Long term follow up of factors influencing caregiver burden in partners of patients with heart failure

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Heart failure

- A serious condition with poor prognosis
- One of the most common chronic diseases worldwide
- Mean age between 75-80 years
- Leading cause for hospitalization in persons above 65 years
- Deterioration often caused by non-adherence to treatment

McMurray et al. Eur J Heart Fail 2012;14(8), 803-869
Societal perspective

- The care system in transition, moving from a hospital based care to a home/community based system
- Expectations from the health care that the family provides support and care
- The health care focus on improving patient outcomes, but the awareness of partners’ and families’ situation is increasing

Clark et al. Dimens Crit Care Nurs 2006;25: 93-100
Caregiver perspective

- Partners have an important role in supporting HF patients with both practical and emotional support
  

- Caregiving range from assisting with basic daily tasks to medication management
  
  Clark et al., 2008, Luttik et al., 2007 Eur J Cardiovasc Nurs 2008;7:3-9

- Structured patient-partner education is rare in standard care despite recommendations in guidelines
  
  McMurray et al. Eur J Heart Fail 2012;14(8), 803-869
Caregiver burden

- Many partners assume caregiving responsibilities without being aware of the burden interrelated with this role

- Almost one third of the partners to patients with HF experienced a moderate caregiver burden
  Pressler et al., 2009, Saunders 2008, Ågren S et al., 2010

- Caregiver burden has been associated with physical exhaustion, mental stress and personal health risks
Caregiver Burden

– Physical burdens
– Social burdens
– Emotional/psychosocial burdens
– Lifestyle burdens
Aim

- To examine caregiver burden over time during 24 months follow-up in partners to patients with heart failure receiving a psycho-educational intervention compared to a control group.
- To describe the long-term effect of morbidity among partners.
• A randomized study design with patient-partner dyads affected by heart failure with a follow-up assessment after 24 months.

• The intervention included a nurse-led psycho-educational 3-session program.

Visit 1

- Increased knowledge
- Improved mental and physical functions
- Daily weighting
- Monitoring symptoms
- Flexible diuretic intake
- Adherence

Visit 2

- Strengthened self-care behaviour
- Increased knowledge on the rationale for lifestyle changes
- Salt and fluid restriction
- Immunisation
- Exercise

Visit 3

- Increased knowledge on self-care
- Improved mutual support and control
- Decreased caregiver burden
- Identifying life priorities and planning for the future
Sample

• Inclusion criteria; partner to patient diagnosed with verified HF according to guidelines cohabiting in a marriage-like relationship.

• Exclusion criteria; diagnosed dementia or other severe psychiatric illness, drug abuse, difficulties to understand or read the Swedish language.
# Instruments

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Instrument</th>
<th>Description of content</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health related quality of life</td>
<td>Short Form-36</td>
<td>8 dimensions, Physical and Mental Component Scale</td>
<td>36</td>
</tr>
<tr>
<td>Depression</td>
<td>Beck Depression Inventory</td>
<td>Symptom of depression</td>
<td>21</td>
</tr>
<tr>
<td>Perceived control</td>
<td>Control Attitude Scale</td>
<td>Perceived control and helplessness in relation to the heart disease</td>
<td>4</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>Caregiver Burden Scale</td>
<td>Perceived burden of caregiving</td>
<td>22</td>
</tr>
</tbody>
</table>
Caregiver Burden Scale (CBS)

- Measures caregiver burden as experienced by caregivers of chronically disabled individuals
- Responses are scored on a scale from 1-4 (not at all, seldom, sometimes, often)
- The total burden index is a summary of all 22-items, higher scores indicate greater burden (range 22-88)

Caregiver Burden Scale

Includes five factors:

General strain (8 item) – lack of personal freedom in relation to caregiving
Isolation (3 item) – limited social interaction and private time
Disappointment (5 item) – loneliness, psychical burden, financial impact, feeling life is unfair
Emotional involvement (3 item) – embarrassment, hurt, anger due to the patients behaviour
Environment (3 item) – inability to handle practical problems related to the care of the patient

Result

155 partners to patients with HF were included in the study and 93 partners concluded 24 months follow-up.

- 526 partners were screened, 371 fulfilled exclusion criteria.

Partners were lost to follow-up due to:
- death of the patient (n=35)
- non responding to questionnaires (n=27)

There were no differences in age, gender, depressive symptoms, patient or partner morbidity between responders and non-responders, however non-responding partners experienced lower physical health and higher caregiver burden at baseline.
### Sociodemographic and clinical characteristics

