Caregiver burden in partners of Heart Failure patients; limited influence of disease severity

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Abstract

Background: In complying with required life style changes Heart Failure (HF) patients often depend on their partners. However providing care may cause burden and affect the health of these partners. The aim of this study was to investigate determinants of caregiver burden in order to identify caregivers who are at risk.

Methods: Using a cross-sectional design, caregiver burden and potential determinants were measured in partners of HF patients. Demographic and clinical data were assessed in HF patients, partners completed questionnaires on caregiver burden (the Caregiver Reaction Assessment, CRA), caregiving tasks performed, physical and mental health status and quality of the marital relationship.

Results: In total 357 partners (75% female, mean age 67 years) participated. The physical health status of HF patients was only significantly associated with two domains of caregiver burden, ‘disruption of daily schedule’ (p<0.01) and ‘loss of physical strength’ (p<0.01). No associations were found with age, co-morbidity and LVEF. All domains of the CRA were mainly associated with the partner’s own mental health (p<0.01) and with providing personal care to HF patients (p<0.01). Gender differences were only found with regard to the domain of ‘feeling a lack of family support’.

Conclusion: The assessment of caregiver burden should focus on the mental strength of partners. Furthermore when assistance in personal care is needed, additional support, either informal or professional, may be indicated.

Keywords: Caregiver; Partners; Burden; Heart Failure; Disease severity

1. Introduction

Managing the consequences of Heart Failure (HF) is a complex issue for patients [1] and social support, especially the support of a partner is essential. The availability of supportive relationships has been shown to affect patient outcome in terms of quality of life [2] re-hospitalisation rates [3,4] and mortality [3–5].

However, the burden of providing care to a chronically ill partner affects the health and well being of these partners. Research in populations with varying chronic conditions has shown that providing care to a chronically ill family member contributes to physical morbidity and even to mortality in caregivers [6,7]. The results of the few studies that have been conducted within the field of HF, indicate increased levels of psychosocial distress [6,8,9], decreased levels of well-being [10,11] and impaired Quality of Life [12]. These adverse effects may eventually undermine the capacity of the couple to cope with the disease.

Because of the beneficial effects on patient outcome, partners of patients with HF warrant the attention of health
care providers. Better understanding of caregiver burden and its determinants is essential to identify and support caregivers who are at risk.

Clinicians in general are primarily involved with treating the patient, and the patient’s environment is often considered from the patient’s perspective. From that point of view it seems logical to assume that more severe HF will indicate higher levels of impairment, placing more demands on the caregiver which will cause increased caregiver burden. However, from research in other chronically ill populations it is known that disease severity is only partly associated with caregiver burden [13]. Within the field of HF conflicting results on the relationship between severity of HF and caregiver burden have been reported [8,9,14–16].

Although it seems evident that the level of patient impairment is directly related to the amount of caregiving tasks, the effect of different types of task on the burden experienced by caregivers is less clear. Caregiving tasks and feelings of burden are only moderately associated and the same amount of caregiving tasks may result in different levels of caregiver burden [17].

In studying determinants of caregiver burden, other variables have to be considered as well. Demographic factors such as gender [8,9,18–20] and age [6,16,20] are known to be related to caregiver burden. Furthermore the partner’s own physical and mental health status is expected to be associated with feelings of caregiver burden [13].

The purpose of this study was to investigate the relative impact of disease severity, objective caregiving demands and caregiver characteristics, on levels of subjective caregiver burden.

2. Methods

2.1. Subjects

The study population consisted of partners of HF patients who participated in the Dutch NHS-COACH trial on the effects of advising and counseling in HF patients [21]. In summary, the following inclusion and exclusion criteria were used. All patients were admitted for HF (NYHA II–IV). Patients were at least 18 years of age, with evidence of structural underlying heart disease. All partners, independent of randomisation group, were approached 12 months after the HF patient was discharged from the initial hospitalisation. There were no specific inclusion or exclusion criteria for partners except that they had to be able and willing to complete a questionnaire.

2.2. Procedure

Baseline clinical data and demographics for all Heart Failure patients were collected by chart review and patient interview during the initial hospital admission. One year after patient discharge, partners were sent a self-report questionnaire at home, which they were asked to complete independently from the patient. Additional data on the patient’s health status at 12 months were collected during visits to the outpatient clinic. Independent interviewers collected the questionnaires by visiting partners at home.

