Het ontwikkelen en valideren van een vragenlijst
een praktijkvoorbeeld

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Eigenaar FamiliezorgGroningen / Training en advies in familiegerichte zorg voor verpleegkundigen en verzorgenden
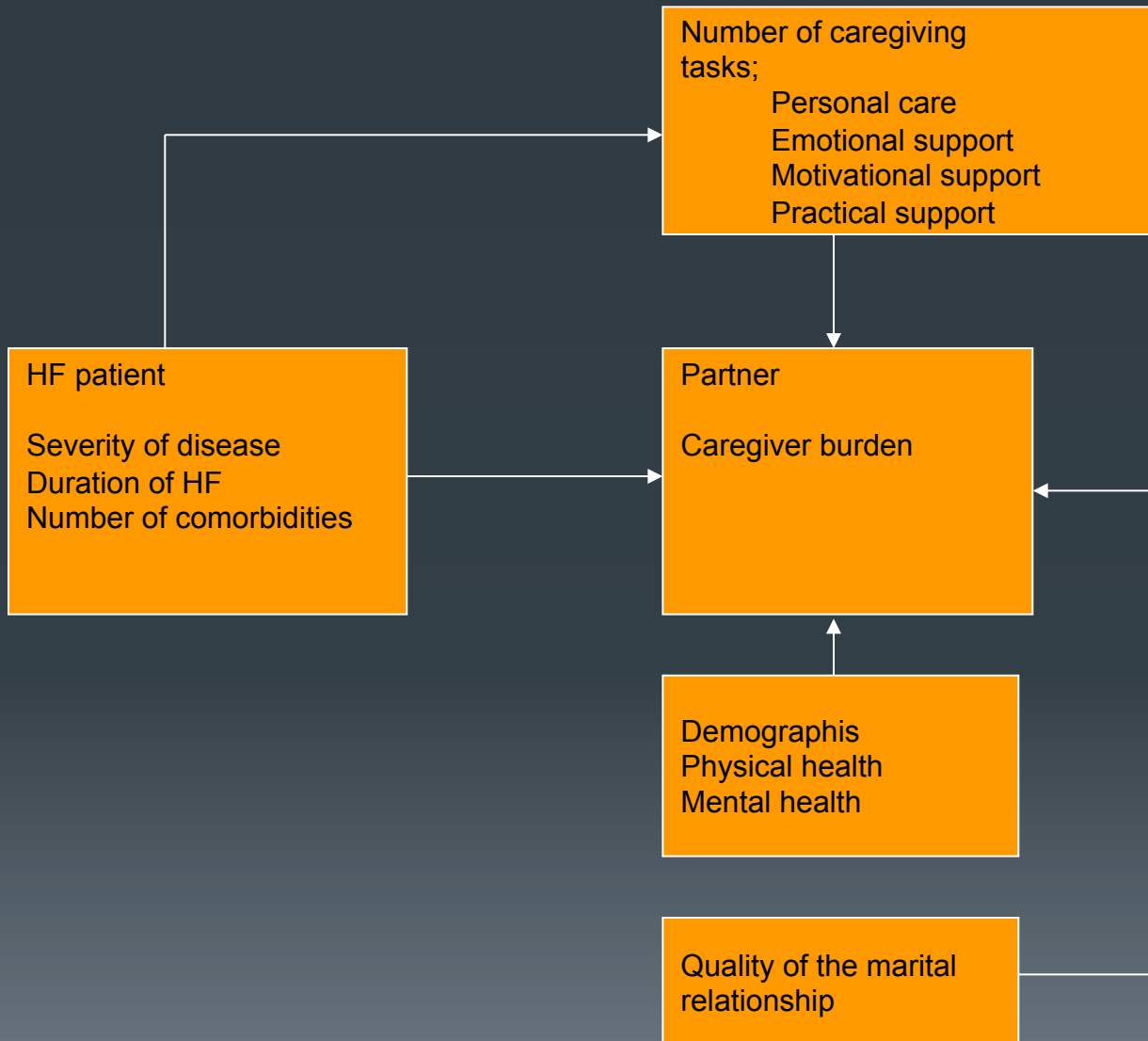
Proefschrift

Patients with HF and their partners;

Both sides of the picture

Benefits for patients and impact on the partners' life

Ontwikkelen en valideren; stapsgewijs

- Ontwikkelen
    - Het concept
    - Operationalisatie en item selectie
    - Pilot testing
    - Hypthesen formuleren (construct validiteit)

- Onderzoek
    - Uitzetten vragenlijst en andere meetinstrumenten
    - Analyses

De verpleegkundige diagnose;
(risico op) overbelasting van de mantelzorger

- cognitieve problemen bij de zorgontvanger
- gezondheidsproblemen van de mantelzorgverlener
- mantelzorgverlener is de partner van de zorgontvanger
- mantelzorger heeft conflicterende verplichtingen (werk)
- complexiteit van de zorgverleningstaken
- vereiste duur van de mantelzorgverlening

- *hoeveelheid en soort zorgverleningstaken*

NANDA-I, 2012-2014

Het concept

- Caregiver burden

  - Subjective caregiver burden
    - Caregiver's appraisal of the caregiving situation

  - **<u>Objective caregiver burden</u>**
    - concrete activities and tasks that caregivers perform resulting from the caregiving process

Doel

- ''to develop and test a comprehensive inventory to assess the full range (kind, number and frequency) of performed caregiving tasks of partners of HF patients, including emotional and motivational tasks''

Operationalisatie en item selectie

Operationalisatie en item selectie

- Op basis van literatuur
  - Duijnstee M. et al. Mantelzorg voor mensen met een chronische ziekte. NCCZ, 1994
  - Timmermans JM. Mantelzorg. SCP, 2003
  - Remme WJ & Swedberg K. Guidelines for the diagnosis and treatment of CHF. Eur Heart J, 2001

- Op basis van bestaande vragenlijsten
  - Stetz KM. Caregiving demands during advanced cancer; the spouse's need. Cancer Nurs, 1987.

