

**A thematic synthesis of qualitative studies about patients' perception of information and education given in relation to implantable cardioverter defibrillator (ICD) implantation**



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## **Preface**

This research was conducted as a completion of a master programme in intensive care nursing at the University of Stavanger. Working with this thesis has been a time-consuming, challenging, but educational process, and it is fulfilling to see the final product of all the hard work.

After working as nurses for several years, something new and exciting was awaiting us as intensive care nurse students. Internship exposed us to a new and challenging working environment, and the need for more knowledge about how's and why's increased in pace with competence reached. It was therefore exciting and enriching to be able to dig deeper in a topic of high relevance to intensive care nurses.

Several persons have contributed academically, practically and with support to this master thesis. We would therefore firstly like to thank our head supervisor, Ingvild Margreta Morken, for the valuable time and constructive comments that she offered throughout the entire process.

The lecturers and fellow students at University of Stavanger also deserve our gratitude. It was with your way of transferring knowledge to us about nursing research and methodology, combined with valuable feedback that made us competent to carry out this research.

The librarians at Stavanger University Hospital: thank you for all the help on how to conduct a proper literature search.

Finally, we would like to thank family and friends for being helpful and supportive during the entire study period, and our co-workers who have shown a genuine interest in our research. We look forward to presenting the results to you.

Stavanger, May 2016

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## **PART 1**

### **INTRODUCTORY PART**

## **ABSTRACT**

The aim of this study was to explore how implantable cardioverter defibrillator (ICD) recipients perceive information and education given by healthcare professionals in relation to device implantation.

Despite the ICD benefits, device recipients might be faced with psychosocial outcomes, which may affect their quality of life. The extent to which recipients understand and grasp information and patient education about ICDs is poorly understood, and despite previous studies about the phenomena, the authors have not found studies that synthesize the results regarding these perceptions. It would therefore be important to explore the recipients' perceived understanding of this information. A systematic review could lead to a high-level overview of primary research on the subject and inform clinical practice.

The approach for this study was a systematic review of qualitative studies, and the data was analysed by the means of thematic synthesis. The selection consists of 11 qualitative articles which all address the candidates' or recipients' informational and educational needs.

The findings indicate that perception of information provided by healthcare professionals varies, and that information gaps do exist and need to be addressed. This requires that healthcare professionals are highly educated and dedicated to educating and supporting device recipients. Simple, comprehensible advice and explanations may help to reduce uncertainty and anxiety amongst device recipients, especially with issues relating to ICD shocks. Through appropriate patient education and effective communication, while also involving and paying attention to each recipient's informational needs, healthcare professionals can ensure that the benefits, risks, and effects of living with an ICD are properly understood. Also shared decision-making between recipients and healthcare professionals will be encouraged.

**Keywords:** implantable cardioverter defibrillator, information, patient education, and patient perspectiv

## **SAMMENDRAG**

Hensikten med denne studien var å se på informasjonsbehovet til bærere av innopererbare hjertestartere, og deres oppfatning av undervisning gitt av helsepersonell i forbindelse med implantasjon.

Det er flere fordeler ved å ha en ICD, men bærere av ICD kan også oppleve uheldige psykososiale utfall som kan påvirke deres livskvalitet. Det er flere studier som har forsket på bærere av ICD, og deres forståelse av informasjon og undervisning gitt av helsepersonell, men forfatterne har ikke funnet forskning som sammenfatter disse studiene. En systematisk oversikt vil kunne føre til økt kunnskap og forståelse, men også informere klinisk praksis.

Tilnærmingen valgt er en systematisk oversikt over kvalitative studier, hvor datamaterialet ble analysert etter inspirasjon fra tematisk syntese. Utvalget består av 11 kvalitative artikler som alle omhandler kandidater til, og bærere av, ICD og deres informasjons- og undervisningsbehov relatert til implantasjon.

Resultatene indikerer at informasjonen gitt av helsepersonell varierer, og at den kan være mangelfull. Det er derfor viktig å identifisere hva som er mangelfullt, slik at ICD bærere kan føle seg velinformert og undervist på en hensiktsmessig måte. Dette krever helsepersonell som er velutdannet og motivert. Enkle, forståelige råd og forklaringer kan bidra til å redusere usikkerhet og symptomer på angst blant pasientene, spesielt når det kommer til spørsmål vedrørende ICD støt. Ved å benytte effektiv kommunikasjon og å gi pasienten mulighet for å være delaktig, samt lytte til behov og bekymringer, kan helsepersonell forsikre seg om at fordeler, ulemper og risiko blir presentert og forstått. Oppgaven oppmuntrer til samvalg mellom pasient og helsepersonell.

**Nøkkelord:** innopererbar hjertestarter, informasjon, pasientundervisning, pasientperspektiv



## **1.0 INTRODUCTION**

This master thesis consists of two parts. Part 1 is an introductory part of the thesis and is meant to provide the reader with an overall introduction to the research topic. This part presents the aim of the thesis and also describes the theoretical framework. The analytical process will be presented in the methodology chapter. Discussion of the main findings will be presented and discussed based on the theoretical framework and previous research. Part 2 of the thesis is a systematic review of qualitative studies developed by means of a thematic synthesis approach with focus on implantable cardioverter defibrillator (ICD) recipients' perception of information and education given in relation to ICD implantation. This part is written in the form of a research article, which the authors hope to submit to the Journal of Advanced Nursing.

### **1.1 Background**

The ICD is a battery-powered device implanted under the skin, like a pacemaker, able to detect and terminate life-threatening ventricular arrhythmias through anti-tachycardia pacing or high-voltage shocks (Agarwal, Singla, Hreybe, & Saba, 2007; Sweeney, 2004). The device has been proven useful in prolonging life by preventing sudden cardiac death in patients at high risk of life-threatening ventricular arrhythmias (Epstein et al., 2008). Due to the widely established benefits of the device over medical therapy, an increasing number of patients are undergoing ICD implantation (Bardy et al., 2005; Mond & Proclemer, 2011).

Despite the benefits of the device, a substantial portion of ICD recipients might be faced with psychosocial outcomes. A systematic review assessed a 20% prevalence rate for both anxiety and depression symptoms post ICD implant, which in turn can impact the adjustment to the device (Magyar-Russell et al., 2011). In addition, research has shown psychosocial and negative quality of life outcomes post ICD implantation (Hallas, Burke, White, & Connelly, 2010). Although healthcare professionals are well versed in relaying the clinical benefits of the ICDs to recipients, there can sometimes be a distinct lack of discussion about the 'cons' and psychosocial impact of implantation (Khan, 2015). Patient education in relation to the risks and benefits of the ICD is fundamental

in the recipient's decision to accept the device (Groarke et al., 2012). Nurse specialists and the implanting physician often deliver this education. The intensive care nurse (ICN) has a teaching and counselling role in health care, and should ensure that the patient properly understands information. The ICN also has to administer her work in the interdisciplinary team as part of a larger unit, and cooperate with other clinicians to provide adequate information and education to the patient (NSFLIS, 2002). However, the extent to which the information delivered is understood and grasped by recipients is poorly understood, and it is therefore important to determine what they understand of ICD therapy and what their expectations of the therapy may be (Groarke et al., 2012). Although several studies have explored the ICD recipients' perception of information and education provided by healthcare professionals, we have not found studies that synthesize the results regarding these perceptions. A systematic review could lead to a high-level overview of primary research on the subject and inform clinical practice.

The aim of the review is therefore to explore the ICD recipients' perception of device information and education. The specific research question was: How do ICD recipients perceive information and education provided by healthcare professionals in relation to device implantation?

Due to the nature of the research question, the review employed a synthesis of qualitative studies inspired by a thematic synthesis approach. In order to discuss and enlighten the significance of the research findings, the importance of shared decision-making (SDM) and the use of effective communication through uncertainty management theory (UMT) are presented in the introductory part of the thesis.

## **1.2 Aim**

**Part 1:** The introductory essay is meant to describe the theoretical framework and how the methodology was applied in the review, and to discuss the significance of the research findings from a broader viewpoint therefore leading to a more precise interpretation of the research phenomenon.

**Part 2:** The systematic review (article) aims to produce a new and integrated understanding, based on principle findings from the included qualitative studies, on how

ICD recipients perceive information and education given by healthcare professionals in relation to device implantation.

In this thesis the concept “healthcare professionals” is synonymously with employees at the hospital. Other concepts used in this thesis will be clarified where they are used.

## **2.0 THEORETICAL FRAMEWORK**

### **2.1 Shared decision-making**

SDM, within healthcare, is a process in which clinicians and patients work together to clarify treatment, management or self-management support goals, and sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of clinical intervention (Coulter & Collins, 2011). In this thesis, the concept SDM is understood as an approach where healthcare professionals and ICD recipients share the best available information when faced with the task of coming to a decision regarding device implantation, and where the ICD candidates are supported to consider options to achieve informed preferences (Elwyn et al., 2012).

Healthcare professionals have an ethical duty to inform the patient about options of care and elicit their preferences (Coulter & Collins, 2011). Through SDM, healthcare professionals can help patients understand the importance of their values and preferences in making the decisions that are best for them (Barry & Edgman-Levitan, 2012). SDM may increase the patient’s participation and prevent the patient from receiving unwanted health care. Such a practice is in line with the principle of patient autonomy. It is common to assert that the following criteria should be met for an act to be autonomous: adequate understanding, consent, and volunteerism. In clinical practice, it is sometimes impossible to meet all these criteria, and often adapting the information and decision-making to the individual patient’s wishes and expectations can be difficult. It is therefore important that healthcare professionals inform the patient sufficiently so that the patient understands the situation (Pedersen, Hofmann, & Mangset, 2007).

## **2.2 Appraisal of information and communication**

In order to understand the information relayed and allow for informed consent from patients, it is required that there is effective communication between healthcare professionals and the patient (Clark et al., 2011). According to Gudykunst's (2006) UMT, the term effective communication refers to the process of minimizing misunderstandings. He wrote, "Communication is effective to the extent that the person interpreting the message attaches a meaning to the message that is relatively similar to what was intended by the person transmitting it".

UMT claims that uncertainty can cause a wider range of emotions than anxiety, and that people are not always motivated to decrease their uncertainty (Bylund, Peterson, & Cameron, 2011). Although anxiety and uncertainty should be managed to achieve effective communication, they are not always bad as minimal levels of both are necessary for better communication. At points where anxiety and uncertainty are so great, people tend to become paralyzed with fear and this may affect the way people communicate. However, if anxiety and uncertainty levels are reduced to within middle range, misunderstandings can be addressed and effective communication achieved (Gudykunst, 2006).

Patients may evaluate uncertainty as negative, neutral or positive, and will therefore strive to decrease, maintain or increase uncertainty depending on how one evaluates the situation (Bylund et al., 2011). This is much in line with Lazarus and Folkman (1984), whose theory asserts that it is the person's own thoughts about the situation he/she is in which determine how they react emotionally. An interaction between factors in the person, social support and the situation at hand determines how one reacts and deals with it i.e. how the person copes with the situation about living with an ICD. Social support especially, may be important for the appraisal of the information and education, and may therefore protect people from the detrimental health effects of stressful events by positively influencing how people appraise and cope with the events. Social support can be understood as having people around that can give emotional, informative and practical support (Lazarus & Folkman 1984).

