

# Patients with implantable cardioverter-defibrillators and their conceptions of the life situation: a qualitative analysis

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## Summary

- The implantable cardioverter-defibrillator (ICD) is today widely used for the treatment of sudden cardiac near-death episodes as a result of malignant ventricular dysrhythmia.
- After examining the literature, only four descriptive studies, all carried out in the USA, with a qualitative analysis based on ICD-patients' own perspectives on their life situation have been found.

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- The aim of this study was to describe how patients living with an ICD-device in south-western Sweden conceive their life situation.
- As the focus was on patients' conceptions seen from a holistic perspective, an analysis inspired by phenomenography was employed on a strategic sample of 15 ICD-patients.
- Six categories emerged: a feeling of safety, a feeling of gratitude, a feeling of being, having a network, having a belief in the future, and gaining awareness.
- Although the findings cannot be generalized because of the descriptive research design, they illuminate the beneficial as well as intrusive effects of such a device, and emphasize the need for support groups for patients and families as well as further education for personnel in hospital and primary health care.

*Keywords:* coronary heart disease, implantable cardioverter defibrillator, life situation, phenomenography, qualitative analysis.

## Introduction

The implantable cardioverter defibrillator (ICD) is today widely used for the treatment of symptomatic patients with documented or suspected life-threatening sudden cardiac near-death episodes as a result of malignant ventricular dysrhythmia (Davidson *et al.*, 1994; Strickberger *et al.*, 1997; Van Wormer & Martin-Sheridan, 1997). About 75–100 000 people around the world have had this device implanted, 1000 of whom are living in Sweden (Blomstrom-Lundqvist *et al.*, 1990; Dougherty, 1997; Schuster *et al.*, 1998). The therapy has dramatically improved the survival rates (Wever *et al.*, 1996) but, as the underlying medical problem still exists, ICD-patients experience the future as very uncertain due to their heart disease as well as the functioning and security of the ICD (Saksena, 1994; Heller *et al.*, 1998). Much knowledge exists concerning the ICD's technical performance and ICD-patients' biophysical life (Bainger & Fernsler, 1995; Rosenqvist *et al.*, 1998), while much more information is needed regarding ICD-patients' life situation comprising a biophysical, emotional, intellectual, socio-cultural and a spiritual-existential life (Mårtensson *et al.*, 1997, 1998). Existing knowledge regarding ICD-patients' life situation is mainly derived from questionnaires, mostly built on theories of quality of life (e.g. May *et al.*, 1995; Vitale & Funk, 1995; Stankowitz *et al.*, 1997) or cost-effectiveness (e.g. Wever *et al.*, 1996; Owens *et al.*, 1997), reflecting the researcher's perspective. After examining the literature, only four descriptive studies with a qualitative approach based on the ICD-patients' own perspectives on their life situation have been found, all carried out in the USA (Dunbar *et al.*, 1993; Burke, 1996;

Dougherty, 1997). Accordingly, the aim of this study was to describe how patients living with an ICD-device in south-western Sweden conceive their life situation.

## LITERATURE REVIEW

Regarding biophysical life, younger patients seem to live a more active and productive life compared to older ones, e.g. with regard to working ability and sex life (May *et al.*, 1995; Dubin *et al.*, 1996). Younger patients report some exercise limitations, and whether these are physiological in nature or self-imposed is not stated, but the majority perceive themselves to be in good condition (Dubin *et al.*, 1996). Concerning emotional life, levels of anxiety, fear and depression increase at the time of ICD-implantation, but seem to decrease to the level before ICD-implantation within the first year (Hegel *et al.*, 1997; Schuster *et al.*, 1998). Patients' intellectual life is also affected, including recognizing, interpreting, accepting and managing ICD discharge sensations, monitoring for dysrhythmia, symptom relief, and managing illness-related symptoms and medication (Cooper *et al.*, 1986; Sneed & Finch, 1992; Dunbar *et al.*, 1993; Lüderitz *et al.*, 1994; Burke, 1996). Regarding socio-cultural life, there is in general a decrease in social interaction, e.g. loss of independence, overprotection by family members and avoidance of activities (Dougherty, 1997; Hegel *et al.*, 1997). Spiritual-existential life comprises achieving self-efficacy and compliance in order to attain quality of life and a belief in life (Heller *et al.*, 1998; Schuster *et al.*, 1998), and seems to be correlated with family support and number of electric shocks from the ICD (Sneed & Finch, 1992; Dunbar *et al.*, 1993; Dougherty, 1997).

