The burden of care:
Family support in Heart Failure

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Family support in HF patients

- Ageing population
- Increase of chronically ill
- Increase of health care costs
- Shortage of health care personnel
Family support in HF patients

Increasing emphasis on patient responsibility for health

Increasing emphasis on the development and support of self-management

Increasing dependency on the care of family and caregivers
Family support in HF patients
PATIENT SUPPORT

PARTNER/FAMILY SUPPORT
Health Outcome

Patient

support

burden

Partner/family

Health Outcome
Family support
Family support

‘Medications? No, I don’t know, I could not handle that, my wife has taken over, she is managing my medications now, you have to ask her about that’
### Number of respondents providing personal and emotional care by group

<table>
<thead>
<tr>
<th></th>
<th>Partners of HF patients (n=338) n (%)</th>
<th>Partners of Healthy Individuals (n=1202) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal Care</strong></td>
<td>172 (51%)</td>
<td>221 (19%)</td>
</tr>
<tr>
<td><strong>Emotional Care</strong></td>
<td>305 (92%)</td>
<td>949 (81%)</td>
</tr>
</tbody>
</table>

Significant differences p < .001

*Hwang et al, 2009*
Number of Respondents Providing Personal Care by Group

<table>
<thead>
<tr>
<th>Activity</th>
<th>Partners of Heart Failure Patients (n = 335) n (%)</th>
<th>Partners of Healthy Individuals (n = 1168) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating and drinking</td>
<td>27 (8)</td>
<td>68 (6)</td>
</tr>
<tr>
<td>Washing and bathing*</td>
<td>48 (14)</td>
<td>60 (5)</td>
</tr>
<tr>
<td>Dressing and undressing*</td>
<td>56 (17)</td>
<td>49 (4)</td>
</tr>
<tr>
<td>Going to the toilet</td>
<td>9 (3)</td>
<td>17 (2)</td>
</tr>
<tr>
<td>Assistance with appearance*</td>
<td>38 (11)</td>
<td>46 (4)</td>
</tr>
<tr>
<td>Walking in and around the house*</td>
<td>57 (17)</td>
<td>45 (4)</td>
</tr>
<tr>
<td>Coming in and out of bed or chair*</td>
<td>20 (6)</td>
<td>39 (3)</td>
</tr>
<tr>
<td>Walking stairs*</td>
<td>21 (6)</td>
<td>31 (3)</td>
</tr>
<tr>
<td>Helping to find a comfortable position in bed</td>
<td>16 (5)</td>
<td>43 (4)</td>
</tr>
<tr>
<td>Being available for 24 hours*</td>
<td>136 (41)</td>
<td>108 (9)</td>
</tr>
<tr>
<td>Providing care at night*</td>
<td>54 (16)</td>
<td>32 (3)</td>
</tr>
</tbody>
</table>

Items significantly different p<.05

Hwang et al, 2009
### Number of Respondents Providing Emotional Care by Group

<table>
<thead>
<tr>
<th>Item</th>
<th>Partners of Heart Failure Patients (n = 332) n (%)</th>
<th>Partners of Healthy Individuals (n = 1169) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing comfort*</td>
<td>194 (58)</td>
<td>549 (47)</td>
</tr>
<tr>
<td>Talking to reduce anxiety*</td>
<td>137 (41)</td>
<td>381 (33)</td>
</tr>
<tr>
<td>Talking to reduce depressive feelings*</td>
<td>140 (42)</td>
<td>378 (32)</td>
</tr>
<tr>
<td>Talking about worries</td>
<td>199 (60)</td>
<td>678 (58)</td>
</tr>
<tr>
<td>Showing understanding*</td>
<td>279 (84)</td>
<td>880 (75)</td>
</tr>
<tr>
<td>Keeping company*</td>
<td>276 (83)</td>
<td>869 (74)</td>
</tr>
</tbody>
</table>

Items significantly different p<.05

Hwang et al, 2009
Family support & Patient Outcome

Health Outcome

Patient support

Partner/family
Family support & Patient Outcome

- Selfcare and Compliance
  - Simpson, 2000
  - Rohrbaugh, 2004
  - Sayers et al, 2008
  - Wu et al, 2008
  - Gallagher et al, 2010

- Depressive symptoms
  - Murberg, 1998
  - Frasure-Smith, 2000
  - Scherer, 2007
Family support & Patient Outcome

