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Psychological distress in patients with an implantable cardioverter defibrillator and their partners

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ABSTRACT

Objectives: Adjustment to life with an implantable cardioverter defibrillator (ICD) may be challenging for some patients and their partners, with disease and individual characteristics likely influencing the process. We examined whether perceived social support and clinical patient characteristics are associated with change in couples' symptoms of anxiety and depression in the first year after ICD implantation, and explored whether the associations differ between patients and partners.

Method: A cohort of consecutively implanted patients (n = 286; 21% women) and their partners completed questionnaires on social support and symptoms of anxiety and depression prior to ICD implantation and 12 months later. Information on demographic and clinical characteristics were captured from patients' medical records or purpose-designed questions. Data were analyzed using multilevel models accounting for the interdependency of scores within couples with adjustment for possible confounders.

Results: Higher ratings of perceived social support prior to ICD implantation were associated with greater reductions in couples' symptoms of anxiety and depression, whereas having received an ICD shock was associated with less improvement. Secondary prevention indication for ICD implantation and symptomatic heart failure were associated with less improvement in anxiety symptoms. These associations applied to both patients' and partners' levels of distress.

Conclusion: The patient's heart disease affects both patients' and partners' psychological adjustment in the first year after ICD implantation. Interventions are warranted that address this issue not only in patients but also in partners. Targeting social support as a resource for both could be one avenue to pursue.

1. Introduction

The implantable cardioverter defibrillator (ICD) is implanted in patients who are at risk for or have survived a sudden cardiac arrest [1]. The medical benefits of ICD treatment are unequivocal, yet the challenges of living with an ICD and underlying heart disease may contribute to psychological distress (i.e. symptoms of anxiety and depression) in both patients and their intimate partners due to the fear of dying or losing a partner, fear of the device giving shocks, limitations to daily routines, and changes in the family dynamic [2, 3]. In that sense the implantation of an ICD and the underlying heart disease can be seen as a "dyadic issue" affecting both the patient and the partner among partnered ICD patients [4].

Of implanted patients with an ICD, 20–30% report significant levels of anxiety and depression [5, 6]. Partners report equal levels of depression and equal or higher levels of anxiety as the patients themselves [6, 7]. Both patients' [5, 8] and partners' [7] distress tends to decrease during the first year after implantation, however, not all studies consistently find decreases [3, 5, 6], and further studies are needed to determine change in symptoms over time [5, 7]. Distress may impair patients' quality of life, pose as barriers to lifestyle changes, and increase their risk of non-adherence to treatment, dropping out of the

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labor market, hospitalizations, life-threatening arrhythmias and premature death [9–11]. Individuals who develop anxiety and depression (e.g. partners) have a similar greater risk for morbidity and mortality [12, 13]. Distress in partners may further impair the quality of support that they provide to the patient [14] and may thus also have a detrimental effect on the patient's wellbeing. Hence, knowledge about factors affecting distress is crucial to identify and target vulnerable patients and partners.

Both available social support and clinical characteristics may influence the adjustment process of patients and partners after ICD implantation. The general literature has established that social support can be a resource in times of stress and act as protection against the full impact of illness [15, 16]. Perceived social support (i.e. one's perception that family and friends would provide effective help during stressful times [17]) has in particular been related to beneficial health outcomes [18]. In line with this, ICD patients with low perceived support have reported higher distress levels [19]. ICD patients and their partners have been shown to be at higher risk for poor social support than heart failure patients [20]. Thus, with social support likely being a resource for ICD partners, it is important to also examine the role of perceived social support in the psychological adjustment process of partners to ICD patients.

Clinical characteristics can be indicators of patients' health status and prognosis that may represent additional strains and challenges and possibly influence patients' and partners' adjustment to the ICD. However, the role of shocks in patients' distress has been debated [21–23], and findings have been inconsistent [5, 6]. With respect to indication for device placement (primary vs. secondary prevention) and other heart-related comorbidities, findings in the literature are similarly inconsistent [5, 6]. Few studies have focused on the role of these clinical characteristics in partners' distress [6, 7]. In 2010, a systematic review concluded that the evidence for the influence of shocks on partners' distress was mixed, while partners' distress levels were higher if patients received the ICD for secondary prevention purposes [7]. A more recent large-scale study found no associations of clinical patient characteristics with partners' distress [6]. Thus, more large-scale studies are needed to further investigate determinants of distress in patients' and partners' adjustment process [5, 7].