## THEORETICAL FRAME

Patients' life situations include their relationship to the environment through healthcare professionals, the family, work and society, and can be observed objectively in one way or another. It is possible to say whether or not patients suffer from a disorder and whether or not they have the resources required to manage various daily tasks. There is a belief that patients can be divided and studied in parts (Fridlund, 1994), but this may easily result in a life situation in which the wholeness and the individual are forgotten. Patients' own resources and their need for help may be neglected. Therefore, it is important for healthcare professionals to study patients from a holistic perspective, focusing on the relationship between body, mind and spirit (Keegan & Keegan, 1992). In the literature there are various holistic descriptions of the patient as a person, in which it is the whole patient who is cared for, not just the disease, injury or functional impairment. The authors have chosen to use Sarvimäki & Stenbock-Hult's (1993) dimensions of the holistic concept, as this describes how a patient's life is based on knowledge of both the wholeness and its parts. According to Sarvimäki & Stenbock-Hult (1993), the holistic concept implies that patients fulfil and express themselves in five dimensions: biophysical life, emotional life, intellectual life, socio-cultural life and spiritual-existential life. The five dimensions are seen as separate, but processes within the various dimensions affect each other and it may be difficult to draw clear distinctions or boundaries between them. From a healthcare perspective, the study of patients should incorporate individuals' own subjective feelings of life.

## The qualitative study

### DESIGN AND METHOD DESCRIPTION

Permission for the study was obtained from the Committee for Ethics in Medical Investigations, Göteborg University, Sweden. As the aim of this study was to map out how patients living with an ICD conceive their life situation, a qualitative descriptive design was used. As the focus was on patients' conceptions, an approach inspired by phenomenography was employed in order to ascertain the qualitative variation of their life situation, as expressed in their answers. Phenomenography has been developed at the Department of Education and Educational Research at Göteborg University, Sweden (Marton, 1981). Fundamental to phenomenography is how something is conceived to be, i.e. a way of experiencing something (Marton & Booth, 1997). This means that a distinction is

made between first-order perspective, which starts with facts that are externally observable, and second-order perspective, which starts with the patient's experience of something, or how something appears to someone. Phenomenography describes experiences from the second-order perspective. Central to phenomenography are conceptions which often represent something that is implied, that which need not be said, or cannot be said, as it has never been reflected upon (Marton & Booth, 1997). Conceptions constitute the frame of reference within which knowledge is gathered or the foundation on which reasoning is built. They are the unreflected basis, created by experience, on which opinions rest. Starting with conceptions, one can analyse how patients function in different situations. Although phenomenography and phenomenology have commonalities, a main difference exists in this context in that phenomenography is substance-orientated (searching for the underlying structure of variance as the essence) whereas phenomenology is basically methodological and/or philosophical (searching for the lowest common denominator as the essence; Marton, 1994).

### INTERVIEW AND PRELIMINARY QUESTIONS

In the phenomenographic approach, open and semi-structured interviews constitute the basis for gathering data (Marton, 1981). In this study, the interview plan consisted of preliminary questions intended to introduce a number of delimited phenomena within the fields of biophysical, emotional, intellectual, socio-cultural and spiritual-existential life in line with Sarvimäki & Stenbock-Hult's holistic concept (1993). In order not to neglect any important aspect of a phenomenon, the interviewer (E-CL) used an interview outline of the questions as the basis for interviews. Based on these preliminary questions, the interviewee could then take part in a conversation, which increased understanding of the interviewee's conception of the phenomenon. The following questions were included in the outline: How do you conceive what has happened to you concerning your ICD-implantation? How do you conceive your bodily functions related to your ICD-implantation? How has the ICD-implantation affected your inner self? How do you conceive the information you have received from healthcare professionals about your ICD-device? How do you conceive the healthcare environment which you as a patient have encountered? How do you conceive that your family and closest friends have been affected by your ICD-device? What is your outlook on the future? How can your family and closest friends influence your future? How can healthcare influence your future?

