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Self Care and Psychological Function in Cardiopulmonary Patients

A comparison of the health status and psychological distress of partners of patients with a left ventricular assist device versus an implantable cardioverter defibrillator: A preliminary study

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ABSTRACT

Objective: To examine if the caregiving for patients with a left ventricular assist device (LVAD) is related to a poorer health status and more distress compared to patients with an implantable cardioverter defibrillator (ICD).
Background: Partners distress may influence patient outcomes and is therefore an important aspect in the care of LVAD and ICD patients.
Methods: Multi-center prospective observational study with 6 months follow-up of 33 LVAD partners (27% men; mean age $= 54 \pm 10$ years) and 414 ICD partners (22% men; mean age $= 60 \pm 12$ years).
Results: LVAD partners reported better physical ($F = 10.71$, $p = .001$) but poorer mental health status ($F = 14.82$, $p < .001$) and higher depression scores compared to ICD partners ($F = 3.68$, $p = .05$) at 6 months follow-up, also in adjusted analyses. There was no significant difference between groups on anxiety.
Conclusion: Caregivers of LVAD patients show higher distress levels compared to caregivers of ICD patients. LVAD partners may have a need for support beyond what is offered currently in clinical practice.
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Introduction

Living with chronic heart disease comprises a significant challenge to both patients and their partners, resulting in a subgroup of patients and partners who may suffer from poor health status and psychological distress.[1,2] Studies in ICD patients and their partners have shown that the psychological distress level of partners is at least equal to or even higher than the distress levels of patients.[3,4] This is not surprising considering that caregiving is known to affect caregivers' physical and mental health, family relationships, employment, personal freedom, sexual functioning, and financial circumstances.[5] Furthermore, partners tend to take on the role as caregiver automatically without regard to the possible consequences for themselves. Partners are also a major source of support for the patient. Previous studies found that emotional distress in partners may influence patients' treatment adherence, psychological adjustment and prognosis.[3,6,7] As a result, there is a shift in the treatment and care of patients toward an approach of family-centered care, in which health care providers also involve the patients' close relatives.[8]

Psychological distress in the partner seems to be influenced by age, gender and personality (i.e., Type D personality).[4,9] Type D

personality refers to the joint presence of two broad and normal personality traits, namely negative affectivity and social inhibition, with individuals with this personality disposition experiencing a broad range of negative emotions while not expressing and sharing them with others.[10] Van den Broek et al found that Type D personality in partners of ICD patients enhanced the risk of emotional distress in the ICD partners as well as the patients.[11] In addition, psychological distress can be influenced by the use of psychotropic medication. In ICD patients it was found that patients experiencing distress but without psychotropic treatment reported a significantly poorer health status than patients without distress and psychotropic treatment or compared to patients without emotional distress who did receive psychotropic treatment.[12]

In comparison to studies on distress in partners of patients with an implantable cardioverter defibrillator (ICD) or heart failure patients, only a paucity of studies have examined the experience of caregivers of patients with left ventricular assist device (LVAD) support.[9,13] LVADs are mechanical circulatory implantable devices that are able to partially or completely replace the function of a failing heart by maintaining blood circulation and vital organ perfusion.[14] LVADs are increasingly used for patients with advanced heart failure whose medical treatment options have been exhausted. It is a complex treatment with a high risk for complications, such as infection, bleeding and thromboembolism, and that requires an extended hospital stay and specific device training.[15] Furthermore, caregiving for an LVAD patient at home is a considerable commitment with responsibilities that may vary from simple tasks, such as monitoring of vital signs, weight, and sterile dressing changes, to more complex procedures, such as monitoring of LVAD function, troubleshooting when alarms go off, and responding to emergency situations.[16] A small number of qualitative studies have found that the burden of caregivers of LVAD patients is large, both at a physical and psychological level.[8,13,16,17]

To our knowledge, no study has compared the functioning of LVAD partners with partners of other cardiac conditions in order to examine if the complexity of care associated with an LVAD leads to poorer health status and more distress compared to partners of other cardiac patients. Although comparing LVAD partners to partners with other cardiac conditions is difficult, mainly because LVAD patients are sicker than most other cardiac patients, it is important as it may identify potential targets that may improve the care for LVAD patients and their families. For this study the partners of ICD patients were selected as a comparison group to partners of LVAD partners since they are both confronted with the potentially life-threatening disease of their partner and are both likely to be uncertain about how to help their partner during recovery, and about the activities that their partner can engage in without eliciting pain or provoking shocks. Hence, this study is an initial exploration to examine to which extent the caregiving for patients with a left ventricular assist device (LVAD) is different to the caregiving for patients with an implantable cardioverter defibrillator (ICD), as reflected by a difference in health status and distress.