### **3.0 METHODOLOGY**

#### **3.1 Pre-understanding**

The authors undertook the study without previous experience on how to conduct a systematic review, and minimal experience within cardiology. Pre-understanding consists of experiences, hypotheses, professional perspective and the theoretical framework that one carries with them from the project's introduction (Malterud, 2011). It is the assumptions one brings with them, their beliefs and perceptions, as well as one's life experiences that determine whether one interprets and finds meaning in a text (Aadland, 2011). The authors' degree of pre-understanding can therefore come off as a strength, or weakness. Pre-understanding may present as strength during the process since the authors have experience with the subject terminology, hospital procedures and patient care. In addition, the authors have empirical knowledge that can be useful in the interpretation of texts. It can sometimes be difficult to interpret without letting one's own experiences affect judgement, which can be a weakness of our own pre-understanding.

#### **3.2 Philosophical considerations**

This thesis is inspired by and embedded within critical realism, and the data was synthesized by means of a thematic synthesis approach. Thematic synthesis is a critical realist approach to qualitative evidence synthesis that entails inductively coding and identifying analytic themes in primary research reports (Harden et al., 2004; Thomas et al., 2007). Barnett-Page and Thomas (2009) define critical realism as knowledge of reality that is mediated by our perceptions and beliefs. It is through critical realism that social realism is modified to note that phenomena exist at different levels, including the level at which they concretely occur and the level at which people experience them, with qualitative data focusing on accounts of these (Nye, Melendez-Torres, & Bonell, 2016). Critical realism argues that both positivism and social constructionism are too superficial, unrealistic and anthropocentric; with social constructionism assuming all knowledge as linked to our social constructions, and positivism assuming all knowledge as coming to us as single sense data linked through human-made theories. Critical realism, in contrast, asserts that there is a world independent of human beings, and also

that there are deep structures in this world that can be represented by scientific theories (Alvesson & Sköldbberg, 2000).

### **3.3 Design**

This study uses a systematic review as the methodological approach in order to answer the research question, based on qualitative studies. A systematic review is a literature review that is designed to locate, appraise and synthesize the best available evidence relating to a specific research question to provide informative and evidence-based answers (Dickson, Cherry, & Boland, 2014). While qualitative research methods seek to explore people's experiences and understandings, a systematic review of qualitative studies is more thorough and gives more accurate answers to questions about "how" and "why" than individual qualitative studies. A systematic review will therefore have greater predictive power than each individual study (Ring, Ritchie, Mandava, & Jepson, 2010).

By broadening perspectives and adding depth to results on experiences and attitudes, reviews can and often aim to generate more comprehensive and generalizing theory, thus making the results of qualitative research more relevant for groups like health policy makers, clinicians and researchers. A systematic review can also provide a thorough insight into the conditions that may limit the facilitation of a measure, and how to effectively achieve change. The main purpose of a systematic reviews is therefore to produce a new and integrated understanding of the principle findings that goes beyond the understanding as stated in the individual studies, thus leading to a more precise interpretation of a phenomenon (Berg & Munthe-Kaas, 2013). There is no standard approach on how to review qualitative research. Reinart and Jamtvedt (2010) and Butler, Hall, and Copnell (2016) suggest the use of a protocol when conducting a systematic review, and it is their protocols the authors are inspired by in development of this review. The format used for writing the article in Part 2 is based upon the IMRAD principle (Reinart & Jamtvedt, 2010) and follows the author guidelines for the publication *Journal of Advanced Nursing* (Appendix 1).

### **3.4 Search method**

An initial search was conducted in Medline, CINAHL, Embase, PsychINFO and Cochrane Library in September 2015. The development of a PICO chart (Table 1) and search was conducted in cooperation with an expert librarian at Stavanger University Hospital, using the keywords and MeSh terms as illustrated in Table 2. This resulted in a few number of hits, which resulted to the authors altering the search strategy in order to increase the number of search results. When searching for qualitative studies, it is particularly desirable with wider searches because these studies use a less standardized conceptual framework. Narrow searches can therefore lead to relevant findings not being included (Sandelowski & Barroso, 2007; Stansfield, Brunton, & Rees, 2014). A new search was therefore conducted, through the same databases, using the keywords and MesH terms as illustrated in Table 3.

### **3.5 Search outcome**

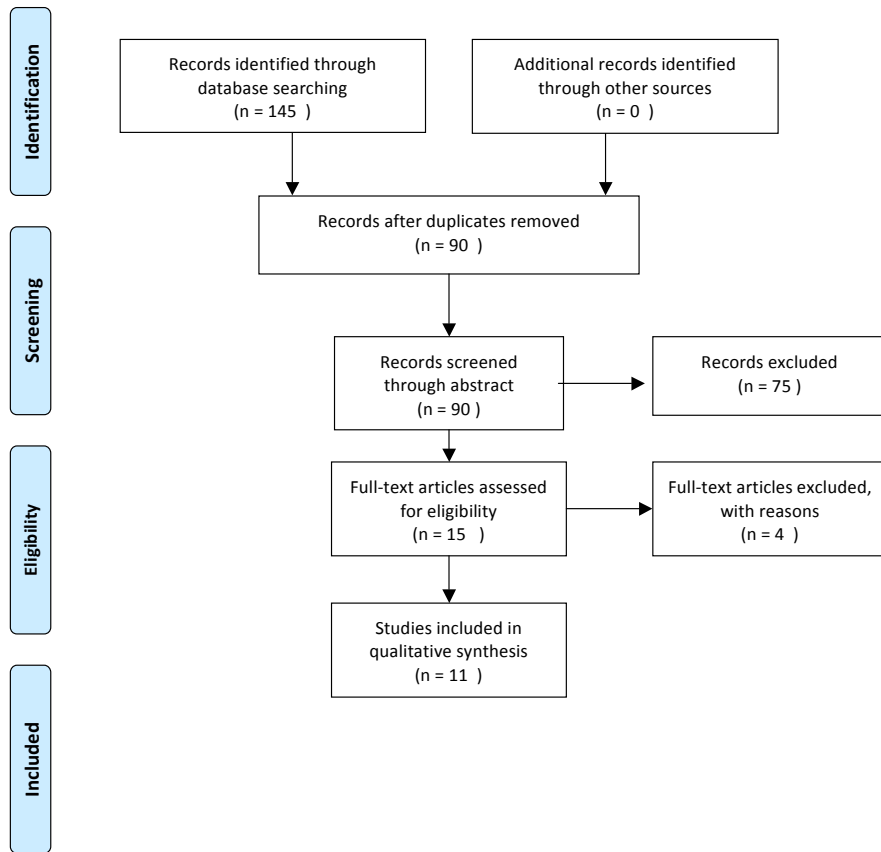
The search through all five databases yielded a total 145 research studies. After eliminating the duplicates, the authors were left with 90 studies, which were screened through for abstract to determine if the inclusion criteria were met. The inclusion and exclusion criteria are presented in Table 4. 15 of the 90 studies met the inclusion criteria. The authors did a full text screening of the remaining 15 studies, of which three were excluded after coming to a consensus that they did not meet the inclusion criteria (Figure 1).

Since the search was only limited to include studies published after 2005, the authors also did a control search for studies published before 2005 just to guarantee that no important data had been excluded. After the control search, it was established that earlier studies only generated data similar to what the authors already had from the search limited to the mentioned time frame, and can therefore assert that saturation was achieved. This implies and therefore supports that it may not always be necessary to locate each and every study, as the results of a conceptual synthesis will not change if ten rather than five studies contain the same concepts, but will rather depend on the range of concepts found in the studies, their context, and whether they are in agreement or not, hence conceptual saturation (Thomas & Harden, 2008).

**Figure 1 PRISMA Flowchart**



**PRISMA 2009 Flow Diagram**



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit [www.prisma-statement.org](http://www.prisma-statement.org).



### **3.6 Quality appraisal**

There has been much debate, and little consensus in regards to assessing the quality of qualitative research, how quality should be assessed, who should assess quality, and whether or not quality can or should be assessed in relation to qualitative research at all (Harden & Thomas, 2008). The authors are of the view that qualitative research needs to be critically assessed in order to ensure that any conclusions drawn from the research are reliable. Critical appraisal involves carefully and systematically examining research to judge its trustworthiness, and its value and relevance in a particular context (Burls, 2009). There is no consensus as to which quality appraisal tool is preferable, therefore the authors used the criteria of the Critical Appraisal Skills Programme (CASP) (Appendix 2). CASP, which addresses the principles and assumptions underpinning qualitative research but does not claim to be a definitive guide, uses a 10-question assessment tool (Tong, Flemming, McInnes, Oliver, & Craig, 2012). CASP approaches research in three main steps: validity, results and clinical relevance (Burls, 2009; Critical Appraisal Skills Programme, 2013). The authors carried out an initial quality assessment of all selected studies individually. The questions were answered, reviewed, and consensus was reached (see Table 1 in Part 2).

Primary qualitative studies are sometimes poorly reported, and tend to shed little detail on how the overall study was conducted, therefore contributing less to the synthesis (Tong et al., 2012). Research also shows that excluding of studies with lower quality does not affect the results from the findings, and can increase the internal validity (Carroll, Booth, & Lloyd-Jones, 2012). The authors wanted to use articles with high levels of validity and reliability, and therefore decided to exclude the articles rated as weak.

### **3.7 Synthesis**

A research synthesis is a general term used to describe the “bringing together” of a body of research on a particular topic. The aim is usually to describe, analyse and draw conclusions on the research evidence, and is often used to make decisions about the effectiveness of healthcare interventions (Ring et al., 2010). Synthesizing qualitative studies therefore provides a range and depth of meanings, experiences, and perspectives of participants across health-care contexts, which will in turn facilitate in the extraction of data across different contexts, generation of new theoretical and conceptual models,

identifying research gaps, informing the development of primary studies, and providing evidence for development, implementation, and evaluation of health interventions (Tong et al., 2012). While methods for the synthesis of quantitative research in health care are well established, many aspects of the methods for synthesizing qualitative research are in the early stages of development. There is currently a range of methods that could be used, one of which is Thomas and Harden's (2008) thematic synthesis (Polit & Beck, 2012). While some methods are intended to elicit directives for practitioners, only thematic synthesis produces findings that can directly inform practitioners without the need for further interpretation for relevance and applicability of the synthesis findings (Hannes & Lockwood, 2011).

This systematic review is conducted by means of a thematic synthesis, inspired by Thomas and Harden (2008). The synthesis takes form of three stages which overlap to some degree: the free line-by-line coding of the findings of primary studies; the organisation of these free codes into related areas to construct descriptive themes; and the development of analytical themes. In the process of analysing data, the authors extracted data, thought to be relevant to the research question, in the form of text units from the study findings. Both first and second order constructs was extracted, meaning that data were extracted from participants' quotations and from the researcher interpretations, assumptions and ideas (Butler et al., 2016). The data extracts were then sorted and categorized into coded text units. After free coding of the text units, the major findings were grouped into a main theme, categories and subcategories. See Appendix 3 for some excerpt from our analysing process.

