

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
- Clark et al. Dimens Crit Care Nurs 2006;25: 93-100
- The health care focus on improving patient outcomes, but the awareness of partners' and families' situation is increasing



Caregiver perspective

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

Luttik et al. Eur J Cardiovasc Nurs 2008;7:3-9

- 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

Rabow et al. JAMA 2004;291:483-91.

- 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

Whitlatch et al. Gerontologist 2006;46:688-94.

Caregiver Burden



- Physical burdens
- Social burdens
- Emotional/psychosocial burdens
- Lifestyle burdens

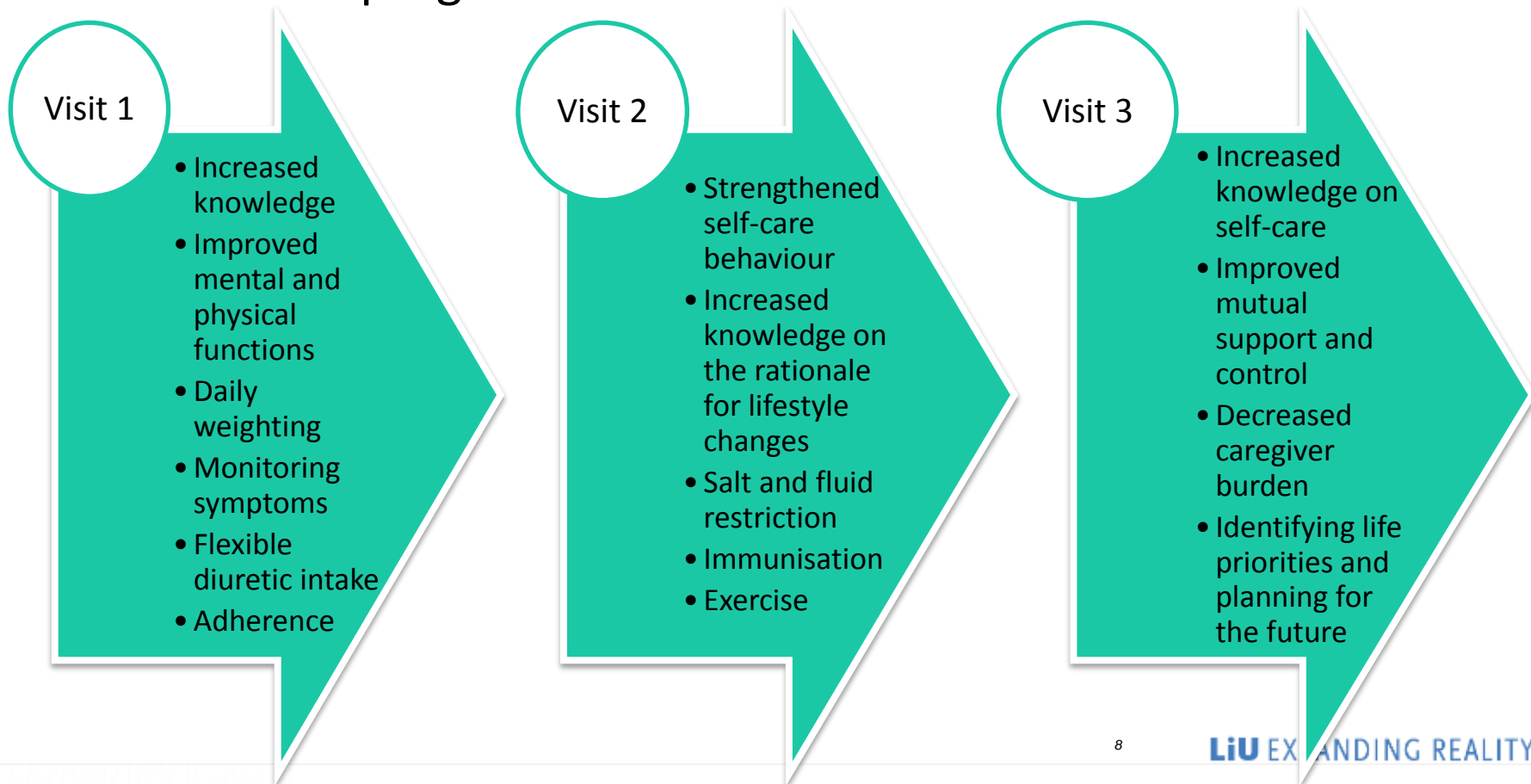


Aim



- 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.





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

Outcome variable	Instrument	Description of content	Item
Health related quality of life	Short Form-36	8 dimensions, Physical and Mental Component Scale	36
Depression	Beck Depression Inventory	Symptom of depression	21
Perceived control	Control Attitude Scale	Perceived control and helplessness in relation to the heart disease	4
Caregiver Burden	Caregiver Burden Scale	Perceived burden of caregiving	22

Caregiver Burden Scale (CBS)

Division of Geriatric Medicine, Lund University, Malmö University Hospital, Malmö, Sweden
Solve Elmståhl ©

Caregiver Burden Scale

Questions

Please, place a tick in the appropriate box.

