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# **Living with life-saving technology**

**Long-term follow up of recipients  
with implantable cardioverter defibrillator**

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Akademisk avhandling

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## ABSTRACT

The evidence that treatment of life-threatening arrhythmia (LTA) with an Implantable Cardioverter Defibrillator (ICD) can prolong life is convincing. Living with a lifelong heart disease will gradually influence the everyday life and encompasses some or all aspects of life. In order to influence health outcomes, the impact of the ICD must be considered in a broader context including not only the physical, but also the psychological and social functioning of the individual.

The general aim of this thesis was to describe everyday life in recipients living with an ICD in a long-term perspective. The aim in Paper I was to describe changes in the life situation of recipients' with an ICD over a period of 1 year. The aim in Paper II was to describe quality of life (QOL) and uncertainty in recipients who have an ICD and to predict QOL at long-term follow-up. Fifty-six recipients participated (I) and 35 of these recipients, who had survived at least five years, were further included (II). The Quality of Life Index-Cardiac version (I, II), Mishel Uncertainty in Illness Scale-Community version (I, II), Patient ICD Questionnaire (I) and multiple regression analysis (II) were used. Higher scores indicate higher QOL and uncertainty. The questionnaires were completed before implantation, three and twelve months after implantation (I) and also five years after implantation i.e. long-term follow up (II). At the long-term follow up, the average ICD recipient had lived with an ICD for six years and nine months (6.9 years). The results showed the overall QOL and QOL in the health/functioning domain were unchanged over time. QOL in the socio-economic ( $p = .002$ ) and psychological/spiritual domains ( $p = .012$ ) decreased in the first year. From baseline to long-term follow up, the QOL in the family domain ( $p = .011$ ) and overall uncertainty ( $p = .002$ ) decreased. Uncertainty related to the information decreased at year 1 in relation to baseline ( $p = .001$ ).

The aim in Paper III was to illuminate the main concern of recipients living with an ICD and how they handle this in their daily life. Sixteen recipients who had lived with an ICD between six to twenty-four months were interviewed. Data was collected and analysed in a simultaneous process according to guidelines for classical grounded theory. In the analysis, a substantive theory was generated explaining the main concern of ICD recipients and how they handle this in their daily life. The core category, labelled "Striving to resume command", illuminates the main concern of ICD recipients. To manage this main concern, the recipients used the following strategies: Economizing resources, Distracting oneself, Submitting to one's fate and Re-evaluating life.

The aim in Paper IV was to explore relationships between QOL, coping strategies, anxiety, depression and perceived control in recipients living with an ICD and to compare those having received an ICD less or more than one year ago and those with a primary or secondary preventive indication. A cross-sectional, correlational, multicenter design was used, and 147 recipients who had lived with an ICD between six to twenty-four months completed Quality of Life Index-Cardiac version, Jalowiec Coping Scale, Hospital Anxiety and Depression Scale and Control Attitude Scale. The results showed that anxiety, depression and perceived control were predictors of QOL. Anxiety was also a predictor of coping with optimistic coping being the most used coping strategy. There was no relationship between QOL and coping. No differences were found in QOL, coping, anxiety, depression and perceived control between recipients implanted either on a primary or secondary preventive indication or having the device less or more than one year.

In this thesis, it was concluded that the ICD recipients strived to resume command over their life (III) and the more control the recipients perceived the more satisfied they were with their QOL (IV) and the more symptoms of anxiety, depression and uncertainty they experienced the less satisfied they were with their QOL (II, IV). Coping strategies were used more frequently by ICD recipient perceiving more anxiety (IV). QOL was fairly good 6,9 years after implantation and ICD recipients felt less uncertain once they had passed the first year of their illness.

Keywords: anxiety, arrhythmia, defibrillators, depression, grounded theory, perceived control, qualitative, quality of life, uncertainty.

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