<table>
<thead>
<tr>
<th></th>
<th>Control (n=84)</th>
<th>Intervention (n=71)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Mean ± SD</td>
<td>70 ± 10</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>68 (80.9 %)</td>
<td>49 (69.1 %)</td>
</tr>
<tr>
<td><strong>Type of co-morbidity (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>Hypertension</td>
<td>30</td>
<td>35</td>
</tr>
<tr>
<td>Diabetes</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Stroke</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Lung disease</td>
<td>12*</td>
<td>1</td>
</tr>
<tr>
<td><strong>Education, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>48 (58)</td>
<td>41 (59)</td>
</tr>
<tr>
<td>High school</td>
<td>22 (28)</td>
<td>26 (37)</td>
</tr>
<tr>
<td>University</td>
<td>14 (14)</td>
<td>4 (4)</td>
</tr>
<tr>
<td><strong>Employment (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>18 (20)</td>
<td>22 (33)</td>
</tr>
<tr>
<td>Pension /Disability pension/sick leave</td>
<td>66 (80)</td>
<td>49 (67)</td>
</tr>
<tr>
<td><strong>Lifestyle (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking/ Ex-smoking</td>
<td>39 (49)</td>
<td>30 (42)</td>
</tr>
<tr>
<td>Exercise 0 min-3 hours/week</td>
<td>43 (56)</td>
<td>35 (51)</td>
</tr>
<tr>
<td>&gt; 3 hours/week</td>
<td>36 (44)</td>
<td>36 (49)</td>
</tr>
</tbody>
</table>
Result

• There were no significant differences in any dimension of caregiver burden or morbidity among the partners in the intervention and control group after 24 months.
## Baseline and follow up score CGS

<table>
<thead>
<tr>
<th></th>
<th>Range</th>
<th>Baseline</th>
<th>Std deviation</th>
<th>24 month</th>
<th>Std deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total CGB</strong></td>
<td>22-88</td>
<td>36,2</td>
<td>12,1</td>
<td>38,1</td>
<td>13,9</td>
</tr>
<tr>
<td>General strain</td>
<td>8-32</td>
<td>13,6</td>
<td>4,9</td>
<td>14,9</td>
<td>5,5</td>
</tr>
<tr>
<td>Isolation</td>
<td>3-12</td>
<td>4,8</td>
<td>2,2</td>
<td>4,9</td>
<td>2,1</td>
</tr>
<tr>
<td>Disappointment</td>
<td>5-20</td>
<td>8,0</td>
<td>2,9</td>
<td>8,2</td>
<td>3,1</td>
</tr>
<tr>
<td>Emotional</td>
<td>3-12</td>
<td>5,1</td>
<td>2,0</td>
<td>4,3</td>
<td>1,9</td>
</tr>
<tr>
<td>Environment</td>
<td>3-12</td>
<td>4,6</td>
<td>1,6</td>
<td>5,3</td>
<td>2,2</td>
</tr>
</tbody>
</table>

**Interpretation Total CGB**
- No or minimal burden: 0 - 20
- Mild to moderate burden: 21 - 40
- Moderate to severe burden: 41 - 60
- Severe burden: 61 - 88
## CGB Change over time

<table>
<thead>
<tr>
<th>Diff baseline – 24 month</th>
<th>Mean difference</th>
<th>Standard deviation</th>
<th>95% confidence interval of the difference</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total CGB</td>
<td>-1.8</td>
<td>8.9</td>
<td>-3.7 to -0.1</td>
<td>0.04</td>
</tr>
<tr>
<td>General strain</td>
<td>-1.2</td>
<td>4.1</td>
<td>-2.1 to -0.4</td>
<td><strong>0.00</strong></td>
</tr>
<tr>
<td>Isolation</td>
<td>-0.1</td>
<td>1.8</td>
<td>-0.5 to -0.2</td>
<td>0.40</td>
</tr>
<tr>
<td>Disappointment</td>
<td>-0.2</td>
<td>2.8</td>
<td>-0.8 to -0.3</td>
<td>0.39</td>
</tr>
<tr>
<td>Emotional</td>
<td>0.8</td>
<td>2.0</td>
<td>0.3 to 1.2</td>
<td><strong>0.00</strong></td>
</tr>
<tr>
<td>Environment</td>
<td>-0.7</td>
<td>2.1</td>
<td>-1.1 to -0.2</td>
<td><strong>0.00</strong></td>
</tr>
</tbody>
</table>
Predictors of caregiver burden

• Higher number of co-morbidities in the patient
• Poorer mental health, more symptoms of depression and a lower level of perceived control over the heart disease in the partner
Methodological aspects

• Caregiver burden scale a generic instrument was used, not disease specific

• Generalizability of study findings
  • Motivated, committed partners participated?
  • 1/3 of the partners were lost to follow-up at 24 months
  • Only partner caregivers
Conclusion and clinical implications

• The first long-term follow up of caregiver burden in partners to patients with HF showing an increase in several aspects of caregiver burden over time

• Patients with multi-morbidity and partners with lower mental health and lower perceived control are more vulnerable to experience higher caregiver burden

• To identify caregivers that experience high caregiver burden and target those with support and interventions can lead to improvement in mental well-being
What education and support do dyads ask for?

- Dyads want more support from, and interaction with, health care providers.
- Continuous guidance and easy access to health care providers is needed during the whole illness trajectory, not just for a limited time after diagnosis or hospitalisation.
- Education and support in patient-partner groups was highlighted as a way to help dyads handle their life situation.
- When both the patient and the partner receive information and support, burden can be shared and the dyads can both support each other and others dyads in the same situation.

Where to go next?

- Joint dyad education and support
- Group sessions
- Partner interventions
- E-health
- Online support groups
A Successful Marriage requires falling in love many times, always with the same person.

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Thank you!