### **3.7 Ethical considerations**

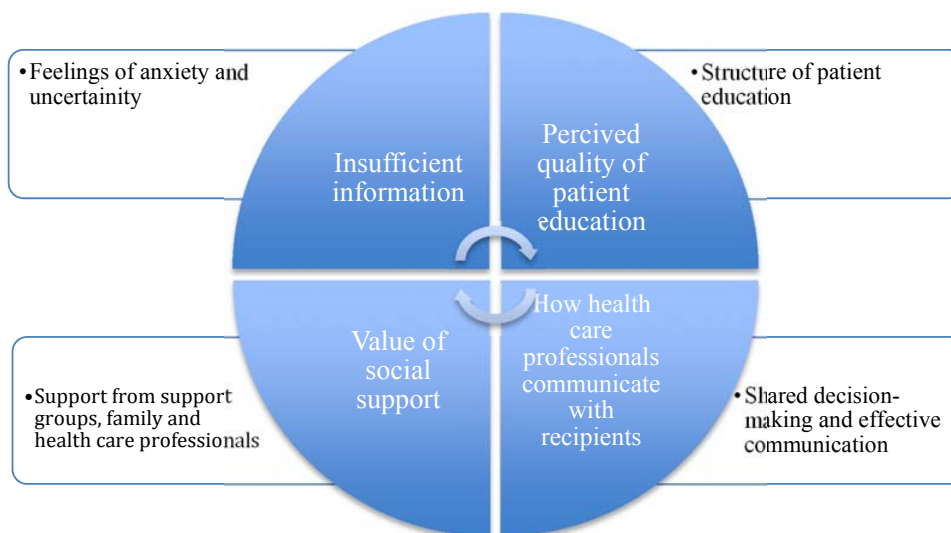
Authors of systematic reviews will be challenged with certain responsibilities, as they are required to follow general conventions on publication ethics and guidelines outlined by various organizations. The authors have kept aware of any special issues that could arise during the research process, especially ensuring that, contributors of the research are properly acknowledged and credited, any potential conflicts of interest were declared and addressed, and that the review does not contain plagiarized material (Hoogenboom & Manske, 2012; Wager & Wiffen, 2011). In addition, the authors also assessed the ethical considerations in the included studies.

#### 4.0 SUMMARY OF THE MAIN FINDINGS

The findings in this study represent recipients' perception of information and education provided in relation to ICD implantation. The findings were identified by systematically going through and analysing the data from the included studies. The analysis resulted in one major theme with three supplementary categories, each with its associated subcategories. The findings are presented clearer in the article, see Part 2 of this thesis. In this part of the master thesis, the findings are presented in a table (see last part of Appendix 3), which is meant to provide the reader with an overview of the main theme, categories and subcategories.

#### 5.0 DISCUSSION AND IMPLICATIONS

This section of the study will discuss the methodological considerations, and study findings will be discussed in varying degrees. Some of the findings presented in the article will be clarified and discussed more in-depth, while other findings will not be discussed any further. The findings will be discussed based on the theoretical framework, and structured in line with the main categories to make the chapter as clear and as transparent as possible. The findings and the context between them, as discussed in the thesis, are illustrated in Figure 2. This chapter will also discuss the study limitations, as well as implication for clinical practice and further research.



**Figure 2** Presentation of findings and the context between them as they are being discussed in the thesis

### **5.1 Methodological considerations**

Systematic reviews based on qualitative research are relatively new, and there are few guidelines on how to synthesize qualitative research. In order to present trustworthy and high-quality recommendations, the use of a systematic review protocol may minimize bias, and enhance transparency and reproducibility. When conducting a systematic review, the search history should contain three parts: relevant databases, reference lists and hand searching, and the grey literature sources (Butler et al., 2016). In this review there were neither hand searches, nor searches done in grey literature due to the scope of the thesis and the limited time frame. This may have resulted in some missing research.

When the authors critically assessed the data material, quality appraisal of the included studies was undertaken individually. This means that three reviewers did the appraisal, implying reduced risk of subjective assessments (Reinar & Jamtvedt, 2010). When extracting data for this review, both first and second order constructs were obtained, allowing the reviewers to view and work with the raw data (quotes) as well as the authors' interpretations. This, according to Butler et al. (2016), helps ensure that the review findings are thoroughly grounded in the original experiences of the participants. During the data analysis, discussions were held and consensus was reached amongst the authors. The use of at least two reviewers is also recommended as this increases the trustworthiness of the review findings by removing personal bias from the review process, and minimizes the potential for error. Discussing the data with other reviewers not only allows the results to be reproduced by other researchers, but also enhances the transparency and overall trustworthiness of the review findings (Butler et al., 2016), and also minimizes the risk of misinterpretation of the text material, thus helping to strengthen the study (Polit & Beck, 2012).

Critiques directed towards the field of qualitative research argue that while individual studies provide rich descriptions and insights of their selective group of focus, the absence of connections drawn between studies limits their usefulness in understanding a phenomenon, informing practice and developing theory. In response to these criticisms, qualitative meta-synthesis serves as a method of interpreting and synthesising qualitative findings across individual studies. Metasynthesis of qualitative research is not just a broad summary of previous findings, but also rather a presentation of new

perspectives on topics through interpreting findings from different qualitative studies to create “third-level” findings for the advancement of knowledge (Nye et al., 2016).

## **5.2 Discussion of findings**

### *Insufficient information*

Findings from this review revealed that there was insufficiency in ICD related information relayed by healthcare professionals to the recipients; hence many recipients expressed a need for more information. Insufficient information amongst ICD recipients can lead to uncertainty, and increased levels of anxiety. The context of “uncertainty” can be described as a state of mind where people feel insecure about their situations, regardless of the actual amount of information they have (Bylund et al., 2011). Uncertainty due to insufficient device information, or knowledge, was evident from the findings and impacted recipients differently. For instance, some recipients expressed receiving insufficient information about how the device would affect their daily life, how they were likely to experience device shocks, and were also uncertain as to what levels of physical activity would trigger a shock (Morken, Severinsson, & Karlsen, 2010). Statements like, “they don’t tell you what it’s going to feel like...” and, “we don’t know what causes it” (Steinke, Gill-Hopple, Valdez, & Wooster, 2005), can reflect that recipients are often faced with uncertainty because of the insufficient information relayed by healthcare professionals. According to UMT, an individual’s perception of uncertainty can change over time and information seeking can be a balancing act for recipients, therefore helping them with managing of uncertainty (Bylund et al., 2011).

In addition to uncertainty, recipients expressed feelings of anxiety related to not knowing when to expect potential device shocks, or what to do after receiving a shock. Previous studies propose that heightened anxiety is most likely to be present in ICD recipients with high levels of concern about being shocked, regardless of whether they have experienced a shock (Sears & Conti, 2002; Pedersen, van Domburg, Theuns, Jordaens, & Erdman, 2005). Many ICD recipients expressed being left in a state of unpredictability, often wondering about the nature of the shocks, which left them terrified and fearful of the unknown i.e. whether or not the shock can be prevented,

what the shock would feel like, what they would be doing when the device triggered a shock, and whether or not they would be alone or if help would be nearby (Flanagan, Carroll, & Hamilton, 2010; Flemme, Johansson, Strömberg, & Hallberg, 2011; Goldstein et al., 2008; Steinke et al., 2005). This is characteristic to shock anxiety, a concept involving negative cognitions and avoidance behaviours related to ICD firing, which seemingly reflects a recipient's concerns about potential shocks, and can according to Lazarus be regarded as a result of the appraisal of uncertainty about how to cope with the ICD shock (Kuhl, Dixit, Walker, Conti & Sears, 2006).

#### *Perceived quality of patient education*

Findings from this review revealed that due to inconsistency and inadequacy of the information given by healthcare professionals, recipients expressed a need for improvement in how patient education was structured (Borse, Hamilton, Flanagan, Carroll, & Fridlund, 2005; Ottenberg, Mueller, Topazian, Kaufman, & Swetz, 2014; Steinke et al., 2005; Ågård, Löfmark, Edvardsson, & Ekman, 2007). In order to do so, it may be of importance that healthcare professionals implement a consulting style that is curious, supportive, non-judgemental and communicates evidence about benefits and risks in an unbiased way (Coulter & Collins, 2011). Hauptman, Chibnall, Guild, and Armbrrecht (2013) assert that communication between patients and healthcare professionals about ICDs is characterized by patient misinformation and a lack of attention to psychosocial and long-term risks.

Communication of unbiased and understandable information on treatment is an ethical imperative, and failure to provide this may be regarded as poor quality care (Coulter & Collins, 2011). According to a study by Tagney (2004), some recipients felt that healthcare professionals were unfamiliar with the device, and therefore information given may have been insufficient and possibly incorrect. Information of low quality may leave the recipient confused and not really understanding the full implications for the device. On the other hand, some recipients are flooded with too much information, which may affect the recipients understanding of the information provided.

### *How healthcare professionals communicate with recipients*

According to the findings some of the ICD recipients were unable to remember being involved, or only played a passive role in the decision about implantation, and that there was lack of involvement in care management (Flanagan et al., 2010; Ottenberg et al., 2014). This is in contrast with the norm of SDM where healthcare professionals and patients should work together to clarify treatment, share information about options and preferred outcomes reaching a mutual agreement of treatment. Training of healthcare professionals about information exchange with ICD recipients may be beneficial to SDM and managing threats about implantation (Hauptman et al., 2013). It is also suggested that most patients want more health information than they are usually given (Coulter & Collins, 2011). However, some findings revealed that some recipients did not feel pressured by healthcare professionals to proceed with implantation and allowing them to make independent decisions (Ottenberg et al., 2014).

Findings also revealed that recipients were not comfortable making complex medical decisions, such as implantation, therefore entrusting the clinician to make the right decision for them (Fluur, Bolse, Strömberg, & Thylén, 2012; Goldstein et al., 2008; Ågård et al., 2007). If ICD recipients perceive themselves medically unqualified, they may avoid information acquisition and rather defer this authority to healthcare professionals (Bylund et al., 2011). Because healthcare professionals are often seen as the only competent decision-makers, patients may have low confidence to engage in SDM, and it may therefore not be uncommon for patients to want, and hereby expect their clinicians to make the decision for them. The temptation for the clinician to do just that may be present due to a busy hospital environment (Coulter & Collins, 2011). This, in our opinion, may hinder the process of SDM. For SDM to be achieved, it is important that there exists effective communication between ICD recipients and the healthcare professionals. Clark et al. (2011) present guidelines adapted from the Australian and New Zealand expert advisory group, which can be applied to achieve effective communication with patients undergoing ICD implantation. The components of these guidelines suggest, in summary, that healthcare professionals should; prepare for the discussion, relate to the person, elicit patient and caregiver preferences, provide information tailored to individual patient needs, acknowledge emotions and concerns, foster realistic hope, encourage questions and further discussions, and document the

discussion. The environment where information is relayed, for instance the outcome-driven health care environment, might also affect effective communication and decision-making, for instance (Ottenberg et al., 2014). Providing patient education in a calm environment may therefore be of importance and could make the recipient feel more involved in the decision making process, and therefor encouraging SDM between the patient and health care professional.

