced by an implantable cardioverter-defibrillator can be significant among patients (Tripp et al., 2019) and specific measures of this form of state anxiety have been developed (Kuhl et al., 2006). Both younger people and those less knowledgeable about their implantable cardioverter-defibrillator may experience greater shock related anxiety (Tripp et al., 2019). Device related knowledge has been demonstrated as a factor associated with better quality of life for people living with these devices (Polikandrioti, 2021).

## Device Related Knowledge and Online Information Seeking

Knowledge related to cardiac implantable electronic devices is most often gained through contact with healthcare professionals, and effective communication in this context has been seen as protecting against adverse psychological experiences (Linder et al., 2013). Systematic reviews by Barisone et al. (2022) and Pike et al. (2022) have indicated that people with an implantable cardioverter-defibrillator often feel that they lack sufficient information about their devices and how to manage living with them. Both reviews suggest that this lack of knowledge is detrimental to the ability of these people to manage their life after implantation. Similar concerns regarding device related knowledge have been seen in people with pacemakers (Patel et al., 2020) and subcutaneous implantable cardioverter-defibrillators (Forman et al., 2018). Furthermore, deficits in knowledge have been cited as a possible reason why people may choose to decline device treatments (Ottenberg et al., 2014), as when deciding on whether to undergo implantation the information provided by healthcare professionals regarding their medical condition is not always sufficient (Johnson et al., 2020). When faced with a lack of information about their health or treatment options, people are increasingly turning to social media to gain insight into their conditions, to seek advice from their peers, and to find information relevant to their circumstances (Chung, 2014; Moorhead et al., 2013).

There are now a number of different websites that people can access in order to gain health information, although, these are often limited in quality (Daraz et al., 2019). Alongside websites that act purely as information sources, social media can allow people to share and discuss their experiences with their peers. In the case of heart failure, these websites can help patients gain knowledge, seek advice, and make treatment decisions (Farnood et al., 2022a). However, social media websites may serve as a source of disinformation (Farnood et al., 2022b). Current literature evaluating how people with a device use social media has focused on those with implantable cardioverter-defibrillators.

Early research indicates that online forums may empower people with an implantable cardioverter-defibrillator to be informed consumers through the provision of information, social interaction, and peer support (Dickerson, 2005). Additionally, online information and interactions with others may decrease experiences of implantable cardioverter-defibrillator shock anxiety (Richards et al., 2016). While this may be the case, advice given on forums about implantable cardioverter-defibrillators may lack quality and overestimate the risks associated with these devices (Knoepke et al., 2018). Alongside this research, studies indicate that people with implantable cardioverter-defibrillators have expressed a need for lived experience groups to fill gaps in their knowledge about living with a device (Bolse et al., 2005; Doolan-Noble et al., 2021; Sert et al., 2021). Therefore, it is likely those living with a cardiac implantable electronic device may turn to social media to address knowledge deficits and receive peer support.

## Theories of Peer Support

Definitions of peer support vary as it occurs both formally, through the provision of lived experience informed medical services, and informally, through naturally formed support groups (Davidson et al., 1999). Both formal and informal forms of peer support have long histories in the context of people experiencing mental illnesses (Shalaby & Agyapong, 2020), but a growing body of evidence indicates the possible effectiveness of formalised interventions in a range of chronic health conditions (Colella & King, 2004; Hossain et al., 2021; Thompson et al., 2022). Formalised peer support within medical services represents a form of mutually agreed social support that draws on the lived experience of providers to aid in the facilitation of health-related education and intervention (Fortuna et al., 2022). On the other hand, informal peer support is better conceptualised as a bond between those who share lived experiences based on collaborative and mutually agreed supporting systems of exchanges (Mead et al., 2001). While peer support has seen extensive adoption and research, Naslund et al. (2016) states that there is a need for research to consider the mechanisms that drive the efficacy of online peer support.

There are currently no well-supported and unified theoretical approaches to explaining the efficacy of peer support, and this is a literature gap to be addressed by future scholarship. Nevertheless, attempts have been made to theorise the mechanisms underpinning peer support. A concept analysis conducted by Dennis (2003) suggested that peer support interventions are generally defined by three attributes: emotional support representing care and acceptance given by a peer, the provision of tangible knowledge, and affirmations of a peer’s psychological state and behaviours. According to Fortuna et al. (2019) the efficacy of peer support has been previously explained through six theories, namely, experiential knowledge, the helper-therapy principle, self-determination theory, social comparison theory, social learning theory, and social support theory. Within the context of digital interventions, Fortuna et al. used these theories to create a model of formalised peer support programs run by specialist providers. As Naslund et al. (2014) highlighted, however, informal peer support that occurs naturally through mediums such as social media has received less attention. No previous research, known to the author, has specifically assessed peer support that occurs naturally between people with cardiac implantable electronic devices using social media.

### The Present Study

Based on available literature, the experiences of people living with an implantable cardioverter-defibrillator are overrepresented (Tagney, 2010). There is a clear need to address gaps in current understandings of how people with other cardiac implantable electronic devices experience living with a device. Additionally, there is limited literature evaluating the use of social media peer support by people with cardiac implantable electronic devices. Consequently, the present study used a qualitive methodology to address the research question "What questions, and information about their experiences, do people living with a cardiac implantable electronic device post to communities intended for them on the social media website Reddit?"

## Method

### Data Source

#### *Reddit as a Data Source*

Reddit is an online social media platform that, at the time of writing, represented the 14th most trafficked website in the world (Alexa, 2022). On Reddit, users who have created an account can post self-generated content, links, and various other forms of media. Users can then comment on these posts, or they can rate them using an up-vote/down-vote popularity-based system. All posts made to Reddit must be assigned to a specific "subreddit" which each represents a user created and moderated community organised around a particular theme, interest, or topic. The curated nature of subreddits has been of particular interest to researchers with them being used extensively to investigate specific topics (see Proferes et al., 2021, for a review). Reddit was used as the data source for the present study as data collection could be constrained to only subreddits intended for the discussion of cardiac implantable electronic devices. For the purposes of the present study, participants were people who had posted to subreddits related to cardiac implantable electronic devices.

### *Ethical Considerations for Working With Reddit Data*

Research using data from online communities can present unique ethical challenges that require safeguards to be considered in regard to the specific aims, samples, and methodologies used (Lomborg, 2013; Roberts, 2015). The present study received low-risk research ethics approval from the University of Adelaide School of Psychology Human Research Ethics Sub-Committee (approval number: 22/27). Approval was granted on the grounds that all data collected were publicly available, no contact was made with participants, and that participant anonymity was maintained. While what constitutes publicly available data has been contested in literature, if collected passively with no harm brought to the community under study, public posts can be seen as textual documents that do not require consent from users to analyse (Roberts, 2015; Smedley & Coulson, 2021; Wilkinson & Thelwall, 2011). As such, private subreddits and those with specific rules prohibiting the collection of user data were excluded from the present study. People who use Reddit, Amaya et al. (2021) argues, may also expect a level of anonymity based on the website's terms of service and user culture. To protect this expectation of anonymity, all personal information that could likely identify participants was excluded from reporting and each username was converted into a numeric pseudonym.

### *Subreddit Selection*

Only subreddits intended for people with cardiac implantable electronic devices were included in the analysis. To find suitable subreddits, the website's internal search engine was used, and all searches were limited to look for subreddits only. The following search terms were used: "artificial pacemaker," "cardiac implantable electronic device," "cardiac pacemaker," "pacemaker," "permanent pacemaker," "ICD," "CRT," "cardiac resynchronization therapy," and "implantable cardioverter defibrillator." Out of the searches performed, only one subreddit called r/PacemakerICD was found to be suitable for inclusion in the present study.

The subreddit r/PacemakerICD was created in August 2014 and is intended for people, or carers of people, with cardiac implantable electronic devices to discuss their experiences, questions, and concerns. At the time of data collection (April 17, 2022) the subreddit consisted of over one thousand members, 484 posts, and 4036 comments. The subreddit had no rules prohibiting the collection of user data or posts.

## Data Collection

Online forums, according to Smedley and Coulson (2021), generally have a hierarchical structure consisting of specific topic areas, with each level of postings able to provide different information for researchers. The present study examined the entirety of the top-level threads on the included subreddit. This was done in order to develop an understanding of what people with cardiac implantable electronic devices posted to the subreddit.

Reddit’s official Application Programming Interface (API) was used, in a manner consistent with the website’s terms of service, to collect posts from the subreddit (Proferes et al. 2021). The API represents a set of programming tools that are intended to allow access to Reddit’s functions and publicly available user data. The ability to use Reddit’s API first required the creation of a Reddit account and for agreement to the website’s terms of service (Reddit, 2021). Then the intention to create a programming script that would collect posts and comments for research purposes was registered through Reddit’s developer application portal (Reddit, n.d.). This was done to gain an OAuth 2.0 client identification number and a client secret number that would allow access to the API. The final step of the process was to agree to the API specific terms of service (Reddit, 2016).

Once access had been granted to use the API, a programming script was created to facilitate the collection of posts made to the subreddit (see Appendix A). The script was created using Python (version 3.9.7) and PRAW (version 7.5.0; Boe, 2021) which allowed the use of Reddit's API functions within the Python ecosystem. To maximise the reliability of the data collection process, the script collected every publicly available post in a sequential fashion. For each post, the textual content, title, date of posting, and poster username was collected. These data were then exported as a .CSV file in which all posts were presented in chronological order.

## Data Analysis

Conventional qualitative content analysis, as described by Hsieh and Shannon (2005), was used to systematically classify the textual data collected into codes, subcategories, and categories, that together provided a hierarchical framework that described the questions and experiences of participants. This method of analysis allowed for the highly heterogeneous information represented in the data corpus to be condensed into a conveyable framework of concepts and for the quantification of recurring patterns (Vaismoradi et al., 2013). The conventional qualitative content analysis process was inductive in nature with codes, subcategories, and categories constructed based on the surface and underlying meaning present in the data corpus (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Furthermore, the present analysis adopted a critical realist theoretical perspective that viewed an underlying reality to the lives of cardiac implantable electronic device patients, in which experiences and scientific observations of this represented fallible socially mediated processes (Clark et al., 2008). This perspective provided insight into both the reality of participants' lives, and the complex social realities that may determine their experiences of cardiac interventions (Clark, 2007).

Before the formal analysis process could begin, each post was read to facilitate the exclusion of posts and the collection of participant demographic information. Out of the 484 posts that were originally collected, 185 posts were excluded resulting in 299 posts being included in the final analysis. For the posts that were excluded, 118 were made by people who did not have a cardiac implantable electronic device, 41 were removed as they were not usable in the analysis (e.g., spam or links to media articles without context), and 26 were made by participants who did not specify if they had a device. A register of participant demographic data was created based on the information conveyed in each post. This register included participant age, gender, type of device at the time of posting, and time lived with their current device.

The conventional qualitative content analysis process was conducted over four stages, that were based on Hsieh and Shannon's (2005) recommendations, using the qualitative data analysis software NVivo 12 Plus (version 12.6.1.970). Firstly, after data collection and exclusion, each post was individually read repeatedly to further gain familiarity with the data corpus. Notes were taken on the content of each post, with the aim of describing small units of meaning within the data. The second stage of the analysis process was to generate the initial codes which each represented a short phrase that captured a piece of meaning or information conveyed by the participants. Thirdly, the different codes were compared to each other, and those with similar content or meaning were arranged into different subcategories. Finally, while reflecting on the research question, these subcategories were then further analysed and compared in order to organise them into categories that captured the broadest level of information conveyed in the data corpus. For readability, typographical errors were corrected in all reported quotations. As participants could not be contacted for feedback on the analysis, which is an important element for establishing the credibility of qualitative research (Cope, 2013), the author's supervisors who are both experienced clinical health psychologists evaluated the codes, subcategories, and categories.

Erlingsson and Brysiewicz (2017) argue that reflexivity is an essential part of the qualitative content analysis process. This is because a researcher must reflect on how their own pre-understandings may have influenced their subjective interpretations of qualitative data. The author of the present study had no previous experience in cardiac research, however, he was motivated to investigate cardiac implantable electronic devices due to the experiences of his father who has lived with a pacemaker for over 10 years. As such, previous knowledge about life with a pacemaker gained through the author's relationship with his father, may have played a role in the development, analysis, and reporting of the study. To assist with the reflexive process, and to bolster the credibility of the analysis, the researcher kept a audit trail which represented reflections on their decisions, assumptions, and biases during each stage of the research process (Cope, 2013). Reflexive practice was further assisted through continual discussion of the project with the author's supervisors who have previously worked with people experiencing cardiovascular diseases in clinical contexts.