## INFORMANTS

Informants were asked to participate in the study during follow-up at the medical clinic of a university hospital in south-western Sweden, when the study was explained and a written explanation was also given. These individuals were contacted one week later, giving them time to consider whether or not they wished to participate. They were informed that participation was voluntary and that they could withdraw from the study at any time. Tape-recorded interviews were conducted in informants' own homes. To ensure breadth of the selection, patients were included using strategic selection (Fridlund, 1998), i.e. taking background variables into consideration, which is usually done in qualitative research. These variables were sex, age, marital status, education, current working situation, time after implantation, ejection fraction (objective measurement of heart failure) and New York Heart Association classification (subjective measurement of heart failure). They resulted in a set of characteristics as shown in Table 1.

## DATA ANALYSIS

A phenomenographic approach means that the study does not start from a finished model or other theoretical structure (Marton & Booth, 1997). This was the starting point for the main researchers (BF and E-CL), who had the methodological and specialist knowledge needed as well as serving as each other's sounding board for the categorization procedure. Initially, interviews were transcribed word by word, and then the analytical work was begun by reading each interview a number of times in order to gain an overall impression. Interviews were then processed by looking for statements by patients which described plausible conceptions of the life situation, as stated in the study aim. There were a total of 454 statements, and saturation of the conceptions was reached when nine interviews had been analysed. The core of the analysis was to compare different statements, which revealed similarities and differences, in relation to the study aim. In order to obtain an overall picture of how these similarities and differences could be connected, they were grouped into patterns. These patterns were scrutinized critically in order to detect dimensions in the answers, in which completely new formulations and categories were needed to describe conceptions. By interaction between the whole and its parts, a final pattern emerged which resulted in six categories. Furthermore, these categories comprised conceptions which hovered between two extremes, the so-called positive and negative poles in this phenomenographic-inspired approach. The

**Table 1** Characteristics of the strategically chosen patients with implantable cardioverter-defibrillators

|  |       |
|--|-------|
| <b>Sex</b>                                       |       |
| Male   | 10    |
| Female   | 5     |
| <b>Age (years)</b>                               |       |
| Mean age   | 61.8  |
| Range  | 33–76 |
| <b>Marital status</b>                            |       |
| Married  | 13    |
| Single   | 2     |
| <b>Education</b>                                 |       |
| Primary school                                   | 6     |
| Secondary school                                 | 5     |
| Upper secondary school                           | 1     |
| Higher education                                 | 3     |
| <b>Working situation</b>                         |       |
| Working  | 5     |
| Sickness pension                                 | 2     |
| Retirement pension                               | 8     |
| <b>Time (months) after implantation</b>          |       |
| Mean time  | 33    |
| Range  | 23–55 |
| <b>Ejection fraction (percentage)</b>            |       |
| Mean value                                       | 42.2  |
| Range  | 20–77 |
| <b>New York Heart Association classification</b> |       |
| NYHA I   | 5     |
| NYHA II  | 5     |
| NYHA III   | 5     |

Ejection fraction = objective measurement of heart failure.

NYHA (New York Heart Association classification) = subjective measurement of heart failure.

NYHA I = slight heart failure without symptoms.

NYHA II = slight heart failure with breathlessness and fatigue in connection with moderate physical activity.

NYHA III = moderate heart failure with breathlessness in connection with light to moderate physical activity.

categories which emerged were formulated so that they described the context and were illustrated with quotes. To clarify in which interviews the conceptions were described, interview numbers are stated after each category and pole.