The present research is based on data from the prospective cohort study entitled Mood and personality as precipitants of arrhythmia in patients with an Implantable Cardioverter Defibrillator: A prospective Study (MIDAS), which includes ICD patients and their partners. One previous MIDAS-paper has focused on partners' distress over time: Based on 196 couples at ICD implantation and 6 months later, Pedersen et al. [24] found increased anxiety levels in partners compared to patients; determinants of partners' distress included patient clinical characteristics, mainly secondary prevention indication. Previous MIDAS-papers focusing on patients suggest that most change in mental health measures occurs within the first months after ICD implantation [25–27]; that perceived social support is a determinant of patients' trajectory of anxiety throughout the first year after implantation [27]; and that clinical factors, such as ICD-shock, secondary prevention indication and symptomatic heart failure are associated with higher distress levels [28, 29], but not consistently so [27], possibly depending on the analytical approach and assessment instruments.

The purpose of the present study is (i) to examine whether perceived social support assessed at the time of ICD implantation and clinical patient characteristics are associated with change in couples' symptoms of anxiety and depression throughout the first year after ICD implantation and (ii) to explore whether the associations differ between patients and partners. We hypothesize (i) that higher degrees of perceived social support are associated with a greater decrease in symptoms of anxiety and depression in both patients and partners, and (ii) that a higher disease burden (as measured by ICD indication, experience of shocks, symptomatic heart failure and coronary artery disease) is associated with less decrease in symptoms of anxiety and depression in both patients and partners over time.

In difference to previous MIDAS-studies, the present study adopts a dyadic approach that examines associations of social support and clinical characteristics with changes in distress in both patients and partners simultaneously, using multilevel models that account for the interdependency of scores within couples. It adds to the literature by examining the association between social support and change in distress in partners, and can further our understanding of the role of patient clinical factors in patients' and partners' distress.

2. Methods

2.1. Procedure

Consecutively implanted patients with an ICD at the Erasmus Medical Center, Rotterdam, the Netherlands, and their partners were enrolled in the MIDAS-study between August 2003 and February 2010. Only patients who had a partner were included in the analyses. Inclusion criteria were patients aged ≥18 having their first ICD implant. Patients were excluded if they, had a life-expectancy < 1 year, were on the waiting list for heart transplantation, had a history of psychiatric illness other than affective/anxiety disorders, or had insufficient knowledge of the Dutch language. Partners were ineligible if they did not have sufficient knowledge of the Dutch language to complete questionnaires.

Prior to ICD implantation, an ICD nurse provided oral and written information about the study to the patient. If the partner was not present at the time of the inclusion of the patient, the patient was asked to invite his/her partner to participate. If both patient and partner provided written informed consent, they were asked to separately complete a similar set of standardized and validated questionnaires at baseline (i.e. one day prior to implantation), and at 10 days, 3, 6 and 12 months post implantation. The present study focuses on the baseline assessment (Time 1, T1) and the 12-months assessment (Time 2, T2) to examine change in anxiety and depression from baseline to one-year post implantation, where patients' distress levels seem to have reached a plateau [25].

The study was conducted according to the Helsinki Declaration and approved by the Medical Ethics Committee of the Erasmus Medical Center (MEC 231.491/2003/148). The University of Southern Denmark (SDU) is the controller for processing of personal data in connection with the project, which has been included in SDU's internal record of processing activities under file number [SDU 17/599964], cf. GDPR Article 30.

2.2. Measures

All measures were obtained for both patients and partners unless otherwise specified.

2.2.1. Symptoms of anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) was used to measure symptoms of anxiety and depression [30] at baseline and 12-months follow-up. Two subscales assess anxiety (HADS-A) and depression (HADS-D) by means of 7 items each. Items are scored on 4-point Likert scales with scores ranging from 0 to 3 and total scores ranging from 0 to 21. Higher scores indicate more symptoms. The HADS has been validated in both the general population and clinical samples [31]. In our sample, Cronbach's alpha ranged from 0.83 to 0.87 for patients and from 0.86 to 0.88 for partners. The outcomes in the present investigation were change in symptoms of anxiety and depression. A change score was computed for both symptoms of anxiety and depression by subtracting the 12-months score from the baseline score. A positive change score indicates decreases in symptoms of anxiety or depression, respectively, i.e. better psychological functioning, at 12-months follow-up.