# Results

## Participant Demographics and Subreddit Information

Each Reddit username was taken to represent a unique individual, and thus, the 299 posts included in the analysis were made by 196 participants. Twenty-six participants identified as male, 19 identified as female, and 151 did not state their gender identity. For the 79 participants who reported their age the mean was 33.1 (*SD* = 13.2), with the youngest participant being 17 years old and the oldest 72. Out of the 93 participants who reported how long they had lived with their current device, the most common time was less than one year. As seen in Table 1, 181 participants reported the type of device with which they were currently implanted, the most common of which being a pacemaker.

**Table 1**

*Reported Participant Device Type*

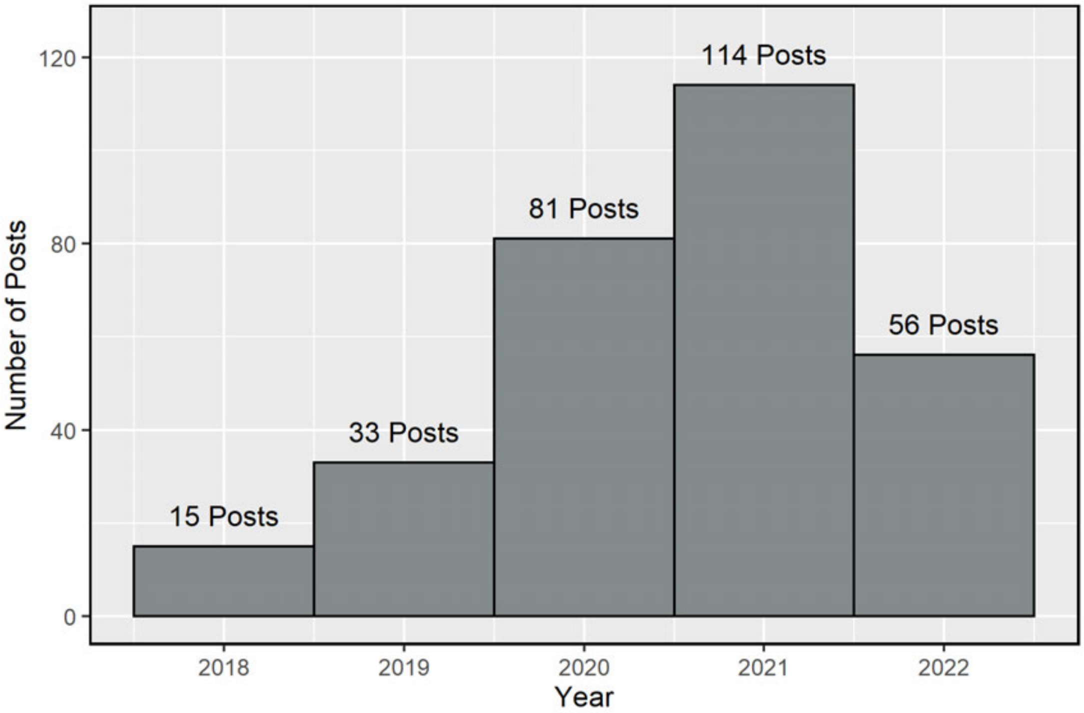
| Device Type | *n* | % of total |
|---|---|---|
| Pacemaker | 101 | 51.5 |
| Implantable cardioverter-defibrillator | 61 | 31.1 |
| Subcutaneous implantable cardioverter-defibrillator | 9 | 4.6 |
| Cardiac resynchronisation therapy device | 6 | 3.1 |
| Leadless pacemaker | 4 | 2.0 |
| Device type not indicated | 15 | 7.7 |

*Note.* N = 196

Figure 1 illustrates the number of posts included in the analysis made each year to the subreddit from January 2018 to April 2022.

**Figure 1**

*Annual Total Number of Posts Included in the Analysis*



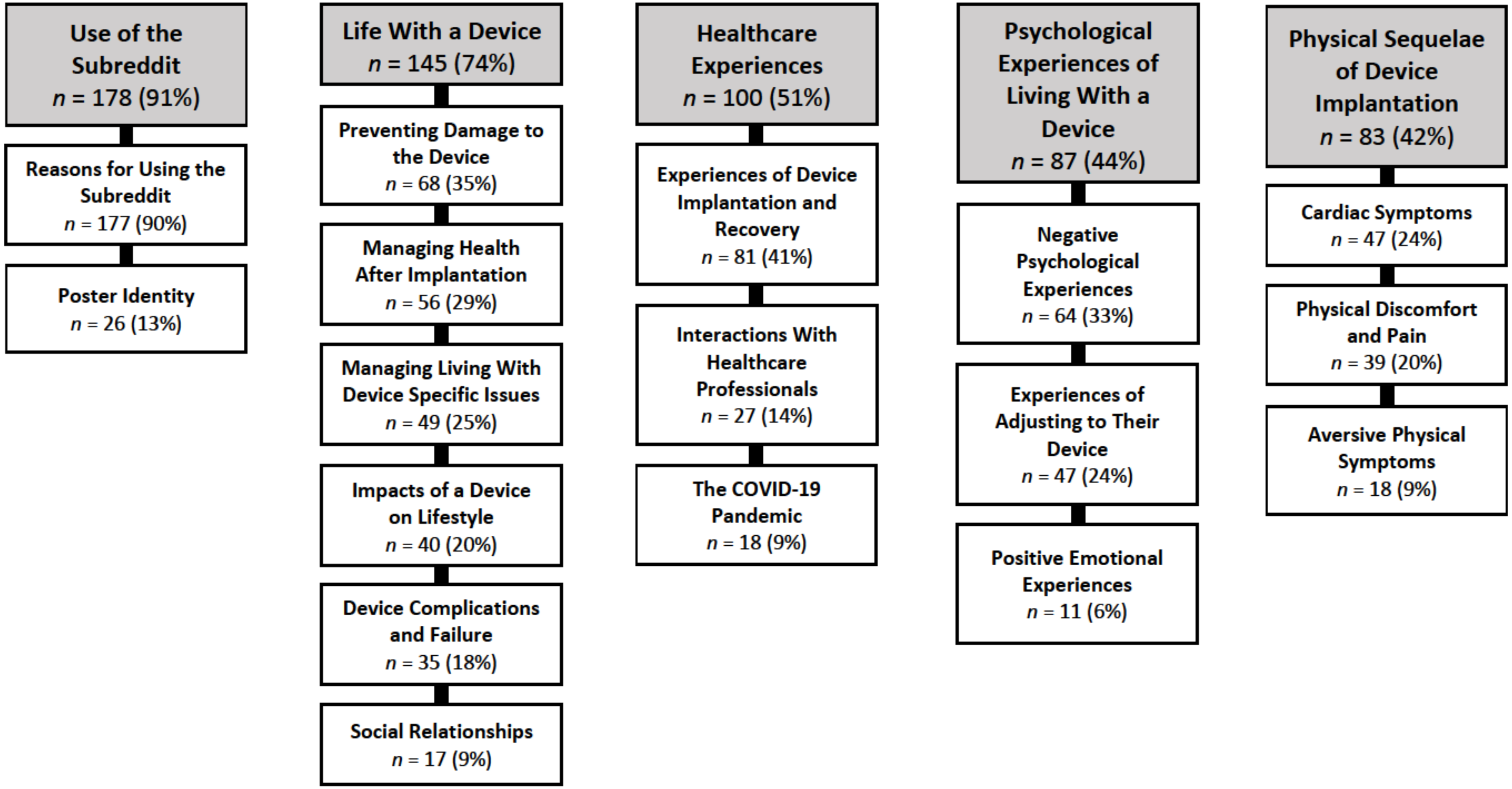
*Note.* N = 299

## Categories, Subcategories, and Codes

A conventional qualitative content analysis (Hsieh & Shannon, 2005) of posts made to the subreddit yielded 104 codes, condensed into 17 subcategories, and five overarching categories (see Appendix B for each code and the full analysis structure). The five overarching categories, associated subcategories, and occurrence frequencies are illustrated in Figure 2. The occurrence frequency for each code, subcategory, and category was calculated based on how many participants produced textual data to which it applied. For example, 145 participants posted content related to “Life with a Device.”

**Figure 2**

*Overarching Categories (Coloured Grey) and Accompanying Subcategories with Occurrence Frequencies*



*Note*. Percentages are calculated based on the total number of participants ($N$ = 196).

### *Use of the Subreddit*

The predominant category established from the data was “Use of the Subreddit” which consisted of two subcategories that captured how participants used the subreddit. The subcategory “Reasons for Using the Subreddit” captured codes related to the declared motivations of participants for posting. Participants generally sought information on the experiences of others (*n* = 115), advice for dealing with their problems (*n* = 68), answers to technical questions (*n* = 17), and to know whether their experiences were normal (*n* = 11). Some participants were motivated to post in order to thank the community for the help they had received (*n* = 16). Additionally, participants shared their experiences of living with a device (*n* = 47), and many often explicitly expressed a desire to do so in order to help other people:

> I know there are a lot of emotions that go along with being different than “what’s normal,” and I would be more than happy to share my experiences, the challenges I’ve overcome and my philosophy on what it means to have such an amazing device. (Participant 21)

The inability to find information about living with a device elsewhere (*n* = 14) also motivated some participants to post: “I got a leadless pacemaker about a month ago. I am still confused about what I can do or not. Anyone else have one? I haven’t found much information on them either” (Participant 171).

The second subcategory “Poster Identity” captured codes related to how participants constructed their identities. Younger participants specifically described themselves as such (*n* = 12) and looked for others of the same age: “I feel so lost being only 18 with an ICD [implantable cardioverter-defibrillator]. Having arrhythmias and having experienced SCA [sudden cardiac arrest] is just terrifying. Anyone young and going through the same thing?" (Participant 91). Furthermore, participants described themselves as cyborgs (*n* = 8), or as belonging to a special club (*n* = 8): "Have y'all ever realized that we're basically cyborgs since our hearts are run by a piece of technology?" (Participant 141).

### *Life With a Device*

The second most predominant category "Life With a Device" captured subcategories related to the intricacies of living with a device. The most frequent subcategory "Preventing Damage to the Device" captured codes that described the experiences of, and questions about, activities or external forces that may harm a device. Participants were most often concerned about electromagnetic interference (*n* = 32), especially from emergent consumer technologies: "I got a smart watch, and the charger is a magnet (hadn't heard of that sort of charger before). Will the magnet in the back of the watch be okay with my pacemaker?" (Participant 168). Participants discussed the activity restrictions (*n* = 30), such as limiting sporting activities or hobbies, required due to having a device and ways they might protect their devices from damage (*n* = 10): "I am going on a skiing holiday, and I have an ICD [implantable cardioverter-defibrillator], has anyone done this before and have recommendations for protecting the device?" (Participant 70). Furthermore, there was concern over complications from taking recreational (*n* = 5) and prescription hormonal (*n* = 1) drugs. Participants wanting to use recreational drugs, including alcohol and caffeine, indicated that there was a lack of information about their use:

> I know illegal substances are bad for you and we shouldn't take them. But I still just want the information and can't find any online. What would happen to my heart if I did a single line of cocaine? Or if I took molly once? Like, would I drop dead or get shocked? I searched online and couldn't find any answers. (Participant 160)

The second most frequent subcategory “Managing Health After Implantation” captured codes related to how participants evaluated and managed their health with a device. The majority of discussion on the subreddit regarding health management after implantation was related to exercise (*n* = 35), and participants reported either improvements (*n* = 16) or declines in their health status (*n* = 13). With regard to exercise, participants generally asked questions about what types of activity were possible with a device:

> I am a 20 F [female] and just had my ICD [implantable cardioverter-defibrillator] placed near the armpit area under the muscle, so I was wondering whether sports like boxing or tennis is still okay, would I be at higher risk for lead displacement? I’m also thinking about whether exercises like push-ups, pull-ups, light weight lifting etc are safe to do since these require arm strength and because of where my ICD [implantable cardioverter-defibrillator] is placed, I’m not entirely sure if that’s a good idea? (Participant 89)

Additionally, participants reported their experiences of deliberately trying to lose weight while living with a device (*n* = 4). Weight loss was associated with pain-related complications due to their device protruding:

> However, one thing I’m noticing is that as I’ve started to slim down, my ICD [implantable cardioverter-defibrillator] is causing me more and more discomfort. Not via shocks or anything, just by kinda poking out. I can feel pressure on it whenever I lie down, whenever I sit in a chair or in the car, and it’s uncomfortable for a while, then gradually starts to become painful. (Participant 156)