3. Measurements

3.1. Outcome variable

Since there are no instruments available that measure caregiver burden in the HF population, a generic measure on subjective caregiver burden was used. Perceived caregiver burden was assessed by the Caregiver Reaction Assessment scale (CRA) [22]. This instrument was developed and tested in a study conducted by Given et al. [22] among caregivers of elderly patients with various disorders, the study revealed good psychometric properties. The CRA was translated into Dutch and its psychometric qualities were tested in a population of partners of cancer patients. Construct validity was supported and reliability proved to be sufficient with Cronbach’s alpha scores for the subscales varying between 0.62 and 0.83 [23]. The CRA consists of subscales which reflect different domains of caregiver burden and can be used independently. For each subscale, the total score was computed as the average of the subsequent item scores, ranging from 1.0–5.0, with a higher score representing a higher burden. The domain ‘disrupted daily schedule’ (5 items) measures the extent to which caregiving interrupts the caregiver’s own daily activities. ‘Lack of family support’ (5 items) measures the extent to which the caregiver experiences a shortage of family support and feels that taking care of the patient is his or her exclusive responsibility. The domain ‘loss of physical strength’ (4 items) assesses the impact of caregiving on the physical health of the caregiver.

3.2. Independent variables

Severity of Heart Failure was assessed in patients using several different measures. Left Ventricular Ejection Fraction (LVEF) was assessed at baseline in the NHS-COACH trial by echocardiography [24]. To assess physical health status we used the RAND 36 questionnaire which is comparable to the SF36 and widely used to assess general health [25]. Data were assessed 12 months after discharge from the initial hospitalisation. Scores on the physical functioning subscale range from 0–100 with 100 indicating optimal physical condition.

Also the duration of HF and the number of co-morbidities were assessed.

The performed caregiving tasks were assessed by the Dutch Objective Burden Inventory (DOBI). The DOBI assesses 38 different kinds of caregiving tasks which can be divided into 4 domains; personal care (11 items), treatment related (practical) assistance (11 items), emotional support (6 items) and motivational support (10 items). For each domain a total score was computed as the average of the
validity of the subscales [26].

Demographic variables (age, gender and educational level) of patients and their partners were assessed during baseline interviews with the patient. Caregiver’s health status was assessed using two subscales of the RAND 36 questionnaire on general health, the subscales on physical functioning and mental functioning [25].

The partner’s perception of the quality of the marital relationship was assessed using a Ladder ranging from 0 to 10 based on the Cantril’s Ladder [27]. A score of 10 represents the best imaginable quality of the relationship, 0 represents the worst imaginable relationship. A global measure of relationship quality allows respondents to base their judgements on aspects of their relationship that are most important to them [28].

4. Statistics

All data were entered into an SPSS database and analysed using descriptive statistics to describe the study population. For number of co-morbidities, we included diabetes, rheumatic diseases, stroke and COPD as categorical variables. Continuous variables that were not normally distributed were categorized in dichotomous or categorical variables. First differences in caregiver burden scores were tested univariately by using univariate regression analysis for the continuous variables and t-tests and one-way ANOVA for dichotomous and categorical variables. The general linear model module of SPSS was used to build three different models, with each subscale of the CRA as the dependent variable. The variables for which burden scores univariately differed significantly \( p = 0.05 \) were entered into the linear model, using the enter method. Gender was forced into all three regression analyses because of its known effect on caregiver burden.

5. Results

5.1. Responses

In total 403 questionnaires were sent out between February 2003 and November 2005. Thirteen partners (3%) appeared unable to complete the questionnaire because of their own deteriorated health status. Ten (2%) partners indicated that it was too much trouble or it was perceived as a stressful confrontation and in 10 cases (2%), reasons for non-response remained unclear. In total 370 (92%) questionnaires were returned, thirteen questionnaires (3%) were incomplete and could not be used.

5.2. Study population

The study population consisted of 357 HF partners. Partners and patients had a mean age of 67 and 68 years respectively. Partners were predominantly female (75%), most couples (96%) were married and thirteen couples were living together (not married). Fifty-four percent of the HF partners had a low (no education–primary school–vocational school) educational level. As shown in Table 1, the mean left ventricular ejection fraction of HF patients was 32% and the mean patient score on the subscale Physical Functioning of the RAND 36 was 48.5 (±29). Forty-five percent of the HF patients had one or more co-morbidities such as diabetes (22%) and COPD (25%). All patients were non-hospitalised at the time of the partner questionnaire.