#### *Value of social support*

According to the findings, recipients valued the support from healthcare professionals (Bolse et al., 2005; Flanagan et al., 2010; Flemme et al., 2011; Morken et al., 2010; Ottenberg et al., 2014), welcomed the involvement of their loved ones (Fluur et al., 2012; Ottenberg et al., 2014) and also reported both positive and negative effects from support groups (Bolse et al., 2005; Flanagan et al., 2010). Patients often make negative appraisals of specific events, and ICD recipients may find device implantation quite stressful, therefore coping with the device may be a challenge that requires a certain degree of support to overcome. The value of social support is often undervalued, and many researchers point to social support as one of the most important recourses for coping with stress situations and stress reactions related to own illness (Taylor, 2012). Lazarus and Folkman (1984) emphasize the importance of social support for the appraisal of information and education, as this may be a determining factor in how a patient deals with the situation at hand. For example, an ICD recipient undergoing implantation could acquire information about the steps involved, potential discomfort, etc. from a peer who underwent the same previously (Taylor, 2012). As reported by some studies however, social support can also act as a stressor as negative responses from social networks may increase distress in some recipients (Bolse et al., 2005; Flanagan et al., 2010).

In addition to social support from family and peers, healthcare professionals could provide the recipient with informational support in form of advice about their device, issues related to device shock, activity restrictions, sexual concerns, etc. This form of support can help the recipient to better cope in the daily living with the ICD.



### **5.3 Clinical implications**

This review can be beneficial to health care by giving a clearer insight into how ICD recipients are affected by the information relayed to them by healthcare professionals. By identifying information gaps and discrepancies in ICD patient education, healthcare professionals can use the findings from this review to implement interventions that can address these issues. Nurses, in particular, are in a key position to implement such interventions that could eventually play a significant role in the improvement of patient education structure, and also enhance effective communication in regards to ICD implantation.

### **5.4 Suggestion for further research**

This review can provide healthcare professionals with an insight into how ICD recipients perceive information and education in relation to ICD implantation. However, there is a need for more research on this area before any further conclusions can be drawn. It may be beneficial to explore how healthcare professionals relay patient education to this patient group, and also to address the information gaps relating to ICD implantation. It may also be beneficial to explore the effects effective communication may have on anxiety and uncertainty, in relation to device implantation.

## **6.0 CONCLUSION**

This review reveals discrepancies and informational gaps in patient education related to ICD implantation. There were reports of insufficient information about purpose and functioning of the device, which were a contributing factor to uncertainty and anxiety amongst ICD recipients that eventually affected how they lived their lives. The review also pointed out a lack of effective communication between healthcare professionals and recipients, with some recipients feeling uninvolved in implantation decisions. There was also evidence of misinformation, perceived as low quality information, as recipients opted for further and alternative sources of information in the hopes of correcting this misinformation. Based on these perceptions of patient education, there is a need for improvement in educational support towards ICD recipients. Addressing these needs would require that; healthcare professionals apply effective communication, not only for achieving SDM, but also to encourage recipients to ask questions relating to their needs,

therefore managing uncertainty and anxiety. Healthcare professionals should also assess and encourage social support for ICD recipients as this may help them to adjust better to living with the device.

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## TABLES

**Table 1** PICO Chart

<b>P</b>	<b>I</b>	<b>C</b>	<b>O</b>
<b>Population Patient Problem</b>	<b>Intervention or Exposure</b>	<b>Comparison</b>	<b>Outcome</b>
<b>Patients, older than 18yrs</b> , diagnosed with cardiac arrhythmias, and eligible for implantation of <b>Implantable Cardioverter Defibrillator (ICD)</b>	<b>Preoperative education and information</b> given to <b>patients</b> by healthcare professionals in relation to <b>ICD implantation</b> , and how the <b>information</b> is <b>communicated</b> .	Not applicable in this research	<b>Patients' views, experiences, attitudes, perceptions</b> , and level of <b>satisfaction</b> in relation to the <b>patient education and information</b> provided by healthcare professionals.

**Table 2** Narrow search

<b>Database</b>	<b>Keywords and MesH terms</b>	<b>Number of hits</b>
CINAHL	Defibrillators, Implantable, implant*, defibrillator*, patient discharge education, preoperative education, patient education, patient*, information, education, communication, patient attitudes, consumer participation, patient satisfaction, patient* view*, perspective*, experience*, attitude*, perception*, satisfaction	10
Medline	Defibrillators, implantable, implant*, defibrillator*, patient education, patient*, information, education, communication, patient*, view*, perspective*, experience*, attitude*, perception*	19
Embase	Defibrillator, implantable, implant*, defibrillator*, patient education, patient*, information, education, view*, perspective*, experience*, attitude*, perception*	18
Cochrane	Defibrillators, implantable, implant*, patient education, information, education, communication, patient*, consumer*, client*, view*, perspective*, experience*, attitude*, perception*, satisfaction	3
PsychINFO	Defibrillator, implantable, implant*, defibrillator*, patient education, patient*, information, education, view*, perspective*, experience*, attitude*, perception*	1

**Table 3** Broad search

<b>Database</b>	<b>Keywords and MesH terms</b>	<b>Number of hits</b>
CINAHL	Implantable cardioverter defibrillator AND qualitative	32
Medline	Implantable cardioverter defibrillator AND qualitative	42
Embase	Implantable cardioverter defibrillator AND qualitative	30
Cochrane	Implantable cardioverter defibrillator AND qualitative	28
PsychINFO	Implantable cardioverter defibrillator AND qualitative	13

**Table 4** Inclusion and exclusion criteria

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Patient education and information in relation to ICD implantation Patient perspective Qualitative studies Aged 18 years or over Published from January 2005- September 2015 Language: English, Norwegian, Swedish and Danish Published in Peer Reviewed Journal	Patient education and information given from ICD manufacturer Healthcare professionals perspective Family members or partners perspectives Qualitative studies with focus on interventions Studies with a focus on follow-up care quality of life, psychological aspects, experiences living with an ICD and acceptance of the ICD

**PART 2**

**ARTICLE**

Editor-in-Chief  
Roger Watson  
Journal of Advanced Nursing

June 2016

Dear Editor-in-Chief,

We are grateful for the opportunity to submit our manuscript: “A thematic synthesis of qualitative studies about patients’ perception of information and education given in relation to implantable cardioverter defibrillator (ICD) implantation”. We hope that you will consider it for publication in the Journal of Advanced Nursing. The authors guarantee the originality of the article, as it does not infringe upon any copyright or third party proprietary rights, nor is it under consideration by any other journal. There is no conflict of interest. All authors have read the manuscript and approved its submission to the Journal of Advanced Nursing.

This manuscript, aims to produce a new and integrated understanding, based on findings from the included qualitative studies, on how ICD recipients perceive information and education given by healthcare professionals in relation to device implantation. The findings indicate that the information provided by healthcare professionals varies, and that information gaps do exist.

This review may prove beneficial for healthcare and nursing practice by providing more specific insight into how ICD recipients feel information and education about the device and implantation is relayed to them, therefore helping healthcare professionals to better structure ICD patient education.

On behalf of all the authors,  
Yours sincerely, Anita Landa

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**CANDIDATES AND RECIPIENTS OF IMPLANTABLE CARDIOVERTER  
DEFIBRILLATORS INFORMATIONAL NEEDS AND THEIR PERCEPTIONS  
OF EDUCATIONAL SUPPORT FROM HEALTHCARE PROFESSIONALS:  
A META-SYNTHESIS**

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**Candidates and recipients of implantable cardioverter defibrillators informational needs and their perception of educational support from healthcare professionals: a meta-synthesis**

**ABSTRACT**

**Aim** To provide a synthesis of implantable cardioverter defibrillator (ICD) recipients' experiences and perception of information and education provided by the healthcare professionals in relation device implantation.

**Background** Despite the ICD benefits, device recipients might be faced with psychosocial outcomes, which may affect their quality of life. The extent to which recipients understand and grasp information and patient education about ICDs is poorly understood, and despite previous studies about the phenomena, the authors have not found studies that synthesize the results regarding these perceptions.

**Design:** A synthesis of qualitative literature was conducted inspired by thematic synthesis.

**Data Sources:** A systematic literature search was conducted for qualitative studies published between January 2005 and September 2015. Databases searched were Medline, CINAHL Embase, PsychINFO and Cochrane Library with the following key words: implantable cardioverter defibrillator and qualitative.

**Review method:** 11 studies were included. The Critical Appraisal Skills Programme was used to critically appraise the quality of the studies.

**Results:** One overall theme "Perception of educational support" revealed three key aspects; how recipients perceived information and education, communication with healthcare professionals, and impact of social support in relation to device implantation. The majority of findings revealed insufficient information, as ICD recipients expressed a general need for more information in regards to issues relating to physical activity, sexual issues, device shocks and end-of-life issues.

**Conclusion** There was evidence of discrepancies in patient education, which revealed a need for improvement in educational support given to implantable cardioverter defibrillator recipients. This may be achieved through; enhancement in educational support, applying better communication skills, and assessing the value of social support.

**Keywords** implantable cardioverter defibrillator, information, patient education, patient perspective

## **Informasjonsbehovet til bærere av innopererbare hjertestartere, og deres oppfatning av undervisning gitt av helsepersonell: en metasyntese**

### **SAMMENDRAG**

**Hensikten** Å gjøre en syntese over informasjonsbehovet til bærere av innopererbare hjertestartere, og deres oppfatning av undervisning gitt av helsepersonell i forbindelse med implantasjon.

**Bakgrunn** Det er flere fordeler ved å ha en ICD, men bærere av ICD kan også oppleve uhendige psykososiale utfall som kan påvirke deres livskvalitet. Det er flere studier som har forsket på bærere av ICD, og deres forståelse av informasjon og undervisning gitt av helsepersonell, men forfatterne har ikke funnet forskning som sammenfatter disse studiene.

**Design** Tilnærmingen valgt var en systematisk oversikt over kvalitative studier, hvor datamaterialet ble analysert etter inspirasjon fra tematisk syntese.

**Datasamling** Et systematisk datasøk etter kvalitative studier publisert mellom januar 2005-september 2015 ble utført. Databasene søkene ble utført i var Medline, CINAHL Embase, PsychINFO og Cochrane Library med følgende søkeord: implantable cardioverter defibrillator og kvalitative.

**Metode** 11 studier ble inkludert. Critical Appraisal Skills Programme ble brukt for å kritisk vurdere kvaliteten av de inkluderte studiene.

**Resultat** Et hovedtema "Oppfatning av informasjonsstøtte" avdekket tre synspunkter; hvordan ICD bærere oppfattet informasjonen og undervisning, kommunikasjonen med helsepersonell og innvirkningen av sosial støtte i relasjon til implantasjon.

Hovedfunnene indikerer at informasjonen ikke er tilstrekkelig nok, da ICD bærere uttrykte et generelt behov for mer informasjon når det kom til følgende tema; psykisk aktivitet, seksuelle bekymringer, ICD støt og utfordringer relatert til livets slutfase.



**Konklusjon** Det ble avdekket et behov for forbedring i pasientundervisning og informasjon som blir gitt til bærere av innopererbare hjertestartere. Dette kan oppnås ved å forbedre; informasjonsstøtten til bærerne, kommunikasjonsegenskapene til helsepersonell, og synliggjøre verdien av sosial støtte.

**Nøkkelord** innopererbar hjertestarter, informasjon, pasientundervisning, pasientperspektiv

## **Introduction**

The implantable cardioverter defibrillator (ICD) is a device implanted under the skin, like a pacemaker, able to detect and terminate life-threatening ventricular arrhythmias through anti-tachycardia pacing or high-voltage shock (Sweeney 2004, Agarwal et al. 2007). The device has been proven useful in prolonging life by preventing sudden cardiac death in patients at high risk of life-threatening ventricular arrhythmias (Epstein et al. 2008). Due to the widely established benefits of ICD over medical therapy, an increasing number of patients are undergoing ICD implantation (Bardy et al. 2005, Mond and Proclemer 2011).