The third subcategory “Managing Living With Device Specific Issues” captured codes related to lifestyle problems specific to being implanted with a device. Participants reported experiences of, and questions about, implantable cardioverter-defibrillator shocks (*n* = 15), rubbing from external objects such as bra straps or seatbelts (*n* = 9), battery life concerns (*n* = 5), concerns about automated device checks (*n* = 4), discomfort caused by device warning alarms (*n* = 3), and medical alert identification information (*n* = 2). The most frequently coded for device specific issue was the monitoring of device and heart function (*n* = 21). This coded for discussion about the use of digital health tracking applications, remote monitoring services provided by device manufacturers, and consumer heart rate monitors. Participants engaged in monitoring practices to ensure the function of their devices and to track their heart rates. This, however, was often reported as source of confusion and concern:

> I have 2 oximeters. I use them to take my pulse. Sometimes when I feel bad (with a lack of air feeling), I take my pulse. It has been in the 40s or 140s (too low or too high) sometimes during those episodes … I've told my dr but he says that everything is ok because my PM [pacemaker] isn't recording those events … Is the oximeter accurate enough for us? Should I trust more the PM [pacemaker] than the oximeter? (Participant 86)

While some participants reported only negligible effects, having their device settings changed (*n* = 9) was reported to help overcome some of the problems experienced living with a device:

> I just had that appointment and they tweaked the settings and it’s AMAZING! I left that hospital and immediately ran 2km without stopping. Since then I’ve been running

> increasing distances every day, went for my first surf since last year, and feel awesome. (Participant 66)

The fourth subcategory “Impacts of a Device on Lifestyle” captured how having a device changed, or might affect, the daily lives of participants. This subcategory included a diverse range of concerns, and experiences, of the reciprocal impacts between devices and work (*n* = 12), driving (*n* = 11), sleep (*n* = 11), simple activities (*n* = 7), school (*n* = 3), sex and masturbation (*n* = 2), and diet (*n* = 1). One participant also inquired about the experiences of others giving birth while living with a device. The reported impacts of living with a device could be caused by its direct physical presence, or the limitations of current technology:

> I am a marine engineer and electrical engineer, currently looking for a work. I can no longer work with magnets or transformer stations, which has already led to me having to avoid certain job options. I’m scared of telling anyone outside my closest family, because employers might consider me damaged goods and reject me. (Participant 35)

While restrictions on the ability of device patients to drive are common during implantation recovery (Imberti et al., 2020), it was apparent that participants with pacemakers experienced difficulties with driving outside of this period. Specifically, participants with a pacemaker reported problems with uncomfortable heart rates: “Lastly, I’m not sure if I’m crazy or just a weirdo but being in my car is awful, my heart races and I feel thumps every time my husband drives me anywhere, anyone else experience this!?” (Participant 49). One participant with a pacemaker who experienced this difficulty driving equated it to the activity responsive pacing functions of their device:

> My pacemaker senses my movement and ramps up my heart rate accordingly. So funny story I'm driving around in my MGB 1971 [a sports car] which has very poor suspension and I glance at my watch which has a heart rate monitor and my heart rate is sitting at 144 bpm due to the bumps in the road. (Participant 194)

The fifth subcategory "Device Complications and Failure" captured the concerns, and experiences, of participants regarding medical complications associated with their device and its failure to operate correctly. Participants expressed concerns about lead dislocation (*n* = 13), dislocation of the device (*n* = 8), and the device malfunctioning (*n* = 4). Additionally, participants reported their experiences of lead failure (*n* = 10) and device related infections (*n* = 4). Concerns about device complications were most common among younger and more physically active participants, and their failure was perceived as significantly impactful:

> However, once I got to high school I ripped or broke my lead and feel like I have been accidentally doing this over the years because of my lead placement over my collar bone. I am now 26 and have recently had a surgery in April to replace a damaged lead and was told by my doc that I only had a certain amount of veins left. I took that to mean I could basically die if I keep this up… I used to be very active so I have limited my activity and no longer do things like weightlifting. I am extremely careful and always conscious of my PM [pacemaker]. (Participant 169)

The final subcategory, "Social Relationships," captured codes related to descriptions of social support (*n* = 14), the perceptions of others related to their device (*n* = 5), and perceived stigma towards devices (*n* = 2). While social support from others not using the subreddit, such as family members, was viewed as beneficial by participants, some raised concerns over the perceptions of others towards their device:

> I was out for dinner with my OH [other-half] and 2 old friends and he drew attention to my pm [pacemaker] wound. They were all laughing and saying it looked like a mouth and that they could animate it and make it look funny. I was completely devastated, they were all just laughing in my face and I just wanted to disappear. How do you deal with these sorts of things? They didn't mean it maliciously but it was really crushing and has massively knocked my confidence, just posting here because I'm struggling to find anyone who understands. (Participant 163)

### ***Healthcare Experiences***

The third category "Healthcare Experiences" consisted of three subcategories related to participant's' experiences of device implantation, interactions with healthcare professionals, and the impacts of the COVID-19 pandemic on their healthcare. The main subcategory "Experiences of Device Implantation and Recovery" consisted of codes related to questions about, and experiences of, recovering from surgery (*n* = 46), device replacement (*n* = 28), implantation surgery (*n* = 20), lead replacement and removal (*n* = 17), implantation complications (*n* = 7), additional surgeries to support heart function (*n* = 7), the costs associated with the device (*n* = 4), and bandages (*n* = 1). While many participants who discussed recovering from implantation surgery only described their experiences, those scheduled for a device replacement often expressed apprehension:

> I am now scheduled to see an electrophysiologist this Thursday and I'm just... Shocked. And really scared. I don't know what to expect or how technology has

> changed. I have an extremely physical job lifting heavy bags of concrete and wood all day. I don’t understand how I’ve kept up and never felt exhausted but am in such bad shape inside. I guess I just need to vent to people who understand but would also like some advice on recovery times, restrictions etc. Are Pacemakers like they were 17 years ago? (Participant 129)

The second subcategory “Interactions With Healthcare Professionals” captured participant engagement with healthcare providers. Participants discussed the medical advice they had received (*n* = 13), their appreciation for some of the professionals with whom they had interacted (*n* = 3), and one female participant expressed discomfort discussing sexual activity with her male healthcare professional. Participants, however, expressed a sense of perceived ambivalence held by their healthcare professionals (*n* = 14) and some disagreed with them about their symptoms (*n* = 7):

> I feel like there’s got to be some device/pacing/programming settings that could be tweaked to alleviate a lot of my issues, but despite being explicit in my descriptions as I can be, nothing’s changed since I got this CTR-D [Cardiac Resynchronization Therapy Defibrillator] implanted. I really hoped my device check-up in February would have led to some problem solving but they said everything with the device is normal, and I can even lower my beta blocker dosage. (Participant 44)

The third subcategory “The COVID-19 Pandemic” captured the impacts of the pandemic on the experiences of participants (*n* = 12), such as public health measures limiting their access to healthcare. Alongside this, some participants reported possible complications from the vaccine (*n* = 3) and others raised questions about who can access the vaccine and concerns about its safety (*n* = 5):

> Has anyone had any discussions with their cardiologist or GP regarding receiving Pfizer of AstraZeneca vaccinations for COVID-19? I have complete heart block, and I have some preliminary concerns about receiving the vaccination in the fear that it may not have been adequately tested. (Participant 154)

### *Psychological Experiences of Living With a Device*

The fourth most predominant overarching category "Psychological Experiences of Living With a Device" consisted of categories related to the emotional and psychological aspects of living with and adapting to a device. Participants most frequently reported aversive psychological aspects of living with a device and codes related to this formed the subcategory "Negative Psychological Experiences." Participants reported being worried (*n* = 30), fearful or scared (*n* = 19), anxious (*n* = 14), depressed or sad (*n* = 12), frustrated (*n* = 9), traumatised or experiencing PTSD (*n* = 6), stressed (*n* = 5), emotionally tired (*n* = 3), feeling lost or empty (*n* = 3), and being cognitively impaired (*n* = 2). Additionally, participants reported anxiety related to shocks from their implantable cardioverter-defibrillator (*n* = 7). Experiences of worry, fear, and anxiety were common and often compounded by other aspects of living with a device, not just its physical presence inside them:

> I'm 21, and I just got mine inserted yesterday. I'm in quite a bit of pain but advil [ibuprofen, an over the counter pain medication] has been working (not that much but it's better that nothing). I've been more anxious about almost everything and it doesn't help that it's my last semester of college so I'm also worrying about school

> work on top of trying to recover. I’ve had two different anxiety attacks just today. My question is: what do you guys do when you feel anxious? (Participant 38)

In some cases, experiences of fear and anxiety could be deliberating and impede on even simple daily activities:

> However, ever since then I have been completely terrified to do anything that I think will elevate my heart rate at all. I’ve been afraid to do the smallest things like shower, drive, or walk up stairs. My employer gave me a few days off work to recoup and relax and I am due to return to work Friday. As it gets closer, my anxiety is getting worse. (Participant 126)

The second subcategory “Experiences of Adjusting to Their Device” captured codes related to how participants came to adapt to living with their device. Participants discussed experiences with, and asked questions about, ways of coping with a device (*n* = 12), returning to normality after implantation (*n* = 10), trying to rebuild their confidence (*n* = 5), that their life had changed (*n* = 4), learning to trust their device and body (*n* = 3), and one participant expressed becoming emotionally attached to their device. While participants experienced difficulty adapting (*n* = 6), some expressed resentment or hatred towards their device (*n* = 4):

> Need a battery change, haven’t made the appointment. Why? I hate this and I’m miserable. I’m afraid of it, it doesn’t make me feel safer, it’s taken my dreams of military service and flying away from me, I can’t do cool hobbies I’m interested in. When I bring this up to people they don’t get it. They think I should be thankful and appreciate that it might save my life. I don’t care. A longer life feels pointless when i

> don’t get to be happy. And there’s not a damn thing I can do about it. Idk [I don’t know] what I’m trying to gain here. I guess I’m just hoping someone finally understands. I’m gonna cry myself to sleep now. (Participant 5)

A minority of participants wanted their device removed or deactivated as it had either become redundant, or because living with it was such an aversive experience (*n* = 3): “I had really bad anxiety and PTSD [from a prior operation]. So now, I am having all those feelings again because I NEVER WANT TO BE SHOCKED AGAIN. My question is can I get it removed or turned off?” (Participant 190). Additionally, younger and more active participants expressed difficulty accepting their device due to their age and health status (*n* = 10):

> I read the other posts and I guess I’m struggling with the whole “why me” crap. I live a healthy lifestyle, never smoked, and am in good health (besides having a battery in my chest). Like a lot of the other posts have stated, it’s more of a mind fuck than anything. (Participant 97)

The least frequent subcategory was “Positive Emotional Experiences” and this captured codes related to the positive emotions expressed by participants about their device. Participants reported being happy with or excited for their new device (*n* = 5), reported being proud of some aspect of living with a device (*n* = 4), or expressed their gratitude for their device (*n* = 2). Positive emotions were most often expressed by participants when their device presented clear benefits over alternatives:

> Got the all clear to send back the LifeVest to Zoll [a wearable external defibrillator] after the longest 5 months of my life. Had to wait until my 2nd week ICD

> [Implantable cardioverter-defibrillator] follow up for the all clear. Everything is working quite nicely. Cheers to life beyond the vest, and freedom from the electrodes, garments, and all the cords! I am most excited about my re-expanded wardrobe options and not lugging that box around my waist anymore. (Participant 115)

### *Physical Sequelae of Device Implantation*

The final category "Physical Sequelae of Device Implantation" captured the physical consequences of devices that participants either explicitly described or asked questions about. The main subcategory "Cardiac Symptoms" captured the discussion of aversive device related cardiac symptoms. The two most predominant codes for this subcategory captured the discussion of heart rates ($n$ = 29) and palpitations ($n$ = 11). Other reported cardiac symptoms included shortness of breath ($n$ = 10), feeling lightheaded or faint ($n$ = 5), losing consciousness ($n$ = 4), feeling dizzy ($n$ = 3), and fluid retention ($n$ = 1). Generally, participants sought the experiences of others and whether to seek medical care:

> All of a sudden these past few days I am feeling dizzy all the time. Getting out of bed, laying in bed, outside, etc; has anyone else experienced anything similar to me? Should I contact my doctor? I get slightly lightheaded and my head starts to space out. (Participant 179)

The second subcategory "Physical Discomfort and Pain" captured codes related to the discussion of different pain and discomfort experiences. Participants reported pain and significant discomfort directly related to the presence of the device generator or leads inside them ($n$ = 16). In addition to this, participants reported general experiences of discomfort and pain ($n$ = 11), insertion site and scar related discomfort and pain ($n$ = 11), and pain and discomfort described as being related to their heart or chest (*n* = 10). Pain was often reported within the context of recovering from surgery, but it could also occur well after implantation: "I've had an ICD [implantable cardioverter-defibrillator] for 20 years (this particular one for 7). The last few months it's become uncomfortable and just more noticeable in my chest" (Participant 30). Additionally, the pain and discomfort experienced by participants was complex and overlapping:

> This stabbing/poking sensation in my heart has been present every moment of every day since my pacemaker was put in. Some positions hurt worse than others, such as leaning on your shoulder in bed at 3 am. The pain radiates up my jaw and into my molar. It's driving me literally crazy. (Participant 12)

Lastly, the subcategory "Aversive Physical Symptoms" captured a heterogeneous range of experiences that were not directly pain or cardiac related. Participants reported changes in body temperature (*n* = 5), physical tiredness (*n* = 5), bruising (*n* = 3), feeling weak (*n* = 2), twitching sensations (*n* = 2), restlessness (*n* = 1), excessive sighing or yawning (*n* = 1), stomach problems (*n* = 1), tingling sensations (*n* = 1), and feeling shaky (*n* = 1). Participants often inquired as to whether these symptoms have been experienced by other people and if they should be concerned: "I recently got a PM [pacemaker] (a couple of months ago), and I've noticed my chest on the left side 'twitches' or kind moves every time my heart beats. Has anyone else experienced this?" (Participant 9).