## Results

### FEELING OF SAFETY (INTERVIEWS 1–5,7–11,13–15)

This category describes the conception in which patients have a feeling of safety in having the ICD-device implanted. The conception is concerned with the fact that the ICD-device saves lives and ranges from the courage to make an effort to fear of overexerting oneself, thereby triggering an electric shock.

*Quote from the positive pole (interview 1)*

The ICD is an aid and a life-saver. True, it hasn't made me well, after all, the damage to my heart is still there, but it's... a feeling of safety that the ICD is there and helps the heart along when needed, and there have been times when it has been needed.

*Quote from the negative pole (interview 5)*

I'm not as fit as I used to be, I'm sorry to say, but it's cowardice. I dare not, I'm sometimes afraid, especially in the beginning I was terribly afraid, and I thought that... and the fear is still there, it hasn't left me. It's that I want to know what it is that makes the heart derail now and then, how far I can go. I dare not test too much when I'm on my own, you can't always have someone with you when you are out jogging. I'm thinking of buying myself a pulse-ometer which I can have on me when I'm jogging.

**FEELING OF GRATITUDE (INTERVIEWS 1,3,4,8-14)**

This category describes the conception in which patients feel gratitude at having the ICD-device implanted. The conception is concerned with happiness at being alive and ranges from the recognition associated with getting an ICD-device implanted to the grief that results from needing such a device.

*Quote from the positive pole (interview 1)*

... so naturally I was grateful for being given the opportunity to have an ICD implanted when I was told how it worked. So after my first thoughts, I felt grateful to the medical care for offering me this help.

*Quote from the negative pole (interview 12)*

I don't like it. Sometimes I forget about it and then I'm glad that I've succeeded in forgetting about it... An alien thing has entered my body... It's the fact that it's something alien that disturbs me sometimes, but I forget about it when I'm together with other people.

**FEELING OF BEING (INTERVIEWS 1-15)**

This category describes the conception in which patients feel more or less dependent on the ICD-device. The

conception is concerned with a state of being and ranges from well-being when their health condition is good in spite of the heart disease and a functioning ICD-device to unwellness when their heart disease and the ICD-device cause infirmity, memory disturbances and discomfort.

*Quote from the positive pole (interview 14)*

I think that the ICD has meant an improvement for me. I actually feel better because I don't get breathless as quickly as before. But I'm not sure if it's because of that. I've thought about it several times, if it's because of those threads that they implanted that I've gradually become better. I get breathless now too if I walk up hills, but I can move more easily now than before, so it has been a good thing and, still, nothing has really been done. That's what's so remarkable. My temper has calmed down, too. I was a bit more fiery previously. I used to snap at people immediately when there was something that annoyed me but somehow I've got over it.

*Quote from the negative pole (interview 8)*

I always want to test myself, how much I can take and I'm not afraid to do it either. I think that I will go on driving myself until the device breaks my heart to pieces... because I think I'm fairly OK now but my brain hasn't caught on yet that I'm not... but I have calmed down a little, I think, I don't have the strength luckily, luckily, you see. I've got two things to struggle with, diabetes and this device... and it's not possible to say at once that it was because of this or that when you're going down the slope. And I suppose I'm more confused than I was before, so let's say probably. A bad memory. My short-term memory is gone, I think, it's gone. It's probably a result of my being gone for so long, but I've certainly lost something.

**HAVING A NETWORK (INTERVIEWS 1,3-5,7-12,15)**

This category describes the conception in which patients have a network of social contacts after having had the ICD-device implanted. The conception is concerned with how supportive the network is and ranges from a helpful and understanding network of family, friends and health-care professionals to a weak, unappreciative and indifferent network, resulting in a feeling of loneliness and a need for professional psychological support.

*Quote from the positive pole (interview 7)*

When I was in the hospital, my wife was so strong, I can't understand that she could be so strong. She managed it splendidly, and I've never seen her sad. I've got many friends too, we travel together to different places, and in the summer we walk in the woods picking berries and mushrooms... Well, I've definitely got many people who support me.