Despite the benefits of the device, a substantial portion of ICD recipients might be faced with psychosocial outcomes. A systematic review assessed a 20% prevalence rate for both anxiety and depression symptoms post ICD implant, which in turn can impact the adjustment to the device (Magyar-Russell et al. 2011). In addition, research has shown psychosocial and negative quality of life outcomes post ICD implantation (Hallas et al. 2010). Although healthcare professionals are well versed in relaying the clinical benefits of the ICDs to recipients, there can sometimes be a distinct lack of discussion about the ‘cons’ and psychosocial impact of implantation (Khan 2015). Patient education in relation to the risks and benefits of the ICD is fundamental in the recipient’s decision to accept the device (Groarke et al. 2012). Nurse specialists and the implanting physician often deliver this education. However, the extent to which the information delivered is understood and grasped by recipients is poorly understood, and it is therefore important to determine what they understand of ICD therapy and what their expectations of the therapy may be (Groarke et al. 2012). Although several studies have explored the ICD recipients’ perception of information and education provided by healthcare professionals, we have not found studies that synthesize the results regarding these perceptions. A systematic review could lead to a high-level overview of primary research on the subject and inform clinical practice.

## **The review**

### **Aim**

The aim of this study is to provide a synthesis of implantable cardioverter defibrillator (ICD) recipients' experiences and perception of information and education provided by the healthcare professionals in relation to device implantation, and is based on qualitative research. The review question is: How do ICD recipients perceive information and education provided by healthcare professionals in relation to device implantation?

### **Design**

A synthesis of qualitative literature was undertaken employing thematic synthesis (Thomas and Harden 2008).

### **Search method**

An initial search was conducted in Medline, CINAHL, Embase, PsychINFO and Cochrane Library for qualitative research studies published between January 2005 and September 2015. The following keywords and MeSH terms were used for the search: implantable cardioverter defibrillator and qualitative. Inclusion criteria were patient education and information in relation to ICD implantation, patient perspective, qualitative studies, aged 18 years or over, published from January 2005- September 2015, language: English, Norwegian, Swedish and Danish and published in Peer Reviewed Journal. The authors scrutinized all references from the identified articles but no additional articles were included. Qualitative studies were included regardless of the theoretical approach, the technique of data collection or method of analysis used. Exclusion criteria were patient education and information given from ICD manufacturer, healthcare professionals perspective, family members and partners perspectives, qualitative studies with focus on interventions, studies with a focus on follow-up care, quality of life, psychological aspects, experiences living with an ICD and acceptance of the ICD.

### **Search outcome**

The search through all five databases yielded a total 145 research studies. After eliminating the duplicates, the authors were left with 90 studies, which were screened through for abstract to determine if the inclusion criteria were met. 15 of these studies met the inclusion criteria. The authors did a full text screening of the remaining 15 studies, of which three were excluded after coming to a consensus that they did not meet the inclusion criteria (Figure 1).

**Please insert Figure 1 about here.**

### **Quality appraisal**

Critical appraisal involves carefully and systematically examining research to judge its trustworthiness, and its value and relevance in a particular context (Burls 2009). As far as the authors know, there is no consensus as to which quality appraisal tool is preferable. The authors used the criteria of the Critical Appraisal Skills Programme (CASP), which uses a 10-question assessment tool. CASP approaches research in three main steps: validity, results and clinical relevance (Critical Appraisal Skills Programme 2013, Burls 2009). The authors carried out an initial quality assessment of all selected studies individually. Discussions were held and consensus was reached (Table 1). Many primary qualitative studies are sometimes poorly reported, and tend to shed little detail on how the overall study was conducted, therefore contributing less to the synthesis. (Tong et al. 2012). Research also shows that excluding of studies with lower quality does not affect the results from the findings, but can increase the internal validity (Carroll et al. 2012). The authors wanted to use articles with high levels of validity and reliability, and therefore decided to exclude the articles rated as weak.

**Please insert Table 1 about here.**

### **Data abstraction**

Included articles were abstracted to determine design, sample size, methodology, and data analysis (Table 2). The authors also revised the included articles in regards to implications for clinical practice.

**Please insert Table 2 about here.**

### **Synthesis**

The systematic review was carried out by means of a thematic synthesis inspired by Thomas and Harden (2008). This synthesis takes the form of three stages which overlap to some degree: the free line-by-line coding of the findings of primary studies; the organization of these free codes into related areas to construct descriptive themes and the development of analytical themes. The aim of this process is to help with the identification of important or recurrent themes. The authors extracted data, thought to be relevant to the research question, in the form of text units from the study findings. The data extracts were then sorted and categorized into coded text units. After free coding of the text units, the major findings were grouped into main theme, categories and subcategories as shown in table (Table 3). An excerpt of the analysis process is illustrated in Appendix 3.

**Please insert Table 3 about here.**

## **Results**

The major theme identified based on the data extracted in relation to information received from healthcare professionals was: perception of educational support. There were three categories, each with respective sub-categories, which emerged from the major theme: information and patient education, communication with healthcare professionals, and impact of social support.

### **Perception of educational support**

The major theme 'perception of educational support' describes how ICD recipients perceive patient education related to (1) information and patient education (2) communication with healthcare professionals, as well as (3) impact of social support from peers, family, friends and healthcare professionals.

#### Information and patient education

This category describes the ICD recipients' perceptions of the information given by healthcare professionals, and contains four subcategories: (1) meeting the needs, (2) perceived quality of information, (3) technical issues, and (4) information gaps.

#### *Meeting the needs*

The findings revealed that ICD recipients expressed a general need for more information in order to achieve an informed decision (Ottenberg et al. 2014). Some ICD recipients were not satisfied with the information given and therefore searched for alternative information (Palacios-Ceña et al. 2011a). They expressed a lack of information and had to find it by themselves (Flemme et al. 2011), and although some recipients understood that they needed an ICD, they did not know more than that (Ågård et al. 2007) and therefore seemed to have many unanswered questions (Flanagan et al. 2010). Despite being told why they needed an ICD, some recipients did not recall ever being presented with the option of alternative treatment and the device associated risks (Ågård et al. 2007). Furthermore, it emerged that even those patients who declined ICD implantation expressed willingness and need for alternative information in order to achieve an informed decision. Some ICD recipients expressed that the health care environment, with demands for effectiveness, imposes stress, and that they need time to process the information given (Ottenberg et al. 2014). Others also expressed the

inability to grasp information about the ICD implantation, but that further clarification about indications for the ICD eliminated previous doubts about the device (Ågård et al. 2007).

Study findings revealed that many ICD recipients are uncertain and insecure about the experiences, as well as the effects of device shocks following implantation (Morken et al. 2010, Flemme et al. 2011, Goldstein et al. 2008). Many recipients expressed a need for information due to fears and anxiety in relation to device shocks and different levels of physical activity (Bolse et al. 2005), and therefore wished to have this information prior to implantation or before hospital discharge. Uncertain as to what constitutes an acceptable degree of physical activity (Morken et al. 2010, Bolse et al. 2005), recipients were concerned with the provocation of device shocks during sexual activity, and if the shock could harm them or their partner (Palacios-Ceña et al. 2011a, Flanagan et al. 2010). Some recipients reported being advised to stop working (Palacios-Ceña et al. 2011a) and were given restrictions on several activities (McDonough 2009), while others were told to “live normally”, but this only led to greater insecurity due to the fear of provoking a shock (Morken et al. 2010). Aware of the risks they were exposed to, some recipients still dared to test limits and increase their physical activity despite advice from healthcare professionals (Flemme et al. 2011).

#### *Perceived quality of information*

The findings from the studies revealed that ICD recipients expressed a need for improvement on how healthcare professionals structure patient education. There were reports that clinicians varied in their approaches to introducing the device, and that they should examine how device consultations are conducted to improve patient knowledge, as some recipients felt that the consultation was more like a sales pitch (Ottenberg et al. 2014). Some findings also revealed recipients’ dissatisfaction with how the device benefits and risks were presented (Ågård et al. 2007), whereas others revealed the recipients did not think the hospital had so much information due to the inadequacy of the information provided (Bolse et al. 2005).

However, it also emerged that some recipients had a positive attitude towards written information as they could refresh their memory about the implantation and treatment (Bolse et al. 2005). This written information as well as further information, such as

newsletters, could help with decision-making if any problems arose following hospital discharge (Steinke et al. 2005).

#### *Technical issues*

Some studies revealed that ICD recipients received information regarding indications and reasons for device implantation (Ottenberg et al. 2014), as well as the possibility for arrhythmia and thereby shocks from the ICD if their heart conditions deteriorated (Fluur et al. 2012). However, many recipients from other studies still expressed a lack of knowledge about the purpose and function of the device. Some recipients also expressed that they did not fully understand the reason why they received their ICD, and the role the device played in their health (Goldstein et al. 2008). For instance, some findings reported that questions about the ICD were numerous, and that recipients through focus group sessions identified gaps in their understanding of the device purpose and function (Ottenberg et al. 2014). There were also reports of recipients having had a technical understanding, but lacked knowledge about how the ICD operated and how it might benefit the underlying heart disease (Fluur et al. 2012).

#### *Information gaps*

Findings showed that recipients not only lacked information, but also occasionally misunderstood, or/and were misinformed about issues relating to device shocks, deactivation and end of life issues, which led to information gaps. Recipients felt misinformed about the device, which led to a misunderstanding about issues like: device shock, how it feels, or how tolerable the ICD is (Goldstein et al. 2008). Others perceived information on the basis of past experiences of friends, as well as those of family members, which brought about misunderstanding about device implantation and associated risks (Ottenberg et al. 2014). It also emerged that some recipients neither knew about, nor were they presented with the option of device deactivation (Goldstein et al. 2008), and that discussions about end of life issues were rare (Fluur et al. 2012). There were misunderstandings about the ICD at end of life, for instance; the belief that deactivating the ICD would cause immediate death, which a minority of recipients compared to active euthanasia (Fluur et al. 2012).



### Communication with healthcare professionals

This category describes the nature and form of communication between the ICD recipients and healthcare professionals as perceived by the recipients. It contains three subcategories: (1) shared decision-making, (2) open communication, and (3) deactivation and end of life issues.

#### *Shared decision-making*

It emerged from some study findings that there was a lack of shared decision-making between healthcare professionals and recipients. Some ICD recipients felt they played a passive role in the decision making process about the device (Palacios-Ceña et al. 2011a). Other recipients expressed a lack of involvement in care management, and some were unable to remember being involved in the decision to have an ICD (Flanagan et al. 2010). Contrary to the above, reports from some findings revealed that recipients rarely felt pressured by clinicians to proceed with implantation, thereby allowing the recipient the ability to make an independent decision (Ottenberg et al. 2014).

#### *Open communication*

Through some studies, it emerged that there was a need for establishment of open communication between ICD recipients, clinicians, and other recipients. It was reported that open communication should be emphasized allowing the recipients to ask questions of clinicians and other ICD recipients (Ottenberg et al. 2014). It was also reported that recipients often did not question the implantation decision, as the discussion between doctors and patients consisted of a one-way form of communication (Ågård et al. 2007). However, some recipients reported discussing the option of the device implantation more than once (Ottenberg et al. 2014).