# Discussion

## Overview of Findings

The present study employed conventional qualitative content analysis to explore what questions, and information about their experiences, that people with cardiac implantable electronic devices posted to communities on the website Reddit. Posts from the one subreddit that met the inclusion criteria of the analysis yielded five overarching categories. These categories captured how the subreddit was used, how participants experienced living with a device, their experiences with healthcare, the psychological experiences of living with a device, and the physical sequelae of implantation. The present study observed a number of novel findings not previously reported in literature and these are presented below. Firstly, this is the first study to provide insight into how people living with these devices engage with online peer support on the social media website Reddit. Secondly, while the present study provides support for previous literature evaluating the impacts of these devices, a number of novel findings regarding the age and health status of participants are presented. Thirdly, this is the first study to provide insight into the experiences of people living with a device during the COVID-19 pandemic.

### *Peer Support and the Informational Needs of Participants*

Participants generally utilised the subreddit in order to gain knowledge, receive advice on the problems they faced, and to have their difficulties affirmed by others living with a cardiac implantable electronic device. This use of the subreddit to receive informational, emotional, and appraisal support was consistent with the defining attributes of peer support put forth by Dennis's (2003) concept analysis of peer support interventions within healthcare contexts. Additionally, a number of participants adopted device related labels, such as being a cyborg or belonging to a special club, that signified a sense of peer solidarity and identity between users of the subreddit. This in mind, the majority of participants sought information about the experiences of others living with a device.

Many different theoretical mechanisms have been used to explain peer support (Fortuna et al., 2019), however, the desire of participants for experiential information is best understood through the lens of social comparison theory (Festinger, 1954). As proposed by Festinger (1954), social comparison theory holds that persons may appraise their identities by evaluating themselves in comparison to others. This process can be directed or unconscious and involves identifying differences and similarities, on real or abstract dimensions, between the person evaluating themselves and others (Wood, 1996). Further developed by Taylor & Lobel (1989), people may draw either downwards comparisons, by comparing themselves to someone perceived as less fortunate, or engage in upwards affiliations by associating with people believed to be more fortunate. This latter process may provide people with role models that serve as a source of inspiration (Helgeson & Taylor, 1993; Taylor & Lobel, 1989; Taylor et al., 2007). Many of the requests for experiential information made by participants expressed a need to know whether others living with a device had successfully managed the same difficult situations that they were currently facing.

These requests for experiential information indicate a possible desire from participants to hear about the successes of others. While studies of people living with an implantable cardioverter-defibrillator have indicated a need to hear from others about their experiences (Bolse et al., 2005; Doolan-Noble et al., 2021; Sert et al., 2021), an explicit desire for positive role-modelling has not been reported. A study by Standing et al. (2018) of people living with ventricular assist devices, a mechanical circulation solution for advanced heart failure, indicated that associating with others who had adapted successfully helped to create a sense of hope and lessen fears. However, not all comparisons are positive; a body of social media research indicates that comparisons to people perceived as more successful are associated with decreased self-esteem (Vogel et al., 2014).

Alongside receiving peer support, participants expressed a desire to help others overcome the challenges they face living with a device. This desire to share information with other people living with a device is consistent with the helper therapy principle (Riessman, 1965; Skovholt, 1974) that has underpinned conceptualisations of peer support (Fortuna et al., 2019). According to Riessman's (1965) seminal paper, when someone renders aid to another the exchange has reciprocal benefits with the helper possibly gaining the most from the relationship. Peer-helpers may benefit as helping provides them with opportunities for personal growth, approval from those they support, and feedback (Skovholt, 1974). Studies have demonstrated benefits for peer-helpers in a variety of contexts including hearing loss support groups (Southall et al., 2019), supporters for bipolar disorder (Proudfoot et al., 2012), and online suicide prevention (Greidanus & Everall, 2010). The present study cannot quantify the possible benefits that providing peer support awards to participant helpers. Findings demonstrate, however, that some people living with a device desired to share their experiences with others. This desire indicates that peer support provides benefits to both people newly implanted with a device and those who have successfully adapted.

Alongside the peer support provided, participants indicated that they came to the subreddit as they could not find other sources of information regarding a variety of topics. These topics ranged from the appropriateness of niche physical activities to sensitive areas of discussion such as recreational drug use. Deficits in knowledge about living with a device and its functions have been previously reported in studies of people with implantable cardioverter-defibrillators (Barisone et al., 2022; Pike et al., 2022), pacemakers (Patel et al., 2020), and subcutaneous implantable cardioverter-defibrillators (Forman et al., 2018). The use of the internet to address knowledge deficits is concerning as social media can act as a source of disinformation (Farnood et al., 2022b) and may overestimate the risks posed by implantable cardioverter-defibrillators (Knoepke et al., 2018). In the case of recreational drug use, misinformation may be particularly prevalent on social media platforms (Suarez-Lledo & Alvarez-Galvez, 2021).

Deficits in knowledge about living with a cardiac implantable electronic device may be due to communication breakdowns with healthcare professionals. Previous studies have highlighted that effective communication with healthcare professionals is important for people living with these devices (Barisone et al., 2022; Linder et al., 2013, Pike et al., 2020; Rahman et al., 2012). Participants reported that they perceived healthcare professionals as approaching their problems with ambivalence, and some disagreed with aspects of their care or symptoms. These communication breakdowns could have limited the ability of healthcare professionals to adequately relay information, and thus, people living with a device may have instead turned to the subreddit to address their knowledge deficits.

### ***The Impacts of Living With a Cardiac Implantable Electronic Device***

Consistent with previous literature, the present study found that the implantation of a cardiac implantable electronic device presented a number of unique impacts and challenges. For participants living with an implantable cardioverter-defibrillator, the most commonly studied type of device (Tagney, 2010), the findings of the present study largely concurred with systematic reviews of patient experiences (Barisone et al., 2022; Pike et al., 2020). Furthermore, participants with an implantable cardioverter-defibrillator discussed a range of psychological experiences that have been reported by previous studies, such as depression (Oshvandi et al., 2020), anxiety (Magyar-Russell et al., 2011) and shock related anxiety (Tripp et al., 2019). For participants living with other device types, findings were consistent with previous literature that reported the biological, psychological, and social consequences of device implantation for both people living with a pacemaker (Beery et al., 2002;

Ghojazadeh et al., 2015; Malm & Hallberg, 2006; Rakhshan et al., 2017) or a subcutaneous implantable cardioverter-defibrator (Forman et al., 2018; van der Stuijt et al., 2020). However, as participants in the present study generally seemed to live more active lifestyles and reported being younger than the average person living with a device, new insights related to these factors were provided.

### *Findings Regarding the Age and Health Status of Participants*

The physical activities that could be conducted while living with a cardiac implantable electronic device were a significant area of discussion on the subreddit. Restrictions on the types of activity possible after implantation of an implantable cardioverter-defibrillator have been reported as a challenge for many people (Bolse et al., 2005; Doolan-Noble et al., 2021; Pike et al., 2022; Tagney et al., 2003). Adolescents with an implantable cardioverter-defibrillator may be particularly impacted by these restrictions as they can prevent them from returning to their pre-implantation levels of activity (Rahman et al., 2012). For people who wish to remain physically active after implantation, healthcare professionals should balance the risks of device associated complications with the consequences of discontinuing physical activities (Sciarra et al., 2021). For young and previously active participants in the present study, it appears that such considerations were not made by their healthcare professionals. Furthermore, restrictions on activity were deeply impactful for the quality of life of these participants.

Younger, and previously active participants, experienced unique struggles with adaptation to their cardiac implantable electronic device based on their age and prior levels of physical ability. At the extreme, participants reported that they hated their device, wanted it removed, or deactivated. These difficulties with adaptation are consistent with studies that have suggested that perceived health status is an important factor when deciding on whether to undergo implantation (Carroll et al., 2013) and that asymptomatic people are more willing to decline implantation (Ottenberg et al., 2014). Younger people who have undergone implantation are also more likely to report not wanting to have their device (Green et al., 2016). While this may be the case, participants reported that they were able to maintain active lifestyles, or experienced improvements in physical ability.

The prevention of damage to one's cardiac implantable electronic device, particularly during physical activity, was a common topic of discussion among participants that has not been extensively evaluated by previous literature. Prevention included passive protection efforts during daily life such as avoiding electromagnetic fields, a known risk for people living with a device (Driessen et al., 2019; Steffen et al., 2019), and active protection efforts including the use of protective sports guards. These active protection efforts included the use of cushioned pads intended to prevent car seatbelts from rubbing against the implantation site, which has been previously reported as a source of discomfort (Niewinski et al., 2019). Alongside the discomfort caused by seatbelts, participants reported elevated and aversive heart rates related to driving that were thought to be due to the activity responsive pacing functions of their devices. Additionally, ways of dealing with the rubbing caused by bra straps was discussed (van der Stuijt et al., 2020). Similar to these protection efforts, participants engaged in attempts to monitor their devices, such as using consumer pulse oximeters in order to verify its functioning. Participants generally saw these efforts as necessary considerations for living with a device that were needed to prevent its failure and their death.

Alongside the discussion of activity restrictions, and device protection, the continuation of deliberate exercise and weight loss was viewed as important. Previous literature has commonly focused on perceptions of device related body image for people living with cardiac implantable electronic devices in general (Gist et al., 2018), implantable cardiovert-defibrillators (Frydensberg et al., 2018), subcutaneous implantable cardioverter-defibrillators (van der Stuijt et al., 2020) and pacemakers (Beery et al., 2002; Davis et al., 2004). The body image concerns of participants were not directly related to their devices, instead discussion of this topic focused on deliberate post-implantation weight loss attempts. Participants who deliberately lost weight experienced pain and discomfort caused by the thinning of tissue around their implantation site. Within medical literature, thinning of the tissue around these devices is a documented phenomenon associated with a lower body mass index (Yatomi et al., 2022) and may pose an increased risk of infection (Polewczyk et al., 2022). Additionally, weight loss for people living with an implantable cardioverter-defibrillator is associated with a greater risk of inappropriate defibrillation (Daimee et al., 2017). The author of the present study is not aware of any literature that has evaluated experiences of deliberate weight loss while living with a device.

Most probably due to the age and health status of participants, the present study did not observe any discussion regarding decisions about the discontinuation of life-sustaining cardiac implantable electronic device therapies. End-of-life decisions regarding the deactivation of these devices has received prior attention in literature (Lewis et al., 2014), with a large focus on implantable cardioverter-defibrillators due to the painful shocks they may administer at the time of death (Svanholm et al., 2015). There was evidence that this topic was discussed by carers using the subreddit whose posts were excluded from the present study.

### *Cardiac Implantable Electronic Devices and COVID-19 Pandemic Experiences*

The impacts of the COVID-19 pandemic on the experiences of people living with a cardiac implantable electronic device were identified as a notable area of discussion on the subreddit. Current pandemic related literature has largely evaluated the remote monitoring of these devices (Iacopino et al., 2020; Magnocavallo et al., 2021), changes in implantation rates (Schwab et al., 2022), and has used device recorded data to measure changes in physical activity (Schmitt et al., 2022). Participants discussed delays accessing healthcare and the difficulties created by public health approaches used to manage the pandemic. There is a need for targeted pandemic related information for this population as questions were posted about the availability of COVID-19 vaccines and possible complications from vaccination.

## Limitations

The results of the present study should be interpreted within the context of limitations posed by the methodology and sample. Firstly, Proferes et al. (2021) has asked whether researchers utilising Reddit as a data source are studying Reddit-specific phenomena or attempting to elucidate broader social phenomena. In the case of the present study, the subreddit analysed may be the last resort for participants who have not been able to receive satisfactory answers to their questions or engage with adequate health services. Additionally, while varying considerably across differing subreddits, Reddit users tend to be younger (Shatz, 2017), and people of higher socioeconomic status may be overrepresented in research utilising social media (Hargittai, 2020). Therefore, the experiences expressed by participants using the one subreddit analysed may be specific to this population.