*Quote from the negative pole (interview 3)*

I was given a bunch of papers that I was told to read, information about the device, etc., but nobody has ever asked me how I feel. I've never been offered any help in the form of therapy conversations, support conversations or similar. That I find unsatisfactory, after all, a person who has been so close to... I could just as well have died, it was just very lucky that I managed, it affects one...

#### HAVING A BELIEF IN THE FUTURE (INTERVIEWS 1,2,4-13,15)

This category describes the conception in which patients believe in the future related to the heart disease and the ICD-device. The conception is concerned with outlook on life and existing possibilities and ranges from hope and confidence that life must go on to anxiety and resignation that the best part of life is behind.

*Quote from the positive pole (interview 13)*

At the social service office they think that I'm sick-listed for too long, so they want to give me early retirement pension. Well, I've been sick-listed for so long that I don't care. I've got my summer cottage and hobbies and... Well, I can see no limitations. It's no different but one has to take it a bit easy in the beginning.

*Quote from the negative pole (interview 6)*

Well, there's not very much that I'm looking forward to, I suppose the only thing to do is to wait until they take me out, feet first... I don't know, after all one is so old now that there isn't very much to look forward to. Of course, one knows that that's the road ahead... but of course, if one's private finances improved... it was a staggering blow to me that I'm not fit to work. I mean it upsets everything. It's because one loses so terribly much from falling ill.

## GAINING AWARENESS (INTERVIEW 1-15)

This category describes the conception in which patients gain an awareness of their life situation related to their heart disease and ICD-device. The conception is concerned with the ability to adapt to one's life as it is and ranges from having accepted it and made the best of the situation to denial and a feeling of limitation in one's life because of the heart disease and ICD-device.

*Quote from the positive pole (interview 5)*

I feel quite normal, I sure do, besides having to engage less in sports I live quite a normal life... but when it comes to career and work, they are not so important any longer.

*Quote from the negative pole (interview 12)*

It's not a bit logical, but I feel violated as a person at not being able to do what I used to do, not to have the agility, to have to think beforehand, do I have the strength to go down there now or... I've been in situations where I have been forced, struggled enormously to get up the hills. It feels very depressing. Then one feels sad several days afterwards. In one way the ICD reminds me that I'm ill.

## Discussion

### METHODOLOGICAL ISSUES

The aim of the study was to describe how phenomena in the environment are conceived, and therefore it was appropriate to employ a method in which the interview was the essential ingredient (Patton, 1990). The phenomenographic approach, or its varieties, is considered to be highly applicable when the aim has been reached and the findings have led to categories which describe different conceptions (Marton & Booth, 1997). A limitation with qualitative research is the impracticality of using large, representative samples for obtaining data. The extent to which the findings can be generalized may therefore be called into question (Polit & Hungler, 1991). However, due to the strategic selection capturing the breadth of the ICD-patients, the information value of the findings ought to be high concerning such patients (Fridlund, 1998). Saturation of the conceptions was reached before all interviews had been completed, which increases the plausibility and validity of the results (Taylor & Bogdan, 1984). However, if more patients had been interviewed, an even larger range of poles regarding categories would

possibly have emerged. On the other hand, with more data there is a risk that the analysis becomes superficial, which would undermine the aim of the work. Reliability of the analytical work is based on the trustworthiness of the data compilation and interpretation (Patton, 1990). Trustworthiness of the findings can be understood in terms of well-prepared researchers from different healthcare professions who discussed the statements and categories in a positive, reflective and systematic manner. In order to increase the accuracy of the study, only one interviewer was used to transcribe the text following each interview. Likewise, one interviewer was used to minimize sources of error such as erroneous interpretations of facts in the interview data (Taylor & Bogdan, 1984). The integrity and dignity of the patients have been respected through asking them for their consent to participate in the study, through the interviews as such, through the storing of the study data, and through the presentation of the findings.