#### *Deactivation and end of life issues*

Findings revealed that despite recipients having the need, they expressed difficulty talking about deactivation and end of life issues (Fluur et al. 2012). In general, recipients were particularly willing to talk about other issues relating to their ICD, but not issues relating to deactivation (Goldstein et al. 2008). Few recipients had discussed deactivation and end of life issues. Some wanted to discuss deactivation and end of life issues when nearing end of life, whereas others wanted to make a decision in advance

(Fluur et al. 2012). Furthermore, it emerged that most recipients relied on, and expected healthcare professionals to make the professional decisions for them: deactivation (Goldstein et al. 2008), end of life issues and battery replacement (Fluur et al. 2012).

#### Impact of social support

The category describes the recipients' perception of support received from healthcare professionals, peer groups, and also family and friends. It contains three subcategories: (1) support from healthcare professionals, (2) support from peers, and (3) support from family and friends.

##### *Support from healthcare professionals*

Findings from some studies reported that recipients showed a need and appreciation for health care support. Some ICD recipients felt that health care teams were accessible and supportive during decision-making (Ottenberg et al. 2014), whereas others showed appreciation for the opportunity for support from healthcare professionals; for example the opportunity to call the cardiologist (Morken et al. 2010). Recipients also expressed a need to ask questions from the nurse in between visits (Flanagan et al. 2010). Others emphasized the value for nursing follow-ups where the recipient could call and ask questions any time (Bolsé et al. 2005, Flemme et al. 2011). Despite having the opportunity for nursing follow-up, some recipients avoided seeking help for fear of bothering healthcare professionals, while others reported not knowing about the possibility for health care support (Flemme et al. 2011).

##### *Support from peers*

The value and effect of support groups and other ICD recipients was emphasized. Although recipients felt that talking with healthcare professionals was one approach, some discussed the option of obtaining information from a support group (Steinke et al. 2005). Recipients expressed the value of information received from other ICD recipients, as they had the opportunity to ask questions of someone who could relate to their experience (Ottenberg et al. 2014). It was however revealed that recipients have both negative and positive experiences with support groups (Bolsé et al. 2005) and some therefore expressed a reluctance to take part in support group sessions due to perception of negative atmosphere (Flanagan et al. 2010). Recipients also expressed a

desire to connect with other people who had similar procedures, for instance through on-line chat rooms (Flanagan et al. 2010).

#### *Support from family and friends*

Findings revealed that recipients welcomed involvement from their loved ones (Ottenberg et al. 2014), and some expressed a need for family involvement on end of life issues (Fluur et al. 2012). Despite the need for support, there were reports from various study findings where recipients suggested they felt a generally high degree of overprotectiveness from their partners and family members who made them feel less independent (Steinke et al. 2005, Bolse et al. 2005, Flanagan et al. 2010, Flemme et al. 2011).

### **Discussion**

The aim of this review was to explore how ICD recipients experienced and perceived information and education provided by healthcare professionals in relation to device implantation. The results of this review highlight several consistent issues appearing in the literature. The issues are (1) insufficient information, (2) perceived quality of patient education, (3) how healthcare professionals communicate with recipients, and (4) value of social support.

#### *Insufficient information*

Findings in this study revealed insufficient information and patient education amongst ICD recipients. According to the evidence from the articles, it is demonstrated that ICD recipients who lacked information were faced with “uncertainty” and “anxiety” about the device, especially issues relating to what might trigger device shocks. The main issue from several studies was that recipients did not know for certain as to what levels of physical activity, sexual activity included, could consequently trigger the device to fire (Palacios-Ceña et al. 2011a, Morken et al. 2010, McDonough 2009, Steinke et al. 2005, Bolse et al. 2005, Flanagan et al. 2010, Flemme et al. 2011, Goldstein et al. 2008). These findings also supported by other studies (Kamphuis et al. 2004, Linder et al. 2013, Hauptman et al. 2013, Carroll and Hamilton 2005), after the ICD is implanted. The recipients report being terrified of the potential shocks from the device, generally wondering about the nature of the shock and what it would feel like, what they would be

doing, and if/whether they would be alone or have help nearby. ICD recipients also often experience fear about the perceived strain of sexual activity on the heart and subsequent potential for device shock, often worrying whether or not the shock would harm their partner during sexual activity (Vazquez et al. 2010). Good quality of information and support from healthcare professionals may be especially important to recipients that fears future shocks. A study indicate that non-constructive support from healthcare professional can increase the tendency to develop post traumatic stress disease symptoms, particularly in those who experience shock anxiety, i.e. fear of future shocks (Morken et al. 2014). Further more, it is interesting to take note from the results that even though ICD recipients felt they had been given information regarding the indications and purpose of the device, there were still reports of uncertainty or lack of knowledge regarding the purpose of the ICD, and how it actually functions (Ottenberg et al. 2014, Goldstein et al. 2008, Fluor et al. 2012). This is supported by (Palacios-Ceña et al. 2011b) who found that recipient shared similar feelings of anxiety and uncertainty about the functioning of the ICD and the delivery of shocks.

#### *Perceived quality of patient education*

According to numerous findings reported in this review, recipients put a lot of emphasis on the value of being properly informed, also citing the need for more, and alternative sources of information, as this was important to help them better understand and cope with how the device implantation would affect their diagnosis and their lives in general (Palacios-Ceña et al. 2011a, Ottenberg et al. 2014, Flanagan et al. 2010, Flemme et al. 2011, Ågård et al. 2007). Coulter and Collins (2011) also emphasize the value of proper and personalized information from well-trained healthcare professionals, especially if supplemented by decision support, personalized care planning, self-management education as well as social support from family, friends and peers. This can, according to Coulter and Ellins (2007), and Loveman et al. (2008) improve the patient's understanding, level of participation, coping skills, and also confidence to self-manage, leading to better health outcomes. The findings also revealed that ICD recipients expressed a need for improvement in how patient education is provided and structured (Ottenberg et al. 2014, Bolse et al. 2005, Ågård et al. 2007). Adding to this, Ottenberg et al. (2014) reported on how clinicians seemed unaware that patients lacked knowledge on the purpose and function of the device itself. This suggests that healthcare professionals should relinquish their role as the single, paternalistic authority and train

to become more effective coaches or partners, by discussing with the patients and identifying what actually matters to them (Barry and Edgman-Levitan 2012).

Findings reported in this review also show that the information given was occasionally misunderstood, and that patients felt misinformed about issues relating to device shocks, deactivation and end of life issues, which led to informational gaps (Ottenberg et al. 2014, Goldstein et al. 2008, Fluor et al. 2012). These findings are supported by Hauptman et al. (2013). Healthcare professionals should help patients participate in their own health care by providing high quality information. They also need to elicit what patients already know, and whether this information is correct (Elwyn et al. 2012).

#### *How healthcare professionals communicate with recipients*

The findings demonstrated the significance of effective communication between ICD recipients and healthcare professionals, and how this could eventually affect the recipient coming to an implantation decision. Despite the increasing use of ICDs, recipients often do not receive effective, timely, and understandable information to support good decision-making prior to, and after device implantation. It has also been noted that there is limited communication regarding both implantation and deactivation of ICDs (Clark et al. 2011). This is evident from the results of some studies which indicate that, although some ICD recipients felt that clinicians allowed them to make independent decisions about device implantation (Ottenberg et al. 2014), others felt they weren't particularly involved in the decision for implantation (Palacios-Ceña et al. 2011a, Flanagan et al. 2010), and wished for a more open communication between themselves and the clinicians, often wanting to discuss their options more than just once in order to allow them enough time to come to a decision. This can be supported by Coulter and Collins (2011) who reported that shared decision-making is not yet the norm and that patients want more involvement in their treatment decisions. Contrary to this, some healthcare professionals express doubts, saying that patients don't want to be involved in decisions, lack the capacity or ability, might make 'bad' decisions, or worry that shared decision-making is just not practical, given constraints such as time pressure (Elwyn et al. 2012). Patients should be educated about the essential role they play in decision-making and be given effective tools to help them better understand their options, consequences of their decisions, as well as be able to express their values and preferences without censure from their clinicians (Barry and Edgman-Levitan 2012).

Some patients, however, tend to have low levels of confidence in shared-decision making, often regarding to clinicians as the competent decision-makers, and therefore expecting and entrusting the clinician with the choice to make the decision for them (Coulter and Collins 2011). This is evident from the study results, which report how recipients find difficulty talking about deactivation and end of life issues, and rely on healthcare professionals to make the professional decisions in regards to these issues (Ågård et al. 2007, Goldstein et al. 2008, Fluor et al. 2012).

#### *Value of social support*

According to the findings in this review, recipients valued the support from healthcare professionals (Ottenberg et al. 2014, Morken et al. 2010, Bolse et al. 2005, Flanagan et al. 2010, Flemme et al. 2011), and welcomed the involvement of their loved ones (Ottenberg et al. 2014, Fluor et al. 2012). As supported by Ozbay et al. (2007), having access to a rich and functional social support network has protective effects on maintaining physical and psychological health. The review reported both positive and negative effects from support groups (Flanagan et al. 2010, Bolse et al. 2005). Some recipients valued the opportunity to ask questions from someone in their situation (Ottenberg et al. 2014), while others felt that the support groups had a negative atmosphere, and therefore chose not to attend (Flanagan et al. 2010). These findings are supported by Williams et al. (2004) who found that the support group sessions were said to have been a way of acquiring current, and more relevant information. However, there were others who did not feel that they needed to attend because they preferred getting on with their lives, and felt that the group was just a reminder that something was wrong with them (Williams et al. 2004). Those who attended support groups had higher trait anxiety and were less satisfied with their social support. These results suggest that people seeking out support groups may actually be trying to improve their ability to cope because they are aware of their greater anxiety and lack of support (Dunbar et al. 2012).

#### **Limitations**

This review has limitations that should be noted. The first is that the studies included in this review used different types of qualitative approaches. This may have led to not including all relevant results when conducting a synthesis of the data. The second

limitation is methodological. To strengthen the quality, the authors discussed and agreed on the final composite analysis and synthesis as well as achieving consensus on the main theme developed. However, it is important to acknowledge that this review represents the researchers' reading of the studies in question, and other authors with divergent interests may arrive at a different conclusion.

### **Conclusion and implications for practice**

This review reveals that there is a need for enhancement in educational support given by healthcare professionals to ICD recipients. The findings indicate that the information provided by healthcare professionals varies, and that information gaps do exist. It is therefore important to address these information gaps so that ICD recipients feel properly informed about the device, indications, and purpose in relation to their underlying diagnosis. This requires that healthcare professionals are highly educated, and dedicated to educating and supporting device recipients. Simple and comprehensible advice and explanations may help to lessen uncertainty and anxiety amongst device recipients, especially when it comes to issues relating to ICD shocks. It would also be significant for healthcare professionals to practice and apply better communication skills in order to ensure that the information relayed to the ICD recipients is properly grasped and clearly understood. By educating recipients in a more calm hospital environment, and also paying attention to each recipient's emotional needs through supportive communication, the recipient could feel more involved in the decision-making process therefore encouraging shared decision-making between ICD recipients and healthcare professionals. Recipients should also be made aware of the importance of having a next-of-kin, if willing, during the decision making process, and that open communication between all parties should be encouraged in order to allow recipients and their next-of-kin to feel comfortable to freely address any additional concerns e.g. sexual concerns. With regards to sexual concerns, it is important that healthcare professionals are comfortable and ready to address these concerns with recipients and their partners as this could provide a more comfortable platform to discuss more about sexual activity and how it may be affected by the device and potential device shocks.