Secondly, there are a number of factors that threaten the validity of data collected from online communities. Users of social media may post incorrect uses of medicalised terminology, inaccurate recounts of their experiences, or even lie (Ravoire et al., 2017). As posts analysed in the present study were treated as textual documentation, participants could not be contacted to provide clarification or address these aforementioned issues. Inaccurate recounting of information may have been particularly problematic for the collection of demographic data, as participants may have been unaware of the correct terminology to identify their device (Wising et al., 2022). Although these limitations do not discredit the findings of the present study, there is need for further research that draws on different methodological approaches to elucidate the experiences of people living with a cardiac implantable electronic device.

## Further Research and Implications for Clinical Practice

Based on the findings of the present study, and existing literature, there is a need for studies that evaluate differences between subgroups of people living with cardiac implantable electronic devices, as they may be particularly impactful for the young and active. Additionally, there is a need for research that evaluates the experiences of people living with devices other than implantable cardioverter-defibrillators, as all devices appear to present significant adaptational challenges. While further research should consider people living with pacemakers, who have been underrepresented in literature (Tagney, 2010), there is a need to evaluate emergent device technologies such as subcutaneous implantable cardioverter-defibrillators as these may be associated with different psychological outcomes (Pedersen et al., 2019). Furthermore, research should aim to triangulate the experiences of people living with these devices and the perspectives of their healthcare professionals to understand differences in perceptions of care. This may provide an explanation as to why participants in the present study expressed difficulties communicating with their healthcare professionals.

Alongside highlighting areas of further research, the present study has several implications for healthcare professionals working with people living with a cardiac implantable electronic device. Due to the communication breakdowns discussed by participants, there may be a need to evaluate and implement communication skills training for healthcare professionals working with people living with a device. Interventions aimed at improving the communication skills of healthcare professionals can contribute to a range of positive patient outcomes (Venktaramana et al., 2022), and have demonstrated potential for people living with cardiovascular diseases (Schoenthaler et al., 2014). The empathy displayed by healthcare professionals is also important as a systematic review by Derksen et al., (2013) indicates that it is associated with lower patient anxiety and distress. Therefore, healthcare professionals must recognise that while these devices may produce clinical benefits, living with a device is a potentially frighting experience that must be approached with empathy.

In addition to improving communication with patients, a greater emphasis on the provision of appropriate educational resources following implantation is needed to address patient concerns. Addressing the knowledge deficits of people living with a cardiac implantable electronic device is important, as greater device related knowledge is associated with improved quality of life (Polikandrioti, 2021). For patients newly implanted with a device, knowledge deficits may be addressed through educational interviews that assess their lifestyle needs (Yildiz et al., 2018). Peer support and lived experience groups may be an additional way of providing both educational information and tangible aid to people living with these devices. As peer support has demonstrated benefits for a number of chronic health conditions (Colella & King, 2004; Hossain et al., 2021; Thompson et al., 2022), opportunities to create peer networks for people living with these devices should be explored. Additionally, the knowledge deficits expressed by participants regarding potentially sensitive issues suggests a need for accessible online evidence-based educational resources to be created.

## Conclusion

Previous literature that has drawn on qualitative approaches to explore the experiences of people living with a cardiac implantable electronic device has largely focused on the those with implantable cardioverter-defibrillators. The present study has contributed to existing literature by exploring the questions, and experiences, of participants with a range of devices posted to an online social media peer support community. Findings highlight the considerable challenges people living with these devices may face and differences in experiences based on their age and health status. Furthermore, the findings of the present study elucidate the beneficial role that peer support can play in assisting adaptation to these devices.

From the findings of the present study, it is clear that understandings of post-implantation quality of life must be approached from a holistic perspective as these devices present numerous biological, psychological, and social challenges. Researchers and healthcare professionals must reflect on the significance of these challenges in order to provide the best post-implantation support. Further work is needed to explore differences in experiences with these devices, and how to best facilitate patient support through improved healthcare communication and device-related health literacy.

# References

Alexa. (2022). *The top 400 sites on the web*. Alexa. Retrieved April 28, 2022, from https://www.alexa.com/topsites

Amaya, A., Bach, R., Keusch, F., & Kreuter, F. (2021). New data sources in social science research: Things to know before working with Reddit data. *Social Science Computer Review*, 39(5), 943–960. https://doi.org/10.1177/0894439319893305

Atreya, A. R., Cook, J. R., & Lindenauer, P. K. (2016). Complications arising from cardiac implantable electrophysiological devices: Review of epidemiology, pathogenesis, and prevention for the clinician. *Postgraduate Medicine*, *128*(2), 223–230. https://doi.org/10.1080/00325481.2016.1151327

Australian Bureau of Statistics (2018, December 12). *Heart, stroke and vascular disease*. https://www.abs.gov.au/statistics/health/health-conditions-and-risks/heart-stroke-and-vascular-disease/latest-release

Australian Bureau of Statistics (2021, September 29). *Causes of Death, Australia.* https://www.abs.gov.au/statistics/health/causes-death/causes-death-australia/2020

Ávila, P., Mercier, L. A., Dore, A., Marcotte, F., Mongeon, F. P., Ibrahim, R., Asgar, A., Miro, J., Andelfinger, G., Mondésert, B., de Guise, P., Poirier, N., & Khairy, P. (2014). Adult congenital heart disease: A growing epidemic [Supplement]. *Canadian Journal of Cardiology*, *30*(12), S410–S419. https://doi.org/10.1016/j.cjca.2014.07.749

Barisone, M., Hayter, M., Ghirotto, L., Catania, G., Zanini, M., dal Molin, A., Sasso, L., & Bagnasco, A. (2022). The experience of patients with an implantable cardioverter-defibrillator: A systematic review and meta-synthesis of qualitative studies. *European Journal of Cardiovascular Nursing,* Article zvab135. Advanced online publication. https://doi.org/10.1093/eurjcn/zvab135

Beery, T. A., Sommers, M. S., Hall, J., & King, K. M. (2002). Focused life stories of women with cardiac pacemakers. *Western Journal of Nursing Research*, *24*(1), 7–27. https://doi.org/10.1177/01939450222045680

Boe, B. (2021). *PRAW: The Python Reddit API Wrapper*. Read the Docs. Retrieved April 15, 2022, from https://praw.readthedocs.io/en/v7.5.0/

Boerschel, C. S., & Schnabel, R. B. (2019). The imminent epidemic of atrial fibrillation and its concomitant diseases – Myocardial infarction and heart failure - a cause for concern. *International Journal of Cardiology*, *287*, 162–173. https://doi.org/10.1016/j.ijcard.2018.11.123

Bögeholz, N., Willy, K., Niehues, P., Rath, B., Dechering, D. G., Frommeyer, G., Kochhäuser, S., Löher, A., Köbe, J., Reinke, F., & Eckardt, L. (2019). Spotlight on S-ICD$^{TM}$ therapy: 10 years of clinical experience and innovation. *EP Europace*, *21*(7), 1001–1012. https://doi.org/10.1093/europace/euz029

Bolse, K., Hamilton, G., Flanagan, J., Caroll, D. L., & Fridlund, B. (2005). Ways of experiencing the life situation among United States patients with an implantable cardioverter-defibrillator: A qualitative study. *Progress in Cardiovascular Nursing*, *20*(1), 4–10.  https://doi.org/10.1111/j.0889-7204.2005.03797.x

Carroll, S. L., Strachan, P. H., De Laat, S., Schwartz, L., & Arthur, H. M. (2013). Patients' decision making to accept or decline an implantable cardioverter defibrillator for primary prevention of sudden cardiac death. *Health Expectations*, *16*(1), 69–79. https://doi.org/10.1111/j.1369-7625.2011.00703.x

Chung, J. E. (2014). Social networking in online support groups for health: How online social networking benefits patients. *Journal of Health Communication*, *19*(6), 639–659. https://doi.org/10.1080/10810730.2012.757396

Clark, A. M., Lissel, S. L., & Davis, C. (2008). Complex critical realism: Tenets and application in nursing research. *Advances in Nursing Scien*ce, *31*(4), E67–E79. https://doi.org/10.1097/01.ANS.0000341421.34457.2a

Clark, A. M., MacIntyre, P. D., & Cruickshank, J. (2007). A critical realist approach to understanding and evaluating heart health programmes. *Health*, *11*(4), 513–539. https://doi.org/10.1177/1363459307080876

Cohen, B. E., Edmondson, D., & Kronish, I. M. (2015). State of the art review: Depression, stress, anxiety, and cardiovascular disease. *American Journal of Hypertension*, *28*(11), 1295–1302. https://doi.org/10.1093/ajh/hpv047

Colella, T. J. F., & King, K. M. (2004). Peer support. An under-recognized resource in cardiac recovery. *European Journal of Cardiovascular Nursing*, *3*(3), 211–217. https://doi.org/10.1016/j.ejcnurse.2004.04.001

Cope, D. G. (2013). Methods and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum*, *41*(1), 89–91. https://doi.org/10.1188/14.ONF.89-91

Daimee, U. A., Biton, Y., Aktas, M. K., Zannad, F., Klein, H., Szepietowska, B., Mcnitt, S., Polonsky, B., Wang, P. J., Zareba, W., Moss, A. J., & Kutyifa, V. (2017). Effect of significant weight change on inappropriate implantable cardioverter-defibrillator therapy. *Pacing and Clinical Electrophysiology*, *40*(1), 9–16. https://doi.org/10.1111/pace.12973

Dalen, J. E., Alpert, J. S., Goldberg, R. J., & Weinstein, R. S. (2014). The epidemic of the 20th century: Coronary heart disease. *The American Journal of Medicine*, *127*(9), 807–812. https://doi.org/10.1016/j.amjmed.2014.04.015

Daraz, L., Morrow, A. S., Ponce, O. J., Beuschel, B., Farah, M. H., Katabi, A., Alsawas, M., Majzoub, A. M., Benkhadra, R., Seisa, M. O., Ding, J. F., Prokop, L., & Murad, M.

H. (2019). Can patients trust online health information? A meta-narrative systematic review addressing the quality of health information on the internet. *Journal of General Internal Medicine*, *34*(9), 1884–1891. https://doi.org/10.1007/s11606-019-05109-0

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology: Science and Practice*, *6*(2), 165–187. https://doi.org/10.1093/clipsy.6.2.165

Davis, L. L., Vitale, K. A., Irmiere, C. A., Hackney, T. A., Belew, K. M., Chikowski, A. M. R., Sullivan, C. A., Hellkamp, A. S., Schron, E. B., & Lamas, G. A. (2004). Body image changes associated with dual-chamber pacemaker insertion in women. *Heart & Lung*, *33*(5), 273–280. https://doi.org/10.1016/j.hrtlng.2004.04.005

Dennis, C. L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, *40*(3), 321–332. https://doi.org/10.1016/S0020-7489(02)00092-5

Derksen, F., Bensing, J., & Lagro-Janssen, A. (2013). Effectiveness of empathy in general practice: A systematic review. *British Journal of General Practice*, *63*(606), e76–e84. https://doi.org/10.3399/bjgp13X660814

Dickerson, S. S. (2005). Technology-patient interactions: Internet use for gaining a healthy context for living with an implantable cardioverter defibrillator. *Heart & Lung*, *34*(3), 157–168. https://doi.org/10.1016/j.hrtlng.2004.08.004

Doolan-Noble, F., Noller, G., Nixon, G., & Stokes, T. (2021). “I’m still here, that’s probably the best part”. Lives of those living rurally with an implantable cardioverter defibrillator: A qualitative study. *Rural and Remote Health*, *21*(1), Article 5659. https://doi.org/10.22605/rrh5659

Driessen, S., Napp, A., Schmiedchen, K., Kraus, T., & Stunder, D. (2019). Electromagnetic interference in cardiac electronic implants caused by novel electrical appliances emitting electromagnetic fields in the intermediate frequency range: A systematic review. *Ep Europace*, *21*(2), 219–229. https://doi.org/10.1093/europace/euy155

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, *7*(3), 93–99. https://doi.org/10.1016/j.afjem.2017.08.001

Farnood, A., Johnston, B., & Mair, F. S. (2022a). Understanding the use of heart failure online health forums: A qualitative study. *European Journal of Cardiovascular Nursing*, *21*(4), 374–381. https://doi.org/10.1093/eurjcn/zvab090

Farnood, A., Johnston, B., & Mair, F. S. (2022b). An analysis of the diagnostic accuracy and peer-to-peer health information provided on online health forums for heart failure. *Journal of Advanced Nursing*, *78*(1), 187–200. https://doi.org/10.1111/jan.15009

Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, *7*(2), 117–140. https://doi.org/10.1177/001872675400700202