Partners of HF patients provide care by performing many different caregiving tasks as measured by the Dutch Objective Burden Inventory. The main emphasis is on practical and treatment related tasks such as achieving medication or observing HF symptoms, and on providing emotional support. Partners of HF patients do not perform many personal care tasks such as bathing and dressing.

Highest scores on the Caregiver Reaction Assessment scale (2.3) were present within the domains ‘disrupted daily schedule’ and ‘loss of physical strength’, the lowest score (2.2) was for ‘lack of family support’. In total 23% of the HF partners indicated disruption in daily activities because of their caregiving responsibilities. Sixteen percent indicated a lack of family support and 20% indicated a loss of physical strength as a result of the caregiving process.

5.3. Univariate analysis

As shown in Table 2, the most prominent differences in caregiver burden scores were found for partner characteristics. Low physical functioning, low mental health and low perception of the marital relationship of partners revealed
significantly higher caregiver burden scores. The performance of different kinds of caregiving tasks resulted in significantly different caregiver burden scores for all three CRA domains. In reference to patient characteristics, limited differences were found for severity of disease, in terms of physical functioning and duration of HF. No differences were found for LVEF, co-morbidity and age.

5.4. Multivariate regression analysis

The variables that added significant value to the multivariable model of ‘disrupted daily schedule’ were: severity of HF in terms of physical functioning ($\beta=-0.14$, $p<0.001$ per 25 units on physical functioning), the performance of caregiving tasks (personal care $\beta=-0.33$, $p<0.001$, emotional support $\beta=0.17$, $p<0.05$ and practical support $\beta=0.34$, $p<0.001$) and the partner’s mental health ($\beta=-0.25$, $p<0.001$ per 25 units on mental functioning). Forty percent of the total variance in this domain of caregiver burden was explained by the identified variables (Table 3).

Burden in terms of ‘lack of family support’ was significantly associated with the partner’s gender ($\beta=-0.22$, $p<0.01$), the partner’s mental health ($\beta=-0.21$, $p<0.001$, per 25 units on mental functioning) and the performance of personal care tasks ($\beta=-0.20$, $p<0.01$). However, the final model explained only 13% of the total variance in this CRA domain.

Variables that added significant value to the multivariable model of ‘loss of physical strength’ were mainly the physical and mental health of the partner ($\beta=-0.27$, $p<0.001$ and...
β = −0.37, p < 0.001 respectively, per 25 units on physical and mental functioning). Furthermore, the performance of personal care tasks was significantly associated (β = −0.15, p = 0.05). Forty-five percent of the variance in this subscale was explained by the identified factors.

6. Discussion

The present study is one of the first to investigate feelings of caregiver burden in partners of HF patients. We tried to elucidate which factors were associated with caregiver burden and to define the impact of patient’s disease severity. The main finding of the present analysis is that patient’s disease severity is not an important issue related to caregiver burden. More important variables to consider are the partner’s own mental health and providing personal care to HF patients.

Although univariately we found significant associations between severity of disease and caregiver burden, in a multivariable model this variable only contributed to a small extent. Consistent with Karmilovich [8], we found no relationship between LVEF, as a measure of HF severity and caregiver burden. More surprisingly, we also did not find a relationship between co-morbidity and the amount of caregiver burden, although co-morbidities were present and are related to more complex care.

The fact that partners have to perform caregiving tasks is also related to feelings of burden, especially when it concerns tasks regarding personal care such as assisting with washing and bathing and moving in and around the house. Gender differences are known to be present in feelings of distress in spousal caregivers [8,9,18,19] with women reporting more distress than men. We found no gender differences in caregiver burden in terms of disruption of daily activities or loss of physical strength. However gender differences were present in caregiver burden defined as feeling a lack of family support with women reporting higher scores on this caregiver burden domain. This finding is consistent with earlier studies that indicate women reporting a higher need for social support than men [18].