This review also revealed the significance that ICD recipients place upon support-groups. Healthcare professionals could therefore consider and assess this option when relaying information to the ICD recipients, which may enable them to acquire additional information and education outside the hospital. Finally, it would be of great value to offer the recipients an opportunity to call the hospital after discharge should any questions arise. This review may prove beneficial for clinical practice by providing more specific insight into how ICD recipients perceive information and education about the device and implantation, therefore helping healthcare professionals better structure ICD patient education.

**Conflict of interest**

The authors have declared no conflict of interest.



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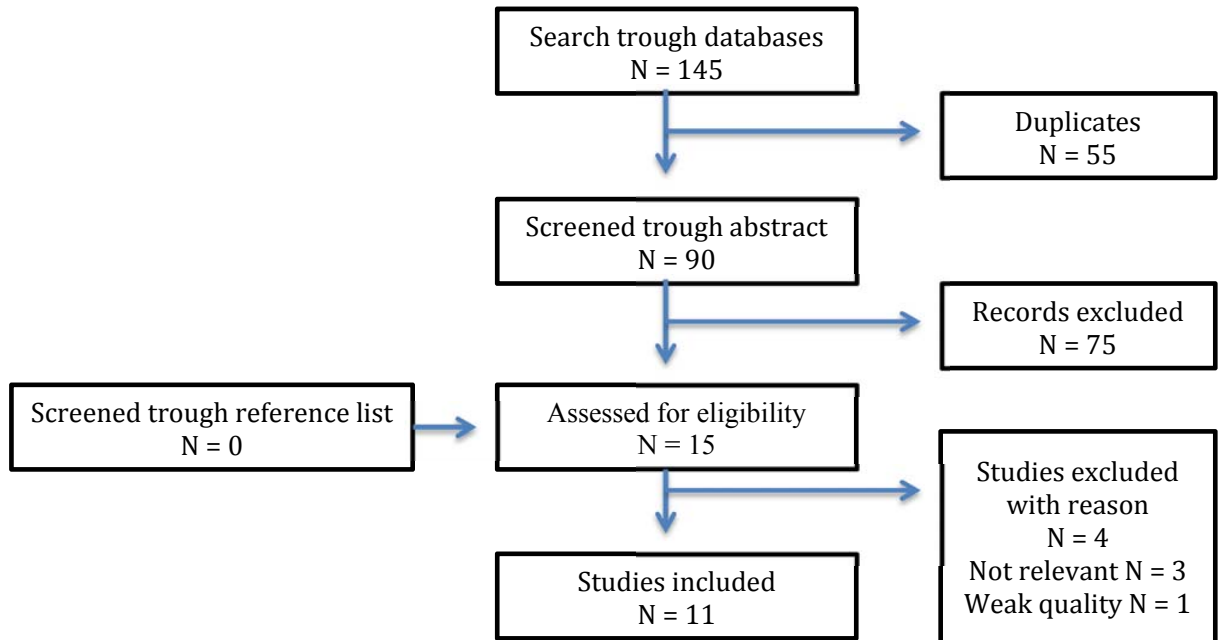
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**Figure 1** Search outcome



**Table 1** Quality appraisal

	Palacios-Ceña et al. (2011a)	Ottenberg et al. (2013)	Morken et al. (2009)	McDonough (2009)	Steinke et al. (2005)	Bolse et al. (2005)	Flanagan et al. (2010)	Flemme et al. (2011)	Ågård et al. (2007)	Goldstein et al. (2007)	Fluur et al. (2013)	Saito et al. (2012)
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	C
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	C	Y	Y	C
4. Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	C
5. Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	C
6. Has the relationship between researcher and participants been adequately considered?	Y	C	N	C	Y	Y	C	Y	Y	Y	Y	N
7. Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	C
8. Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9. Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10. How valuable is the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Total</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Strong</b>	<b>Weak</b>

Y = yes  
C = can't tell  
N = no

**Table 2** Summary of qualitative studies included in the review

Author (year), country	Qualitative Design	Participants	Data Collection	Data analysis	Key Findings
Palacios-Ceña, D. et al. (2011a), Spain	Phenomenological using a Giorgi-type methodology	22 Pt M: 22 F: 0	Unstructured, semi-structured + question guide. Field notes, diaries, personal letters. Transcribed verbatim.	Giorgi analysis	The defibrillator was perceived positively and was considered to be a form of life insurance, whereas the discharge was a limiting factor. The recipient's outlook on life changed. Acceptance of the changes resulting from the implant lead to the development of strategies to facilitate everyday life.
Ottenberg, A. L. (2013), USA	Qualitative approach. Specific design unspecified.	13 Pt M: 11 F: 2	Focus groups, semi-structured interviews. Recorded and transcribed.	Thematic analysis	Focus group findings revealed patients decline implantation of CIEDs for various reasons.
Morken, I. M. et al. (2010), Norway	Qualitative approach inspired by grounded theory	16 persons M: 11 F: 5	Semi-structured interviews audiotaped and transcribed verbatim.	Grounded theory inspired by Strauss and Corbin and Charmaz	The majority of the ICD participants experienced one or more shocks from the defibrillator, which resulted in a feeling of unpredictability, to which they adapted in several ways over time.
McDonough (2009), USA	Qualitative descriptive methodology	20 persons M: 8 F: 12	Telephone interviews and internet interviews, tape-recorded and transcribed verbatim.	NVIVO 7.0 software (Telephone transcripts and internet interviews were compared)	Young adults with ICDs experienced concerns of childbearing, childrearing, and are worried about their financial security.
Steinke, E. E. et al. (2005), USA	Qualitative descriptive approach, according to Sandelowski's description	12 Pt, 4 P&C M: 11 Pt, 1 P&C F: 2 Pt, 3 P&C	Semi-structured interviews, recorded and transcribed verbatim.	Qualitative descriptive approach	Themes that emerged from the interviews was anxiety and apprehension regarding sexual activity, partner overprotectiveness and fear of ICD firing during sexual activity; they need information and sexual counselling
Bolse, K. et al. (2005), Sweden	Qualitative descriptive design based on a phenomenographic approach	14 Pt M: 8 F: 6	Open-ended semi-structured telephone interview. Recordings were transcribed verbatim.	Dahlgren and Fallsberg's 7 steps	The categories showed how patients trusted in the organization, how patients adapted to living with a device and how patients considered that they received support



Flanagan, J. M. (2010), USA	Hermeneutic, phenomenologic method (Van Manen's, 1990)	14 M: 8 F: 6	Telephone interviews, recorded and transcribed verbatim.	Van Manen's hermeneutic phenomenologic method (1990)	All patients generally feared a loss of independence and felt some degree of anxiety from others who were close to them. Other concerns was sexual relationships, driving, and avoidance of activities they feared would trigger a shock were reported.
Flemme, I. et al. (2011), Sweden	Grounded theory	16 outpatients M: 9 F: 7	Interviews, audiotaped and transcribed verbatim.	Constant comparative analysis	Recipients were not paralyzed by uncertainty. Instead they incorporated uncertainty in life by using strategies to handle their daily life.
Ågård, A. et al. (2007), Sweden	Content analysis, specific design unspecified	31 Pt M: 25 F: 6	Semi-structured interviews made up of open-ended questions, tape-recorded and transcribed verbatim.	Qualitative content analysis	Patients who needed an ICD were not told about alternative treatments. Because of their illness, they trusted doctors' recommendation's
Goldstein, N. E. et al. (2007), USA	Qualitative focus groups	15 Pt M: 10 F: 5	Focus group interviews, audiotaped and transcribed.	Constant comparative method	Patients were either unable or unwilling to engage in conversations about deactivation of the ICD.
Fluur, C. et al. (2012), Sweden	Qualitative descriptive design	37 Pt M: 23 F: 14	Semi-structured in-depth interviews, transcribed verbatim.	Qualitative content analysis	The majority had not reflected on battery replacement or elective ICD deactivation. Healthcare professionals had rarely discussed these issues with patients.

\* ICD, implantable cardioverter defibrillator, CIED, cardiovascular implantable electronic device, M, male, F, female, Pt, patient, P&C, partner and caregiver

**Table 3:** Overview of abstracted theme, categories and subcategories

Theme	PERCEPTION OF EDUCATIONAL SUPPORT		
Category	INFORMATION & PATIENT EDUCATION	COMMUNICATION WITH HEALTH CARE PROFESSIONALS	IMPACT OF SOCIAL SUPPORT
Subcategory	<p>Meeting the needs Perceived quality of information Technical issues Information gaps</p>	<p>Shared decision making Open communication Deactivation and EOL</p>	<p>Support from healthcare professionals Support from peers Support from family and friends</p>

## Appendix 1

### Journal of Advanced Nursing, Author Guidelines

#### Journal of Advanced Nursing

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Online ISSN: 1365-2648

#### Systematic review or other type of review paper

*Last updated: November 2015*

*JAN* publishes high quality qualitative, quantitative and mixed method systematic reviews, systematic methodological, economic and policy reviews, realist and integrative reviews, of relevance to nursing. Authors should demonstrate the appropriate choice and use of methodology for a specific review question or context.

Manuscripts should not exceed 5,000 words for the main text, excluding the abstract, summary statement, tables and references. However, at the discretion of the Editor-in-Chief, a more flexible approach to the word limit may be approved for reviews of exceptional quality and importance. Authors who anticipate that their review requires more than 5,000 words to adhere to international reporting standards should first make maximum use of supplemental online files (see [Supporting Information](#)), and then outline the reason for requiring additional words in the main text in their cover letter. Additional flexibility with the word count will be considered on a case by case basis.

Authors should also consider page length even if the text of their paper is under 5,000 words. Very long or numerous tables and figures are not compatible with the page allowance that is available for any single issue of the print journal. Please make maximum use of supplemental online files (see [Supporting Information](#)). Look at some examples of review papers in recent issues of *JAN* to see how tables can be formatted using space economically. If appropriate contact the Editor for advice about designing tables of included studies for the print journal.

## **Organising your manuscript:**

Separate files to be created and uploaded onto [ScholarOne Manuscripts](#):

### **Title Page**

Your title page should include the following information:

- Full title (maximum 25 words)
- Running head
- Author details: names (please put last names in CAPITALS), job titles and affiliations (maximum of 3 per author), qualifications (maximum of 3 per author, including RN/RM where appropriate)
- Acknowledgements (if applicable)
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The title should begin with a descriptor that best describes the type of review, such as: 'Systematic review:', 'Quantitative Systematic review:', 'Qualitative Systematic Review', 'Meta-analysis', 'Integrative review'.

In general we do not include country names in published articles and therefore encourage you to omit these from your manuscript title.

**Impact Statement** □ We ask all authors to prepare a short statement (approximately 100 words), using bullet points if necessary, on any impact you see your paper having in terms of patients, clinical practice, education, or wider social and economic issues. This will be seen by editors and reviewers and may be used for promotional purposes.