Forman, J., Baumbusch, J., Jackson, H., Lindenberg, J., Shook, A., & Bashir, J. (2018). Exploring the patients' experiences of living with a subcutaneous implantable cardioverter defibrillator. *European Journal of Cardiovascular Nursing*, *17*(8), 698–706. https://doi.org/10.1177/1474515118777419

Fortuna, K. L., Brooks, J. M., Umucu, E., Walker, R., & Chow, P. I. (2019). Peer support: A human factor to enhance engagement in digital health behavior change interventions. *Journal of Technology in Behavioral Science*, *4*, 152–161. https://doi.org/10.1007/s41347-019-00105-x

Fortuna, K. L., Solomon, P., & Rivera, J. (2022). An update of peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Quarterly, 93*(2), 571–586. https://doi.org/10.1007/s11126-022-09971-w

Friis, K., Lasgaard, M., Pedersen, M. H., Duncan, P., & Maindal, H. T. (2019). Health literacy, multimorbidity, and patient-perceived treatment burden in individuals with cardiovascular disease. A Danish population-based study. *Patient Education and Counseling, 102*(10), 1932–1938. https://doi.org/10.1016/j.pec.2019.05.013

Frydensberg, V. S., Skovbakke, S. J., Pedersen, S. S., & Kok, R. N. (2018). Body image concerns in patients with an implantable cardioverter defibrillator: A scoping review. *Pacing and Clinical Electrophysiology, 41*(9), 1235–1260. https://doi.org/10.1111/pace.13421

Gallacher, K., May, C. R., Montori, V. M., & Mair, F. S. (2011). Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *The Annals of Family Medicine, 9*(3), 235–243. https://doi.org/10.1370/afm.1249

Ghojazadeh, M., Azami-Aghdash, S., Sohrab-Navi, Z., & Kolahdouzan, K. (2015). Cardiovascular patients' experiences of living with pacemaker: Qualitative study. *ARYA Atherosclerosis, 11*(5), 281–288.

Gist, K. M., Marino, B. S., Palmer, C., Fish, F. A., Moore, J. P., Czosek, R. J., Cassedy, A., LaPage, M. J., Law, I. H., Garnreiter, J., Cannon, B. C., & Collins, K. K. (2018). Cosmetic outcomes and quality of life in children with cardiac implantable electronic devices. *Pacing and Clinical Electrophysiology, 42*(1), 46–57. https://doi.org/10.1111/pace.13522

Green, A. R., Jenkins, A., Masoudi, F. A., Magid, D. J., Kutner, J. S., Leff, B., & Matlock, D. D. (2016). Decision-making experiences of patients with implantable cardioverter defibrillators. *Pacing and Clinical Electrophysiology*, *39*(10), 1061–1069. https://doi.org/10.1111/pace.12943

Greidanus, E., & Everall, R. D. (2010). Helper therapy in an online suicide prevention community. *British Journal of Guidance & Counselling, 38*(2), 191–204. https://doi.org/10.1080/03069881003600991

Gura, M. T. (2015). Considerations in patients with cardiac implantable electronic devices at end of life. *AACN Advanced Critical Care*, *26*(4), 356–363. https://doi.org/10.4037/NCI.0000000000000111

Han, H. C., Hawkins, N. M., Pearman, C. M., Birnie, D. H., & Krahn, A. D. (2021). Epidemiology of cardiac implantable electronic device infections: Incidence and risk factors. *EP Europace*, *23*(Supplement_4), iv3–iv10. https://doi.org/10.1093/europace/euab042

Hargittai, E. (2020). Potential biases in big data: Omitted voices on social media. *Social Science Computer Review*, *38*(1), 10–24. https://doi.org/10.1177/0894439318788322

Helgeson, V. S., & Taylor, S. E. (1993). Social comparisons and adjustment among cardiac patients. *Journal of Applied Social Psychology*, *23*(15), 1171–1195. https://doi.org/10.1111/j.1559-1816.1993.tb01027.x

Hossain, S. N., Jaglal, S. B., Shepherd, J., Perrier, L., Tomasone, J. R., Sweet, S. N., Luong, D., Allin, S., Nelson, M. L. A., Guilcher, S. J. T., & Munce, S. E. P. (2021). Web-based peer support interventions for adults living with chronic conditions: Scoping review. *JMIR Rehabilitation and Assistive Technologies*, *8*(2), Article e14321. https://doi.org/10.2196/14321

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Hussein, A. A., & Wilkoff, B. L. (2019). Cardiac implantable electronic device therapy in heart failure. *Circulation Research*, *124*(11), 1584–1597. https://doi.org/10.1161/CIRCRESAHA.118.313571

Iacopino, S., Placentino, F., Colella, J., Pesce, F., Pardeo, A., Filannino, P., Artale, P., Desiro, D., Sorrenti, P., Campagna, G., Fabiano, G., Peluso, G., Giacopelli, D., & Petretta, A. (2021). Remote monitoring of cardiac implantable devices during COVID-19 outbreak: “Keep people safe” and “focus only on health care needs.” *Acta Cardiologica*, *76*(2), 158–161. https://doi.org/10.1080/00015385.2020.1847459

Imberti, J. F., Vitolo, M., Proietti, M., Diemberger, I., Ziacchi, M., Biffi, M., & Boriani, G. (2020). Driving restriction in patients with cardiac implantable electronic devices: An overview of worldwide regulations. *Expert Review of Medical Devices*, *17*(4), 297–308. https://doi.org/10.1080/17434440.2020.1742108

Johnson, A. E., Bell, Y. K., Hamm, M. E., Saba, S. F., & Myaskovsky, L. (2020). A qualitative analysis of patient-related factors associated with implantable cardioverter defibrillator acceptance. *Cardiology and Therapy*, *9*(2), 421–432. https://doi.org/10.1007/s40119-020-00180-9

Knoepke, C. E., Slack, D. H., Ingle, M. P., Matlock, D. D., & Marzec, L. N. (2018). Quality of medical advice provided between members of a web-based message board for patients with implantable defibrillators: Mixed-methods study. *JMIR Cardio*, *2*(2), Article e11358. https://doi.org/10.2196/11358

Kovacs, A. H., Brouillette, J., Ibeziako, P., Jackson, J. L., Kasparian, N. A., Kim, Y. Y., Livecchi, T., Sillman, C., & Kochilas, L. K. (2022). Psychological outcomes and interventions for individuals with congenital heart disease: A scientific statement from the American Heart Association. *Circulation: Cardiovascular Quality and Outcome*, *15*(8), Article e000110. https://doi.org/10.1161/hcq.0000000000000110

Kuhl, E. A., Dixit, N. K., Walker, R. L., Conti, J. B., & Sears, S. F. (2006). Measurement of patient fears about implantable cardioverter defibrillator shock: An initial evaluation of the Florida Shock Anxiety Scale. *Pacing and Clinical Electrophysiology*, *29*(6), 614–618. https://doi.org/10.1111/j.1540-8159.2006.00408.x

Lewis, K. B., Stacey, D., & Matlock, D. D. (2014). Making decisions about implantable cardioverter-defibrillators from implantation to end of life: An integrative review of patients' perspectives. *The Patient*, *7*(3), 243–260. https://doi.org/10.1007/s40271-014-0055-2

Linder, J., Hidayatallah, N., Stolerman, M., McDonald, T. V., Marion, R., Walsh, C., & Dolan, S. (2013). Perceptions of an implantable cardioverter-defibrillator: A qualitative study of families with a history of sudden life-threatening cardiac events and recommendations to improve care. *The Einstein Journal of Biology and Medicine*, *29*(1–2), 3–14.

Lippi, G., & Sanchis-Gomar, F. (2020). Global epidemiology and future trends of heart failure. *AME Medical Journal*, *5*(15), 1–6. https://doi.org/10.21037/amj.2020.03.03

Lippi, G., Sanchis-Gomar, F., & Cervellin, G. (2021). Global epidemiology of atrial fibrillation: An increasing epidemic and public health challenge. *International Journal of Stroke*, *16*(2), 217–221. https://doi.org/10.1177/1747493019897870

Locsin, R. C., Tulloch, S. P., Campling, A. S., Kissel, K. A., Purnell, M. J., & Wilson, G. Z. (2010). The lived experience of persons with life-sustaining cardiac devices. *International Journal of Human Caring*, *14*(1), 44–50. https://doi.org/10.20467/1091-5710.14.1.44

Lomborg, S. (2013). Personal internet archives and ethics. *Research Ethics*, *9*(1), 20–31. https://doi.org/10.1177/1747016112459450

Magnocavallo, M., Bernardini, A., Mariani, M. V., Piro, A., Marini, M., Nicosia, A., Adduci, C., Rapacciuolo, A., Saporito, D., Grossi, S., Santarpia, G., Vaccaro, P., Rordorf, R., Pentimalli, F., Giunta, G., Campari, M., Valsecchi, S., & Lavalle, C. (2021). Home delivery of the communicator for remote monitoring of cardiac implantable devices: A multicenter experience during the covid-19 lockdown. *Pacing and Clinical Electrophysiology, 44*(6), 995–1003. https://doi.org/10.1111/pace.14251

Magyar-Russell, G., Thombs, B. D., Cai, J. X., Baveja, T., Kuhl, E. A., Singh, P. P., Montenegro Braga Barroso, M., Arthurs, E., Roseman, M., Amin, N., Marine, J. E., & Ziegelstein, R. C. (2011). The prevalence of anxiety and depression in adults with implantable cardioverter defibrillators: A systematic review. *Journal of Psychosomatic Research*, *71*(4), 223–231. https://doi.org/10.1016/j.jpsychores.2011.02.014

Malm, D., & Hallberg, L. R. M. (2006). Patients' experiences of daily living with a pacemaker: A grounded theory study. *Journal of Health Psychology*, *11*(5), 787–798. https://doi.org/10.1177/1359105306066642

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, *25*(2), 134–141. https://doi.org/10.1037/h0095032

Mond, H. G., & Proclemer, A. (2011). The 11th World Survey of Cardiac Pacing and Implantable Cardioverter-Defibrillators: Calendar year 2009 – A World Society of Arrhythmia's project. *Pacing and Clinical Electrophysiology*, *34*(8), 1013–1027. https://doi.org/10.1111/j.1540-8159.2011.03150.x

Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A., & Hoving, C. (2013). A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of Medical Internet Research*, *15*(4), Article E85. https://doi.org/10.2196/jmir.1933

Naslund, J. A., Aschbrenner, K. A., Marsch, L. A., & Bartels, S. J. (2016). The future of mental health care: Peer-to-peer support and social media. *Epidemiology and Psychiatric Sciences*, *25*(2), 113–122. https://doi.org/10.1017/S2045796015001067

Naslund, J. A., Grande, S. W., Aschbrenner, K. A., & Elwyn, G. (2014). Naturally occurring peer support through social media: The experiences of individuals with severe mental illness using YouTube. *PLOS ONE*, *9*(10), Article e110171. https://doi.org/10.1371/journal.pone.0110171

Ngo, L., Nour, D., Denman, R. A., Walters, T. E., Haqqani, H. M., Woodman, R. J., & Ranasinghe, I. (2021). Safety and efficacy of leadless pacemakers: A systematic review and meta-analysis. *Journal of the American Heart Association*, *10*(13), Article e019212. https://doi.org/10.1161/JAHA.120.019212

Niewinski, P., Jagielski, D., Josiak, K., Nowak, K., Biel, B., Tubek, S., Walczak, T., Szemplinska, I., Siennicka, A., Banasiak, W., & Ponikowski, P. (2019). Seat belts-related behaviors in car drivers with cardiac implantable electronic devices. *Pacing and Clinical Electrophysiology*, *42*(4), 400–406. https://doi.org/10.1111/pace.13617

Oshvandi, K., Khatiban, M., Ghanei Gheshlagh, R., & Razavi, M. (2020). The prevalence of depression in patients living with implantable cardioverter defibrillator: A systematic review and meta-analysis. *Irish Journal of Medical Science*, *189*(4), 1243–1252. https://doi.org/10.1007/s11845-020-02208-4

Ottenberg, A. L., Mueller, P. S., Topazian, R. J., Kaufman, S., & Swetz, K. M. (2014). “It’s not broke, so let’s not try to fix it”: Why patients decline a cardiovascular implantable electronic device. *Pacing and Clinical Electrophysiology*, *37*(10), 1306–1314. https://doi.org/10.1111/pace.12433

Patel, D., Hu, P., Hilow, H., Lambert, C. T., Moufawad, M., Poe, S., Hussein, A. A., Baranowski, B., Bhargava, M., Rickard, J. W., Cantillon, D. J., Saliba, W., Wilkoff,

B. L., Wazni, O., & Tarakji, K. G. (2020). The gap between what patients know and desire to learn about their cardiac implantable electronic devices. *Pacing and Clinical Electrophysiology*, *43*(1), 118–122. https://doi.org/10.1111/pace.13850