- Mortality & Hospital Readmissions:
  - Vinson, 1990
  - Happ, 1997
  - Krumholz, 1998
  - Murberg, 2001
  - Chin & Goldman, 1997
Background

Chin and Goldman, 1997
Family support & Patient Outcome

- Mortality & Hospital Readmissions;
  - Coyne, 2001
  - Rohrbaugh, 2006
Coyne, Am J Card, 2001
Caregiver burden

*Impact on everyday life*

*Impact on relationships*

Aldred, 2005
Caregiver burden

‘My daughter wants me to come along to go to the sea side, taking the dog with us. But I’m afraid to go, to go out for a whole day is much too long’

Luttik, 2007
Caregiver burden

**Quantitative approaches**

- Disruption of daily activities
- Negative impact on physical health
- Diminished financial well-being
- Deteriorating future outlook

(Luttik, 2007/Bakas, 2006)
## Caregiver burden

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>range 1-4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Burden Score</strong></td>
<td>1.77 (0.54)</td>
<td></td>
</tr>
<tr>
<td>high burden</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>medium burden</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>low burden</td>
<td>68%</td>
<td></td>
</tr>
<tr>
<td><strong>General strain</strong></td>
<td>1.88 (0.64)</td>
<td></td>
</tr>
<tr>
<td><strong>Isolation</strong></td>
<td>1.80 (0.77)</td>
<td></td>
</tr>
<tr>
<td><strong>Disappointment</strong></td>
<td>1.72 (0.63)</td>
<td></td>
</tr>
<tr>
<td><strong>Emotional Involvement</strong></td>
<td>1.66 (0.63)</td>
<td></td>
</tr>
<tr>
<td><strong>Environment</strong></td>
<td>1.63 (0.56)</td>
<td></td>
</tr>
</tbody>
</table>

*Agren, 2010*
## Caregiver burden

<table>
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<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Disrupted daily schedule (range 1-5)</td>
<td>2.3</td>
<td>2.4</td>
<td>2.8</td>
</tr>
<tr>
<td>Loss of physical strength (range 1-5)</td>
<td>2.3</td>
<td>1.9</td>
<td>2.9</td>
</tr>
</tbody>
</table>
Caregiver burden & family health outcome

Patient → burden → Partner/family → Health Outcome
Caregiver burden & family health outcome

- Quality of Life and Well-being
  - Karmilovich, 1994
  - Rohrbaugh, 2002
  - Evangelista, 2002
  - Dracup, 2004
  - Luttik, 2009
Well being

Mean levels of well being

patient partner
well being (0-10)
male female

Luttik et al, J Card Fail, 2009
Well being

Interaction $F (1,754) = 10.23, p < .01$
Social functioning

- Male: No tasks
- Female: No tasks

- Male: Tasks
- Female: Tasks
Caregiver burden & family health outcome

Mortality

- **Schulz, 1999**
  - Caregivers experiencing strain; 63% higher mortality risk compared to caregivers without strain and non-caregivers

- **Christakis, 2006**
  - The hospitalization of a female patient with HF raises the risk of death in the male partner with 12% (15% for female partners of male patients)
Family oriented interventions

- Educational and psycho-educational
  - Knowledge
  - Self management

- Family functioning/relationship oriented
  - Communication
  - Joined problem solving
Family oriented interventions

- Hartmann et al. (2010)
  - Meta-analysis
  - 52 RCT’s; 27 focussed on cardiovascular disease and stroke
  - 56% educational (especially in cv studies), 44% relationship focused (oncology)
  - Effects on
    - Physical health patient; especially when a spouse is involved
    - Family member’s health; especially relationship focused interventions
Interventions

- Duhamel and colleagues *(Clin Nurse Spec, 2007)*
  - Pilot Family Nursing Intervention with 4 dyads

- Dunbar and colleagues *(Nursing Research, 2005)*
  - Family Partnership Intervention
  - 29 couples
  - Dietary sodium self-management
Interventions

- **Stromberg & Agren (in progress)**
  - Integrated care program with education and psychosocial support to older patients with heart failure and their partners
  - Goals:
    - *to promote appropriate and effective support from family members,*
    - *to facilitate of supportive relationships,*
    - *to promote family centred problem-solving,*
Future research

- Measuring support

- Focus also on relationship support
It is time to re-conceptualize HF care as a family phenomenon

The family perspective provides new opportunities to further improve patient outcome
Thank you for your attention!