### **Main file, to include:**

**Abstract:** 250 words. The abstract should include the following headings: Aims (of the paper), Background, Design, Data Sources (include search dates), Review Methods, Results, Conclusion. The abstract should not contain abbreviations or detailed statistics. The Aim should simply state: 'To...'

**Summary Statement:** Please see the [Summary Statement guidelines](#).

**Keywords:** A maximum of 10. Should include 'literature review' and other MeSH headings appropriate for the specific review, such as 'systematic review', as well as nurses/midwives/nursing and subject-specific keywords.

**Main Text:** To include the headings below and references.

**Tables and figures** should be uploaded separately.

The main text of your paper should include the following headings and sub-headings:

### INTRODUCTION

Include rationale, conceptual or theoretical context, and international relevance of topic.

## **Background**

Present the scientific, conceptual or theoretical framework that guided the review, identifying and providing an overview of the conceptual model and/or theory where appropriate. Identify key concepts or variables.

## THE REVIEW

### **Aim/s**

Include research topic/objectives/questions/hypothesis(es): for example, 'The aim of the (type) review was to...'.  
Structure the review question(s) as appropriate for the review type.

### **Design**

The review design should be the most appropriate for the review question. Identify type of review and describe design and methods used in detail (e.g. meta-ethnography, Cochrane intervention review, realist synthesis etc). Report original methodological sources of reference for the review design and methods. Report processes and steps used and any methodological adaptations/deviations (if any) with supporting rationale.

### **Search methods**

Include: Development, testing and choice of search strategies (consider using a supplemental information file to report searches), inclusion/exclusion criteria, databases searched, keywords, languages and inclusive dates of the literature searched

### **Search outcome**

Search outcome and audit trail - application of inclusion/exclusion criteria, retrieval and selection of references and handling. Summarise included studies (and, if appropriate, excluded studies) in separate tables.

### **Quality appraisal**

Please note that for most systematic review approaches quality appraisal is mandatory and considered the primary marker of a systematic review. Include a description of approaches used, outcome of appraisal process and audit of discarded studies. Make clear the criteria that were used for discarding studies. If quality appraisal was not undertaken provide a convincing and robust explanation, and in the limitations section outline the potential impact on the credibility of the review findings. *JAN* is less likely to publish reviews where quality appraisal of evidence is considered important but was not undertaken.

### **Data abstraction**

Describe the methods and process(es).

### **Synthesis**

Include clear description of process(es) used.

## RESULTS

Present the results of your review using appropriate subheadings outlined here and adhere to relevant standard(s) of reporting (e.g. [PRISMA](#) for systematic review of

RCTs, or RAMESES publication standards for [realist syntheses](#) and [meta-narrative reviews](#)). Include a flow diagram illustrating the flow of literature through the review. Review methods that involve multiple methodological stages/processes should report the outcome of each stage/process. If appropriate, identify the conceptual or theoretical context of each definition or discussion of the concept found in the literature.

#### DISCUSSION

Draw out the applicability, theoretical and practical implications of the review findings. End with limitations and strength and generalisability/transferability of the evidence.

#### CONCLUSION

This should not be a summary/repetition of the findings. Clarify the contribution of the review to existing knowledge, highlight gaps in knowledge and understanding, outline future research, report implications/recommendations for practice/research/education/management as appropriate, and consistent with the limitations. If appropriate, consider whether one or more theoretical frameworks could guide future research about the topic of the review.

#### **Links to useful resources** □

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7) –

[www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1000097](http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1000097)

[Centre for Reviews and Dissemination](#)

[Cochrane Collaboration](#)

[The Evidence for Policy and Practice Information and Co-ordinating Centre \(EPPI-Centre\)](#)

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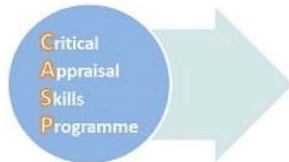
[RAMESES Publication Standards for Realist Syntheses](#)

[RAMESES Publication Standards for Meta-narrative Reviews](#)

[Reporting meta-ethnography](#)

[Guidelines for reporting non complex qualitative evidence syntheses](#)

## Appendix 2



### 10 questions to help you make sense of qualitative research

#### How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- **Are the results of the review valid?**
- **What are the results?**
- **Will the results help locally?**

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**These checklists were designed to be used as educational tools as part of a workshop setting**

There will not be time in the small groups to answer them all in detail!

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## Screening Questions

**1. Was there a clear statement of the aims of the research?**

Yes  Can't tell  No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

**2. Is a qualitative methodology appropriate?**

Yes  Can't tell  No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

**Is it worth continuing?**





Detailed questions

**3. Was the research design appropriate to address the aims of the research?**

Yes     Can't tell     No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

---

**4. Was the recruitment strategy appropriate to the aims of the research?**

Yes     Can't tell     No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

**5. Was the data collected in a way that addressed the research issue?**

Yes

Can't tell

No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

**6. Has the relationship between researcher and participants been adequately considered?**

Yes

Can't tell

No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  - (a) Formulation of the research questions
  - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

**7. Have ethical issues been taken into consideration?**

 Yes Can't tell No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

---

**8. Was the data analysis sufficiently rigorous?**

 Yes Can't tell No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

### 9. Is there a clear statement of findings?

Yes  Can't tell  No

HINT: Consider

- If the findings are explicit
  - If there is adequate discussion of the evidence both for and against the researchers arguments
  - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
  - If the findings are discussed in relation to the original research question
- 

### 10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

### Appendix 3

Analysis process

From text units to initial coding (Excerpt)

<b>Text unit</b>	<b>Initial code</b>
The recipient usually plays a passive role when the decision is made to have the implant, with the cardiologist's recommendations usually being followed. The options presented by the specialist when taking the decision to implant an ICD are usually limited and are presented in a dichotomous manner (good or bad, live or die)	Recipients played a passive role in decision making
They don't tell you what it's going to feel like (discharge) and even if they did, you still wouldn't understand."	Anxiety in relation to discharge
When I had the ICD implanted, they sent me home with a lot papers to read about implanting and the treatment and so on. Even now I can refresh my memory	Recipients had a positive attitude towards written information
Each participant described in a different way a desire to be in touch with other people who had the same procedure	Desire to hear from other recipients
The decision was not questioned and the discussion between doctors and patients mainly consisted of one-way communication	Lack of open communication

Data extraction at descriptive level, compressing of codes (Excerpt)

Text unit	Initial code	Descriptive code
Recipients search for alternative information, because they are not satisfied with the information given	Recipients expressed a need for more knowledge	<i>There was a general need for more information</i>
Patients remarked again and again on the value of collecting as much information as possible in order to make an informed decision	Recipients expressed a need for more information	
Rather, the patients appreciated receiving more information that could be used to make an informed choice	Recipients expressed a need for more information	
Participants had many unanswered questions and utilized the interview as an opportunity to raise them	Recipients expressed lack of information	
Some recipients lacked information and had to find it by themselves or were just given a brochure without further information	Lack of adequate information	
The respondents understood that they had had a serious event and that it was important for them to get something called an ICD, but not much more than that	Lack of adequate device information	

From compressed codes to theme, categories and subthemes

<b>PERCEPTION OF EDUCATIONAL SUPPORT</b>			
<b>Theme</b>	<b>INFORMATION AND PATIENT EDUCATION</b>	<b>COMMUNICATION WITH HEALTH CARE PROFESSIONALS</b>	<b>IMPACT OF SOCIAL SUPPORT</b>
<b>Category</b>			
<b>Subcategory</b>	<p><b>Meeting the needs</b>  <b>Quality of information</b>  <b>Technical issues</b>  <b>Information gaps</b></p>	<p><b>Shared decision making</b>  <b>Open communication</b>  <b>Deactivation and EOL</b></p>	<p><b>Support from healthcare professionals</b>  <b>Support from peers</b>  <b>Support from family and friends</b></p>
<b>Subcategory Codes</b>	<p><b>Meeting of needs</b>  <i>There was a general need for more information (1, 2, 7, 8, 9)</i></p> <p><i>Need for information about sexual issues, level of physical activity and device shock (1,3, 4, 5, 6, 7, 8, 10)</i></p> <p><i>Some expressed a need for more or alternative sources of information (2)</i></p> <p><i>Lack of information about risks and alternative treatment (9)</i></p> <p><i>Healthcare professionals recommendation affected recipients lives (1, 3, 4)</i></p> <p><i>Patients need time to process information (2, 9)</i></p> <p><b>Perceived quality of information</b>  <i>Patients' need for improvement in how to structure patient education (2, 5, 6, 9)</i></p> <p><i>Recipients had a positive attitude towards written information (6)</i></p>	<p><b>Shared decision making</b>  <i>Lack of shared decision making between healthcare professionals and recipients (1, 7)</i></p> <p><i>Clinicians allowed recipients to make independent decisions. (2)</i></p> <p><b>Open communication</b>  <i>The need for open communication with clinicians and other recipients should be emphasized (2, 9)</i></p> <p><i>Discussing the option of implantation more than once. (2)</i></p> <p><b>Deactivation and EOL</b>  <i>Recipients rely on healthcare professionals to make the professional decisions, ex. deactivation and EOL issues (9, 10, 11)</i></p> <p><i>Despite the need, recipients expressed difficulty talking about deactivation and EOL issues (10, 11)</i></p> <p><i>Recipients wanted to discuss deactivation and EOL issues (11)</i></p>	<p><b>Support from healthcare professionals</b>  <i>Recipients showed a need and appreciation of health care support (2, 3, 6, 7, 8)</i></p> <p><b>Support from peers</b>  <i>The value and effect of support groups and other ICD recipients (2, 5, 6, 7)</i></p> <p><b>Support from family and friends</b>  <i>Patients welcomed the involvement of their loved ones (2, 11)</i></p> <p><i>Overprotectiveness by family members (5, 6, 7, 8)</i></p>

<p><b>Subcategory</b> <i>Codes</i></p>	<p><b>Technical issues</b> <i>Information about clinical indication and purpose of the device were explained (2, 11)</i></p> <p><i>Recipients lack knowledge of the purpose and how the ICD function (2, 10, 11)</i></p> <p><b>Information gaps</b> <i>Recipients neither knew about nor was they presented with the option about deactivation of the ICD (10, 11)</i></p> <p><i>Discussions about EOL were rare (11)</i></p> <p><i>Recipients perceived information based on personal experiences, as well as those of family and friends (2)</i></p> <p><i>Misunderstandings about shock, deactivation and EOL issues (2, 10, 11)</i></p>		
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1) Palacios-Cena et al. 2011a 2) Ottenberg et al. 2014 3) Morken et al. 2010 4) McDonough 2009 5) Steinke et al. 2005 6) Bolse et al. 2005 7) Flanagan et al. 2010 8) Flemme et al. 2011 9) Ågård et al. 2007 10) Goldstein et al. 2008 11) Fluor et al. 2012



## **Appendix 4**

### **Abbreviations**

CASP	Critical Appraisal Skills Programme
EOL	end of life
ICD	implantable cardioverter defibrillator
ICN	intensive care nurse
IMRAD	Introduction, Methods, Results and Discussion
PICO	Patient/problem – Intervention – Comparison – Outcome
SDM	shared decision-making
UMT	uncertainty management theory