Pedersen, S. S., Carter, N., Barr, C., Scholten, M., Lambiase, P. D., Boersma, L., Johansen, J. B., & Theuns, D. A. M. J. (2019). Quality of life, depression, and anxiety in patients with a subcutaneous versus transvenous defibrillator system. *Pacing and Clinical Electrophysiology*, *42*(12), 1541–1551. https://doi.org/10.1111/pace.13828

Pike, A., Dobbin-Williams, K., & Swab, M. (2020). Experiences of adults living with an implantable cardioverter defibrillator for cardiovascular disease: A systematic review of qualitative evidence. *JBI Evidence Synthesis*, *18*(11), 2231–2301. https://doi.org/10.11124/JBISRIR-D-19-00239

Polewczyk, A., Jacheć, W., & Kutarski, A. (2022). Risk of skin erosion and local pocket infections in population of patients with cardiac implantable electronic devices undergoing transvenous lead extraction. *Journal of Cardiovascular Electrophysiology*, *33*(8), 1857–1862. https://doi.org/10.1111/jce.15612

Polikandrioti, M. (2021). Patient perceptions and quality of life in pacemaker recipients. *The Journal of Innovations in Cardiac Rhythm Management*, *12*(11), 4769–4779. https://doi.org/10.19102%2Ficrm.2021.121103

Potpara, T. S., Mihajlovic, M., Zec, N., Marinkovic, M., Kovacevic, V., Simic, J., Kocijancic, A., Vajagic, L., Jotic, A., Mujovic, N., & Stankovic, G. R. (2020). Self-reported treatment burden in patients with atrial fibrillation: Quantification, major determinants, and implications for integrated holistic management of the arrhythmia. *EP Europace*, *22*(12), 1788–1797. https://doi.org/10.1093/europace/euaa210

Proferes, N., Jones, N., Gilbert, S., Fiesler, C., & Zimmer, M. (2021). Studying Reddit: A systematic overview of disciplines, approaches, methods, and ethics. *Social Media + Society*, *7*(2), 1–14. https://doi.org/10.1177/20563051211019004

Proudfoot, J. G., Jayawant, A., Whitton, A. E., Parker, G., Manicavasagar, V., Smith, M., & Nicholas, J. (2012). Mechanisms underpinning effective peer support: A qualitative analysis of interactions between expert peers and patients newly-diagnosed with bipolar disorder. *BMC Psychiatry*, *12*(1), 1–11. https://doi.org/10.1186/1471-244X-12-196

Pyngottu, A., Werner, H., Lehmann, P., & Balmer, C. (2019). Health-related quality of life and psychological adjustment of children and adolescents with pacemakers and implantable cardioverter defibrillators: A systematic review. *Pediatric Cardiology*, *40*(1), 1–16. https://doi.org/10.1007/s00246-018-2038-x

Rahman, B., Macciocca, I., Sahhar, M., Kamberi, S., Connell, V., & Duncan, R. E. (2012). Adolescents with implantable cardioverter defibrillators: A patient and parent perspective. *Pacing and Clinical Electrophysiology*, *35*(1), 62–72. https://doi.org/10.1111/j.1540-8159.2011.03229.x

Rakhshan, M., Hassani, P., Ashktorab, T., & Majd, H. A. (2017). Dual perspective on experiences of Iranian patients with pacemaker: A mixed method study. *Online Journal of Health and Allied Sciences*, *16*(4), 1–6. https://www.ojhas.org/issue64/2017-4-6.html

Ravoire, S., Lang, M., Perrin, E., Audry, A., Bilbault, P., Chekroun, M., Demerville, L., Escudier, T., Guéroult-Accolas, L., Guillot, C., Malbezin, M., Maugendre, P., Micallef, J., Molimard, M., Montastruc, F., Pierron, E., Reichardt, L., & Thiessard, F. (2017). Advantages and limitations of online communities of patients for research on health products. *Therapies, 72*(1), 135–143. https://doi.org/10.1016/j.therap.2016.11.058

Reddit. (2016). *Reddit API Terms of Use*. Google Forms. Retrieved April 28, 2022, from https://docs.google.com/forms/d/e/1FAIpQLSezNdDNK1-P8mspSbmtC2r86Ee9ZRbC66u929cG2GX0T9UMyw/viewform

Reddit. (2021, September 12). *Reddit User Agreement.* Reddit. Retrieved April 28, 2022, from https://www.redditinc.com/policies/user-agreement-september-12-2021

Reddit. (n.d.). *Developed Applications*. Reddit. Retrieved April 28, 2022, from https://www.reddit.com/prefs/apps

Richards, K., Freeman, L. k., & Sears, S. F. (2016). The influence of social media use, online information seeking, and acceptance on implantable cardioverter defibrillator patient shock anxiety. *Journal of Consumer Health on the Internet, 20*(4), 156–166. https://doi.org/10.1080/15398285.2016.1201787

Riessman, F. (1965). The “helper” therapy principle. *Social Work*, *10*(2), 27–32. https://doi.org/10.1093/sw/10.2.27

Roberts, L. D. (2015). Ethical issues in conducting qualitative research in online communities. *Qualitative Research in Psychology*, *12*(3), 314–325. https://doi.org/10.1080/14780887.2015.1008909

Schmitt, J., Wenzel, B., Brüsehaber, B., Anguera, I., Sousa, J., Nölker, G., Bulava, A., Marques, P., Hatala, R., Golovchiner, G., Meyhöfer, J., & Ilan, M. (2022). Impact of lockdown during COVID-19 pandemic on physical activity and arrhythmia burden in heart failure patients. *Pacing and Clinical Electrophysiology, 45*(4), 471–480. https://doi.org/10.1111/pace.14443

Schoenthaler, A., Kalet, A., Nicholson, J., & Lipkin, M., Jr. (2014). Does improving patient-practitioner communication improve clinical outcomes in patients with cardiovascular diseases? A systematic review of the evidence. *Patient Education and Counseling*, *96*(1), 3–12. https://doi.org/10.1016/j.pec.2014.04.006

Schwab, J. O., Wiese, J., & Hauser, T. (2022). The influence of the 2020 COVID-19 pandemic on the implantation rates of cardiac implantable electronic devices in Germany: Changes between 2020 Q1–Q3 and 2019 Q1–Q3. *European Heart Journal-Quality of Care and Clinical Outcomes*, *8*(2), 104–112. https://doi.org/10.1093/ehjqcco/qcab091

Sciarra, L., Salustri, E., Petroni, R., Calò, L., Delise, P., Penco, M., & Romano, S. (2021). Sport activity in patients with cardiac implantable electronic devices: Evidence and perspectives. *Journal of Cardiovascular Medicine*, *22*(5), 335–343. https://doi.org/10.2459/JCM.0000000000001093

Sears, S. F., St Amant, J. B., & Zeigler, V. (2009). Psychosocial considerations for children and young adolescents with implantable cardioverter defibrillators: An update. *Pacing and Clinical Electrophysiology*, *32*(s2), S80–S82. https://doi.org/10.1111/j.1540-8159.2009.02391.x

Sert, M., Kavradim, S. T., & Özer, C. Z. (2021). Living at the boundary between life and death: A qualitative study of how patients' lives are impacted by the implantable cardioverter defibrillator. *Journal of Advanced Nursing*, *77*(2), 934–947. https://doi.org/10.1111/jan.14650

Shalaby, R. A. H., & Agyapong, V. I. O. (2020). Peer support in mental health: Literature review. *JMIR Mental Health*, *7*(6), Article e15572. https://doi.org/10.2196/15572

Shatz, I. (2017). Fast, free, and targeted: Reddit as a source for recruiting participants online. *Social Science Computer Review*, *35*(4), 537–549. https://doi.org/10.1177/0894439316650163

Skovholt, T. M. (1974). The client as helper: A means to promote psychological growth. *The Counseling Psychologist*, *4*(3), 58–64. https://doi.org/10.1177/001100007400400308

Slotwiner, D., Varma, N., Akar, J. G., Annas, G., Beardsall, M., Fogel, R. I., Galizio, N. O., Glotzer, T. V., Leahy, R. A., Love, C. J., McLean, R. C., Mittal, S., Morichelli, L., Patton, K. K., Raitt, M. H., Pietro Ricci, R., Rickard, J., Schoenfeld, M. H., Serwer, G. A., . . . Yu, C. M. (2015). HRS Expert Consensus Statement on remote interrogation and monitoring for cardiovascular implantable electronic devices. *Heart Rhythm*, *12*(7), e69–e100. https://doi.org/10.1016/j.hrthm.2015.05.008

Smedley, R. M., & Coulson, N. S. (2021). A practical guide to analysing online support forums. *Qualitative Research in Psychology*, *18*(1), 76–103. https://doi.org/10.1080/14780887.2018.1475532

Southall, K., Jennings, M. B., Gagné, J. P., & Young, J. (2019). Reported benefits of peer support group involvement by adults with hearing loss. *International Journal of Audiology*, *58*(1), 29–36. https://doi.org/10.1080/14992027.2018.1519604

Standing, H. C., Exley, C., MacGowan, G. A., & Rapley, T. (2018). ‘We’re like a gang, we stick together’: Experiences of ventricular assist device communities. *European Journal of Cardiovascular Nursing*, *17*(5), 399–407. https://doi.org/10.1177/1474515118754738

Steffen, M. M., Osborn, J. S., & Cutler, M. J. (2019). Cardiac implantable electronic device therapy: Permanent pacemakers, implantable cardioverter defibrillators, and cardiac resynchronization devices. *Medical Clinics of North America*, *103*(5), 931–943. https://doi.org/10.1016/j.mcna.2019.04.005

Stein, D. J., Benjet, C., Gureje, O., Lund, C., Scott, K. M., Poznyak, V., & van Ommeren, M. (2019). Integrating mental health with other non-communicable diseases. *BMJ*, *364*, Article l295. https://doi.org/10.1136/bmj.l295

Suarez-Lledo, V., & Alvarez-Galvez, J. (2021). Prevalence of health misinformation on social media: Systematic review. *Journal of Medical Internet Research*, *23*(1), Article e17187. https://doi.org/10.2196/17187

Surendran, P. J., Jacob, P., Selvamani, D., Papasavvas, T., Swaminathan, N., Mathew, G., & Praveen, R. (2021). Upper extremity dysfunctions in patients with cardiac implantable electronic devices: A systematic review. *International Journal of Therapy and Rehabilitation*, *28*(7), 1–18. https://doi.org/10.12968/ijtr.2020.0160

Svanholm, J. R., Nielsen, J. C., Mortensen, P., Christensen, C. F., & Birkelund, R. (2015). Refusing implantable cardioverter defibrillator (ICD) replacement in elderly persons—The same as giving up life: a qualitative study. *Pacing and Clinical Electrophysiology*, *38*(11), 1275–1286. https://doi.org/10.1111/pace.12702

Tagney, J. (2010). A literature review comparing the experiences and emergent needs of adult patients with permanent pacemakers (PPMs) and implantable cardioverter defibrillators (ICDs). *Journal of Clinical Nursing*, *19*(15–16), 2081–2089. https://doi.org/10.1111/j.1365-2702.2009.03031.x

Tagney, J., James, J. E., & Albarran, J. W. (2003). Exploring the patient's experiences of learning to live with an implantable cardioverter defibrillator (ICD) from one UK centre: A qualitative study. *European Journal of Cardiovascular Nursing*, *2*(3), 195–203. https://doi.org/10.1016/S1474-5151(03)00061-6

Taylor, C. L. C., Kulik, J., Badr, H., Smith, M., Basen-Engquist, K., Penedo, F., & Gritz, E. R. (2007). A social comparison theory analysis of group composition and efficacy of cancer support group programs. *Social Science & Medicine, 65*(2), 262–273. https://doi.org/10.1016/j.socscimed.2007.03.024

Taylor, S. E., & Lobel, M. (1989). Social comparison activity under threat: Downward evaluation and upward contacts. *Psychological Review*, *96*(4), 569–575. https://doi.org/10.1037/0033-295X.96.4.569

Thompson, D. M., Booth, L., Moore, D., & Mathers, J. (2022). Peer support for people with chronic conditions: A systematic review of reviews. *BMC Health Services Research*, *22*(1), 1–16. https://doi.org/10.1186/s12913-022-07816-7

Tripp, C., Huber, N. L., Kuhl, E. A., & Sears, S. F. (2019). Measuring ICD shock anxiety: Status update on the Florida Shock Anxiety Scale after over a decade of use. *Pacing and Clinical Electrophysiology*, *42*(10), 1294–1301. https://doi.org/10.1111/pace.13793