In contrast to the results of other studies [9], the quality of the marital relationship in our study did not contribute significantly to any of the domains of caregiver burden, although low perceived marital quality versus high perceived marital quality was borderline significant. A possible explanation may be in the way quality of the marital relationship was measured, as a single-item score, and the lack of variance in this score. This may also relate to the way that marital quality was assessed. Patients and partners were instructed to complete the questionnaire independently from each other, but since questionnaires were completed at home without the researcher being present, there is no guarantee that these instructions were followed precisely.

Our study is one of the first to measure burden related to the caregiving process. Only one other study in HF partners is known [29] measuring the concept of caregiver burden. In this study scores on the CRA subscales seem higher (only percentages are described) compared to our study population; however, this may be due to the fact that the study

| Table 3 |

<table>
<thead>
<tr>
<th>Multivariable linear regression models</th>
<th>Outcome variables</th>
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<tbody>
<tr>
<td>Independent variables</td>
<td>Disrupted daily schedule</td>
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<tr>
<td></td>
<td>R² = 0.40</td>
</tr>
<tr>
<td>Severity of Heart Failure</td>
<td>β</td>
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<tr>
<td>LVEF</td>
<td>–</td>
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<tr>
<td>Physical functioningα</td>
<td>–0.14</td>
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<tr>
<td>Duration of HF (≤ 18 months)b</td>
<td>–0.01</td>
</tr>
<tr>
<td>Number of co-morbidities</td>
<td>–</td>
</tr>
<tr>
<td>Performed caregiving tasks</td>
<td>–0.33</td>
</tr>
<tr>
<td>Emotional support</td>
<td>0.17</td>
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<tr>
<td>Motivational support (low intensity)b</td>
<td>–0.08</td>
</tr>
<tr>
<td>Practical support</td>
<td>0.34</td>
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<tr>
<td>Partner characteristics</td>
<td></td>
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<tr>
<td>Age</td>
<td>–</td>
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<tr>
<td>Gender (male)b</td>
<td>–0.005</td>
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<tr>
<td>Educational level (low)b</td>
<td>–</td>
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<tr>
<td>Physical functioningα</td>
<td>–0.03</td>
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<tr>
<td>Mental functioningα</td>
<td>–0.25</td>
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<tr>
<td>Quality marital relationshipb</td>
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<td>0–7</td>
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<td>8</td>
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α Increase in CRA per 25 units of the RAND 36 (physical functioning and mental functioning).

b Non-presented β is zero.
population consisted of partners of patients with end-stage HF receiving intensive home treatment. Caregivers in our study population indicated less problems on ‘disrupted daily schedule’ and ‘loss of physical strength’ compared to partners of patients with stroke or rheumatoid arthritis [30]. Scores on the subscale ‘lack of family support’ were comparable. However, burden in HF partners was comparable to burden in partners of patients with cancer [23]. These findings are at least remarkable considering the severe debilitating impact of HF along with the grim prognosis.

Some limitations of our study need to be mentioned. The use of a cross-sectional design limits the findings to the level of associations between variables. The design does not permit inferences about whether caregiver burden impacts on health status or impaired health status causing caregiver burden. In the future, prospective studies are necessary to unravel the exact nature of the relationship between these concepts. As mental health seems an important influencing factor, it may also be relevant for future studies to measure depression in partners as well as in HF patients, as depression is recognized as an increasingly prevalent prognostic factor in the area of HF. Another limitation may have been the lack of instrument validity for the measurement of caregiver burden. The instrument used was developed as a generic instrument and has not been evaluated in the HF population. Such an instrument may not address those issues that are specifically relevant to partners of this particular patient population. Qualitative research is necessary to investigate specific and burdensome aspects of the caregiving situation of HF partners. Finally, as in much caregiver research, our population consisted mainly of women. Future research should attempt to include male caregivers in order to really explore this specific experience.

7. Conclusion

Objective measures of disease severity such as LVEF and co-morbidity or age are not primary considerations when assessing a family’s ability to care for a patient with HF. The focus should be on the mental health status of caregivers and on the perceived physical health of both caregivers and HF patients. Future interventions to support partners should provide knowledge on the treatment of HF and should focus on how patients and partners cope both individually and as a couple. Studies in other chronically ill populations have shown that the counseling of couples can be effective in improving coping and reducing psychosocial distress in patients and their partners [31,32]. Furthermore, when patients deteriorate to a level where personal care is needed, it is important to initiate external support either informally or professionally.

Acknowledgment

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