#### LIFE SITUATION ISSUES

The findings show that all five dimensions of the life situation according to Sarvimäki & Stenbock-Hult's (1993) holistic concept – the biophysical, the emotional, the intellectual, the socio-cultural and the spiritual-existential – are present and represented in ICD-patients' conceptions, as Table 2 illustrates. However, again the findings demonstrate how difficult it is, if it is at all possible, to divide a person into parts (Keegan & Keegan, 1992). Furthermore, the findings that have emerged from this study are not surprising and quite reasonable conceptions of living with a life-threatening disease which is treated with such a technically complicated device as the ICD. No such study has been carried out before in Europe or Scandinavia, only in the USA (Dunbar *et al.*, 1993; Burke, 1996; Dougherty, 1997), but there are similarities between the US studies and this one.

The conceptions of the experienced life situation are of great interest. In comparison with both quantitative and qualitative studies (e.g. Schuster *et al.*, 1998), the conceptions describe a complex life situation after ICD-implantation, which is naturally affected by the underlying life-threatening disease, but which also includes both beneficial and intrusive effects in line with Burke's qualitative study (1996). In the present study the conceptions describe intrusive effects such as grief that results from needing an ICD as well as suffering infirmity and discomfort due to it. Life becomes limited due to the ICD, which also creates fear of over-exertion triggering an electric shock, an emotional reaction also to be found in Dunbar *et al.*'s qualitative study (1993). A lack of social relations of both a lay and professional character, when anxiety and resignation increase due to 'bad' thoughts that the best part of life is past, generates a feeling of unwellness. On the other hand, and with regard to the beneficial effects, ICD-patients gain a feeling of safety and recognition from having the ICD implanted. Together with a supportive network comprised of family, friends, work colleagues and healthcare professionals (Dunbar *et al.*, 1993; Dougherty, 1997; Heller *et al.*, 1998), these patients make the best of their life situation. This involves hope and confidence in the future and in the long run brings well-being.

From a healthcare intervention perspective, it becomes very obvious that ICD-patients manage their life situation and are supported by their environment very differently. The role of healthcare professionals must be to assess the ICD-patient's life situation and where he or she is positioned in terms of the positive and negative poles of the life dimensions. As Dougherty's qualitative study (1997) implies, it is of equal importance that the ICD-patient's family members are also assessed in the same manner, as it is they who support patients most. Another support group of great importance is the healthcare

**Table 2** Schematic description of conceptions among patients with implantable cardioverter-defibrillators regarding their life-situation, mapped against Sarvimäki & Stenbock-Hult's (1993) holistic concept

| Conceptions                   | Life situation |           |              |                |                       |
|-------------------------------|----------------|-----------|--------------|----------------|-----------------------|
|                               | Biophysical    | Emotional | Intellectual | Socio-cultural | Spiritual-existential |
| Feeling of safety             | X              | X         | X            |                |                       |
| Feeling of gratitude          |                | X         | X            |                |                       |
| Feeling of being              | X              | X         | X            | X              | X                     |
| Having a network              |                | X         | X            | X              |                       |
| Having a belief in the future |                | X         | X            |                | X                     |
| Gaining awareness             |                | X         | X            |                | X                     |

professionals who are expected to give ICD-patients skilful and reliable answers, i.e. personnel in hospitals as well as in primary healthcare. All these groups need information, guidance and further education regarding what an ICD is and how to live with it, as well as how to treat such a device with regard to all five life dimensions conceived by the ICD-patients. Today very few healthcare centres in Europe, if any, offer such possibilities but ICD-patients have attracted more attention in the USA (Dougherty, 1997).

#### CONCLUSION AND IMPLICATIONS

The findings of this Swedish qualitative study seem not to differ to any significant extent from those from the US regarding the life situation of patients living with an ICD. Six conceptions emerged: a feeling of safety, a feeling of gratitude, a feeling of being, having a network, having a belief in the future, and gaining awareness. Even if the findings cannot be generalized due to the descriptive research design, they can illuminate the beneficial and intrusive effects of such a device, i.e. how well patients cope with the ICD as well as how well they are supported by lay people and healthcare professionals. The findings highlight the need for support groups for patients and families as well as further education for personnel in hospital and primary healthcare. It would therefore be of great value to study such interventions under controlled design conditions.

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