No 1. Do you feel tired and worn out?

- Not at all¹
- Seldom²
- Sometimes³
- Often⁴

No 2. Do you feel lonely and isolated because of your relative's problem?

- Not at all¹
- Seldom²
- Sometimes³
- Often⁴

No 3. Do you think you have to shoulder too much responsibility for your relative's welfare?

- Not at all¹
- Seldom²
- Sometimes³
- Often⁴

No 4. Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?

- Not at all¹
- Seldom²
- Sometimes³
- Often⁴

No 5. Do you find yourself facing purley practical problems in the care of your relative that you think are difficult to solv?

- Not at all¹
- Seldom²
- Sometimes³
- Often⁴

No 6. Do you ever feel offended and angry with your relative?

- Not at all¹
- Seldom²
- Sometimes³
- Often⁴

- 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)

Elmståhl et al. Arch Phys Med Rehabil 1996;77:177-82

Ågren et al. Eur J Cardiovasc Nurs 2010;9: 254-62

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

Elmståhl et al. Arch Phys Med Rehabil 1996;77:177-82



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

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

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

	Range	Baseline	Std deviation	24 month	Std deviation
Total CGB	22-88	36,2	12,1	38,1	13,9
General strain	8-32	13,6	4,9	14,9	5,5
Isolation	3-12	4,8	2,2	4,9	2,1
Disappointment	5-20	8,0	2,9	8,2	3,1
Emotional	3-12	5,1	2,0	4,3	1,9
Environment	3-12	4,6	1,6	5,3	2,2

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

Diff baseline – 24 month	Mean difference	Standard deviation	95% confidence interval of the difference		Sig. (2-tailed)
			Lower	Upper	
Total CGB	-1,8	8,9	-3,7	-0,1	0,04
General strain	-1,2	4,1	-2,1	-0,4	0,00
Isolation	-0,1	1,8	-0,5	-0,2	0,40
Disappointment	-0,2	2,8	-0,8	-0,3	0,39
Emotional	0,8	2,0	0,3	1,2	0,00
Environment	-0,7	2,1	-1,1	-0,2	0,00



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.

Liljeroos et al. J Clin Nurs. 2014;23, 2928–2938

Where to go next?



- *Joint dyad education and support*
- *Group sessions*
- *Partner interventions*
- *E-health*
- *Online support groups*

En bra plats

Här du någon i din närhet extra hjälp

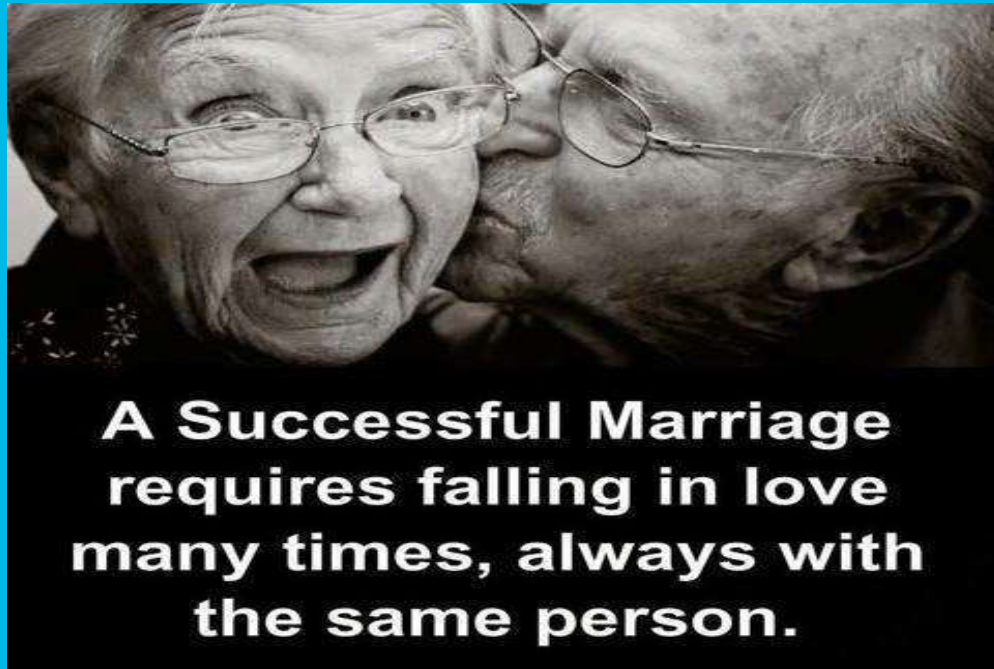
VI HAR SKAPAT EN BRA PLATS

heartfailuremothers.org

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- Understanding heart failure
- What can your doctor do
- What can you do
- Living with Heart Failure
- For caregivers
- Warning signs
- FAQ
- Ask Your Doctor

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Thank you!