Methods

Study population and design

Partners of patients who underwent implantation with an axial-flow HeartMate II LVAD (Thoratec) or centrifugal-flow HVAD (HeartWare) as bridge-to-transplant were eligible for study participation, and were recruited from the University Medical Center, Utrecht and the Erasmus Medical Center, Rotterdam, the Netherlands and the Heart Center at St. Paul's Hospital in Vancouver, Canada, between January 2011 and February 2013. The comparison cohort consisted of partners of patients receiving an

ICD implantation between August 2003 and February 2010 at the Erasmus Medical Center, Rotterdam, the Netherlands, who took part in the MIDAS study (*Mood* and personality as precipitants of arrhythmia in patients with an *Implantable cardioverter Defibrillator: A prospective Study*).[2] In both studies, the partners of the patients were almost always also their caregiver. In the case that the partner and the caregiver were not the same person, which was due to various reasons (i.e. physically incapable), both the partner and the caregiver were enrolled in the study.

Both study protocols were approved by the Medical Ethics Committees of the Erasmus Medical Center, Rotterdam, the Netherlands. The study was conducted in accordance with the most recent version of the Helsinki Declaration (2008). Every patient was informed about the study both orally and in writing and provided written informed consent.

The inclusion criteria were similar for both cohorts. Partners were eligible for inclusion only if the patient consented, were ≥18 years of age, were sufficiently proficient in the Dutch or English language to be able to complete the study questionnaires and had no history of psychiatric illness other than cognitive-affective disorders. For LVAD patients, data collection of the partners stopped once the LVAD patients deceased or received a heart transplantation.

Both cohorts of partners were asked to complete a set of standardized and validated questionnaires at baseline (LVAD partners: 3–4 weeks; ICD partners: 1 day prior to ICD implantation) and a 3- and 6 months follow-up. The baseline assessment of the LVAD partners was performed when the LVAD patients were given the LVAD-training just prior to hospital discharge. The follow-up assessments were scheduled at the same time points as the patients' visits to the outpatient clinic. The questionnaires were returned in stamped and pre-addressed envelopes. If the questionnaires were not returned within two weeks, partners received a reminder telephone call or letter. Participants were ensured that their results would not be shared with their significant others.

Measures

Demographic and clinical variables

Information on demographic variables included sex, age, marital status, and educational level. Information on clinical variables included the use of psychotropic medication and smoking. All were assessed by means of purpose-designed questions in the questionnaires.

Health status

Health status was measured using the 12-item Short Form Health Survey (SF-12), with these 12 questions overlapping with the SF-36. Scoring algorithms are applied to produce the Physical Component Summary (PCS) and Mental Component Summary (MCS) scores.[18] The score ranges from 0 to 100, with 100 being the best possible health status. Test-retest (2-week) correlations of .89 and .76 were observed for the PCS and the MSC, respectively, in the general US population ($n = 232$). Reliability statistics of the MCS and PCS scales is good with a Cronbach's alpha of .84 and .87, respectively.[19]

Symptoms of anxiety and depression

The 14-item Hospital Anxiety and Depression Scale (HADS) was used to assess symptoms of depression and anxiety. Items are answered on a four-point Likert Scale from 0 to 3 (score range 0–21). The HADS is a valid and reliable measure, with good internal consistency (Cronbach's α HADS-A = .80, HADS-D = .81).[20,21] We used a cut-off of ≥8 to indicate the presence of clinically relevant levels of anxiety and depression, as this has been found in large-scale studies to be the optimal cut off.[22] The HADS has shown to