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, *15*(3), 398–405. https://doi.org/10.1111/nhs.12048

van der Stuijt, W., Quast, A. F. B., Baalman, S. W., Olde Nordkamp, L. R., Wilde, A. A., & Knops, R. E. (2020). Improving the care for female subcutaneous ICD patients: A qualitative study of gender-specific issues. *International Journal of Cardiology, 317*, 91–95. https://doi.org/10.1016/j.ijcard.2020.05.091

Venktaramana, V., Loh, E. K. Y., Wong, C. J. W., Yeo, J. W., Teo, A. Y. T., Chiam, C. S. Y., Foo, D. J. M., Teo, F., Liang, J., Raveendran, V., Chng, L. C. L., Xiao, S., Chong, K., Quek, S. L., Chiang, C. L. L., Toh, R. Q. E., Ng, C. W. H., Lim, E. G., Leong, S., . . . Krishna, L. K. R. (2022). A systematic scoping review of communication skills training in medical schools between 2000 and 2020. *Medical Teacher, 44*(9), 997–1006. https://doi.org/10.1080/0142159x.2022.2054693

Vogel, E. A., Rose, J. P., Roberts, L. R., & Eckles, K. (2014). Social comparison, social media, and self-esteem. *Psychology of Popular Media Culture*, *3*(4), 206–222. https://doi.org/10.1037/ppm0000047

Ward, C., Henderson, S., & Metcalfe, N. H. (2013). A short history on pacemakers. *International Journal of Cardiology*, *169*(4), 244–248. https://doi.org/10.1016/j.ijcard.2013.08.093

Westaway, S., Nye, E., Gallagher, C., Tu, S. J., Clarke, N., Hanna-Rivero, N., Emami, M., Kadhim, K., Pitman, B. M., Mahajan, R., Lau, D. H., Young, G. D., Sanders, P., & Wong, C. X. (2021). Trends in the use, complications, and costs of permanent pacemakers in Australia: A nationwide study from 2008 to 2017. *Pacing and Clinical Electrophysiology*, *44*(2), 266–273. https://doi.org/10.1111/pace.14161

Wilkinson, D., & Thelwall, M. (2011). Researching personal information on the public web: Methods and ethics. *Social Science Computer Review*, *29*(4), 387–401. https://doi.org/10.1177/0894439310378979

Wising, J., Mattsson, G., Rambaree, K., Willmer, M., Wallhagen, M., & Magnusson, P. (2022). ‘Life with a device’: the octogenarians’ experiences with an implantable cardioverter-defibrillator — A qualitative study. *European Journal of Cardiovascular Nursing*, *21*(2), 161–168. https://doi.org/10.1093/eurjcn/zvab033

Wood, J. V. (1996). What is social comparison and how should we study it? *Personality and Social Psychology Bulletin*, *22*(5), 520–537. https://doi.org/10.1177/0146167296225009

World Health Organization (2021, June 11). *Cardiovascular Diseases (CVDs).* https://www.who.int/news-room/fact-sheets/detail/cardiovascular-diseases-(cvds)

Yatomi, A., Takami, M., Fukuzawa, K., Kiuchi, K., Sakai, J., Nakamura, T., Sonoda, Y., Takahara, H., Nakasone, K., Yamamoto, K., Suzuki, Y., Tani, K., Iwai, H., Nakanishi, Y., & Hirata, K. (2022). Factors related to the skin thickness of cardiovascular implantable electronic device pockets. *Journal of Cardiovascular Electrophysiology*, *33*(8), 1847–1856. https://doi.org/10.1111/jce.15613

Yildiz, B. S., Findikoglu, G., Alihanoglu, Y. I., Kilic, I. D., Evrengul, H., & Senol, H. (2018). How do patients understand safety for cardiac implantable devices? Importance of postintervention education. *Rehabilitation Research and Practice, 2018,* Article 5689353. https://doi.org/10.1155/2018/5689353

# Appendix A

## Data Collection Script

```
from concurrent.futures import thread
import praw
import pandas as pd
from praw.models import MoreComments

from sympy import true

reddit = praw.Reddit(client_id='[redacted]',
client_secret='[redacted]',
                       user_agent="Comment Extraction (by /u/[redacted])",
timeout = 60)

a=0
posts = []
ml_subreddit = reddit.subreddit('PacemakerICD')
for post in ml_subreddit.new(limit=999):
    posts.append([post.title, post.author, post.selftext,
post.created_utc])
    a+=1
    posts.append(["~~~~~~~", "~~~~~~~", "~~~~~~~","~~~~~~~"])
posts = pd.DataFrame(posts, columns=['title_of_parent', 'author',
'content', 'date_created'])

print("posts num:", a)

posts.to_csv('data_fin.csv', encoding='utf-8', index=False)
```

# Appendix B

## Analysis Structure

**Table B1.**

*The Structure of Categories, Subcategories, and Associated Codes*

| Category | Subcategory | Codes | *n* | % of *N* |
|---|---|---|---|---|
| Use of the Subreddit | Reasons for Using the Subreddit | Seeking the Experience of Others | 115 | 59.0% |
| | | Seeking Advice From Others | 68 | 35.0% |
| | | Sharing Personal Experiences With a Device | 47 | 24.0% |
| | | Seeking Answers to Technical Questions | 17 | 9.0% |
| | | Giving Thanks to the Community | 16 | 8.00% |
| | | Seeking Information not Found Elsewhere | 14 | 7.0% |
| | | Asking Whether Their Experiences are Normal | 11 | 6.0% |
| | Poster Identity | Identifying as a Younger Person | 12 | 6.0% |
| | | Identifying as a Member of a “Club” | 8 | 4.0% |
| | | Identifying as a “Cyborg” | 8 | 4.0% |
| Life With a Device | Preventing Damage to the Device | Concerns About Electromagnetic Interference | 32 | 16.0% |
| | | Restrictions Placed on Activity to Protect the Device | 30 | 15.0% |
| | | Ways of Protecting the Device From Damage | 10 | 5.0% |
| | | Concerns About Recreational Drug Use | 5 | 3.0% |
| | | Concerns About Hormonal Drug Use | 1 | 0.5% |

| Category | Subcategory | Codes | *n* | % of *N* |
|---|---|---|---|---|
| | Managing Health After Implantation | Questions About and Experiences of Exercising | 35 | 18.0% |
| | | Perceived Improvements in Health Status | 16 | 8.0% |
| | | Perceived Declines in Health Status | 13 | 7.0% |
| | | Experiences With Weight Loss | 4 | 2.0% |
| | Managing Living With Device Specific Issues | Monitoring Their Device and Heart Function | 21 | 11.0% |
| | | Experiences of and Questions About Implantable Cardioverter-Defibrillator Shocks | 15 | 8.0% |
| | | Experiences of Having Their Device Settings Changed | 9 | 5.0% |
| | | External Objects Rubbing Against the Device | 9 | 5.0% |
| | | Battery Life Concerns | 5 | 3.0% |
| | | Concerns About Automated Device Checks | 4 | 2.0% |
| | | Discomfort From Device Warning Alarms | 3 | 2.0% |
| | | Questions About Medical Alert Identification | 2 | 1.0% |
| | Impacts of a Device on Lifestyle | Impacts on Work | 12 | 6.0% |
| | | Impacts on Driving | 11 | 6.0% |
| | | Impacts on Sleep | 11 | 6.0% |
| | | Impacts on Performing Simple Activities | 7 | 4.0% |
| | | Impacts on School | 3 | 2.0% |
| | | Questions About Sex and Masturbation | 2 | 1.0% |
| | | Impacts on Diet | 1 | 0.5% |

| Category | Subcategory | Codes | *n* | % of *N* |
|---|---|---|---|---|
| | | Questions About Pregnancy | 1 | 0.5% |
| | Device Complications and Failure | Concerns About Lead Dislocation | 13 | 7.0% |
| | | Experiences of Lead Failure | 10 | 5.0% |
| | | Concerns About Device Dislocation | 8 | 4.0% |
| | | Concerns About Device Malfunction | 4 | 2.0% |
| | | Experiences of Device Related Infections | 4 | 2.0% |
| | Social Relationships | Social Support Experiences and Impacts | 14 | 7.0% |
| | | Perceptions of Others | 5 | 3.0% |
| | | Perceived Stigma | 2 | 1.0% |
| Healthcare Experiences | Experiences of Device Implantation and Recovery | Recovery from Surgery | 46 | 23.0% |
| | | Device Replacement | 28 | 14.0% |
| | | Implantation Surgery | 20 | 10.0% |
| | | Lead Replacement and Removal | 17 | 9.0% |
| | | Implantation Complications | 7 | 4.0% |
| | | Additional Surgeries to Support Heart Function | 7 | 4.0% |
| | | Costs Associated With the Device | 4 | 2.0% |
| | | Bandages | 1 | 0.5% |
| | Interactions With Healthcare Professionals | Perceived Healthcare Practitioner Ambivalence | 14 | 7.0% |
| | | Medical Advice From Healthcare Practitioners | 13 | 7.0% |
| | | Disagreement About Symptoms | 7 | 4.0% |

| Category | Subcategory | Codes | *n* | % of *N* |
|---|---|---|---|---|
| | | Appreciation for Healthcare Practitioners | 3 | 2.0% |
| | | Uncomfortable Discussing With Male Healthcare Practitioner | 1 | 0.5% |
| | The COVID-19 Pandemic | Impacts of the COVID-19 Pandemic on Experiences | 12 | 6.0% |
| | | COVID-19 Vaccine Questions and Concerns | 5 | 3.0% |
| | | COVID-19 Vaccine Complications | 3 | 2.0% |
| Psychological Experiences of Living With a Device | Negative Psychological Experiences | Worried | 30 | 15.0% |
| | | Fearful or Scared | 19 | 10.0% |
| | | Anxious | 14 | 7.0% |
| | | Depressed and Sad | 12 | 6.0% |
| | | Frustrated | 9 | 5.0% |
| | | Implantable Cardioverter-Defibrillator Shock Anxiety | 7 | 4.0% |
| | | Traumatised or Experiencing PTSD | 6 | 3.0% |
| | | Stressed | 5 | 3.0% |
| | | Emotionally Tired | 3 | 2.0% |
| | | Feeling Lost or Empty | 3 | 2.0% |
| | | Experiencing Cognitive Impairment | 2 | 1.0% |
| | Experiences of Adjusting to Their Device | Ways of Coping With a Device | 12 | 6.0% |
| | | Difficulty Accepting Due to Age and Health | 10 | 5.0% |
| | | Returning to Normal After Implantation | 10 | 5.0% |

| Category | Subcategory | Codes | *n* | % of *N* |
|---|---|---|---|---|
| | | Difficulty Adapting | 6 | 3.0% |
| | | Trying to Rebuild Their Confidence | 5 | 3.0% |
| | | Descriptions of Life Being Changed by the Device | 4 | 2.0% |
| | | Resentment and Hatred Towards Their Device | 4 | 2.0% |
| | | Wanting Device Removal or Deactivation | 3 | 2.0% |
| | | Learning to Trust the Device and Their Body | 3 | 2.0% |
| | | Becoming Emotionally Attached to the Device | 1 | 0.5% |
| | Positive Emotional Experiences | Happy With or Excited for the Device | 5 | 3.0% |
| | | Proud to be Living With a Device | 4 | 2.0% |
| | | Grateful for the Device | 2 | 1.0% |
| Physical Sequelae of Device Implantation | Cardiac Symptoms | Heart Rate Experiences and Concerns | 29 | 15.0% |
| | | Heart Palpitations | 11 | 6.0% |
| | | Shortness of Breath | 10 | 5.0% |
| | | Lightheaded or Faint | 5 | 3.0% |
| | | Loss of Consciousness | 4 | 2.0% |
| | | Dizziness | 3 | 2.0% |
| | | Fluid Retention | 1 | 0.5% |
| | Physical Discomfort and Pain | Device Related Discomfort and Pain | 16 | 8.0% |
| | | General Discomfort and Pain | 11 | 6.0% |
| | | Insertion Site and Scar Related Discomfort and Pain | 11 | 6.0% |

| Category | Subcategory | Codes | *n* | % of *N* |
|---|---|---|---|---|
| | | Heart and Chest Related Discomfort and Pain | 10 | 5.0% |
| | Aversive Physical Symptoms | Body Temperature Changes | 5 | 3.0% |
| | | Physically Tired | 5 | 3.0% |
| | | Bruising | 3 | 2.0% |
| | | Feeling Weak | 2 | 1.0% |
| | | Twitching Sensations | 2 | 1.0% |
| | | Restlessness | 1 | 0.5% |
| | | Excessive Sighing and Yawning | 1 | 0.5% |
| | | Stomach Problems | 1 | 0.5% |
| | | Tingling Sensations | 1 | 0.5% |
| | | Feeling Shaky | 1 | 0.5% |

*Note*. *N* = 196