Sub-schalen en antwoord categorieën

- Zes domeinen
  - Assistance in physical care and transportation
  - Feeling responsible and being available
  - Assistance in household activities
  - Assistance in financial activities
  - Assistance in disease related activities
  - Emotional or motivational support in following the treatment regimen

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- Eerste concept versie; 50 items
- Omzetten in vragen met antwoord categorieën
- Likert-type respons format (1 never - 3 always)
- Invul instructie

Pilot testing

- Content validity; expert (nurses and caregivers) opinion

- Feasibility and clarity of questioning

  - Geen items verwijderd
  - Sommige items anders geformuleerd

Hypothesen formuleren

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- Women are expected to perform more tasks than men

- A worse health status is expected to result in more caregiving tasks regarding personal care

- Patient with a low mental health status or symptoms of depression are expected to be in need for more emotional support

- Subjective feelings of caregiver burden is expected to be associated with the amount of caregiving tasks performed

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Uitzetten van de vragenlijst en andere meetschalen

- De concept vragenlijst; 50 items

- Vuistregel 5-10 respondenten per item

- Op basis van de hypothesen
  - RAND 36 physical and mental health
  - NYHA classificatie
  - CES-D depressie
  - Caregiver Reaction Assessment Scale (CRA); subjective caregiver burden

Analyses

- Studie populatie
- Feasibility
- Construeren van componenten
- Validiteit
- Betrouwbaarheid

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Context; COACH studie

- COACH-studie; 1023 patiënten met HF

- Effectiviteit van voorlichting en begeleiding aan patiënten met HF op heropnames en overleving

- Sociale steun belangrijke beïnvloedende factor

Table 1 Study population (n = 321).

Table 1
Study population ($n=321$)

Partners		Mean or % ($\pm$ SD)
Partner characteristics		
Age	Years	67 $\pm$ 12
Gender	Female	75%
Educational level [a]	Low	54%
Patient characteristics		
Age	Years	70 $\pm$ 12
Gender	Male	75%
Physical functioning RAND 36		47 $\pm$ 29
Mental functioning RAND 36		76 $\pm$ 17
NYHA class		
II		53%
III–IV		47%
LVEF (%)		32 $\pm$ 14
Number of comorbidities		
None		43%
One		33%
2–5 comorbidities		24%

[a] Educational level low = no education/primary school/lower vocational school.

Feasibility

- Percentage missende waarden < 5%
- 78% had geen missende waarden
- 18% had een of twee missende waarden

(vragenlijsten werden evt met hulp van interviewer ingevuld)

Construeren van componenten

- Principal Component Analysis
  - Vier domeinen
    - Personal care
    - Motivational support
    - Emotional support
    - Practical support
- Tien items verwijderd
  - Item loading < 0.40
  - Of het item laadt op meerdere componenten
- Hoeveelheid verklaarde variantie per component (minimaal 5%)

Table 2.
Rotated component matrix with percentage of explained variance.

Table 2
Rotated component matrix with percentage of explained variance

In the previous 3 months did you support the patient in or by		Component			
		1 [a]	2 [b]	3 [c]	4 [d]
Eating and drinking	1a	.67			
Washing and bathing	4a	.60			
Dressing	5a	.69			
Toileting	6a	.67			
Assisting with appearance	7a	.49			
Mobility at home	8a	.61			
Helping in and out of bed	9a	.80			
Walking stairs	10	.63			
Helping with comfortable position in bed	14a	.72			
Household activities light	15a		.31		.37
Household activities heavy	16a				.44
Shopping	17a				.51
Doing the finances	18a				.70
Filling in forms of reimbursement	19a				.67
Arranging care when necessary 20a					.66
Arranging physical aids	21a				.71
Availability for 24 h	22a	.44			
Caring at night	23a	.50			
Achieving prescription for medication	27a				.54
Achieving medication	28a				.54
Contacting a professional	32a				.42
Following fluid prescriptions	33a		.64		
Following diet prescriptions	34a		.57		
Regular weighing	35a		.55		
Following exercise prescriptions	36a		.49		
Providing comfort	38a			.74	
Talking to reduce anxiety	39a			.76	
Talking to reduce depressive feelings	40a			.78	
Talking to reduce worries	41a			.76	
Showing understanding	42a			.64	
Keeping company	43a			.57	
Motivating to follow diet	44a		.61		
Motivating to quit smoking	45a		.33		
Motivating to be active	46a		.53		
Motivating to take medications	47a		.69		
Motivating to follow fluid prescriptions	48a		.73		
Motivating to start working again	49a		.43		
Participating in conversations with professionals	50a			.36	.35
Percent of variance explained		22.75	7.48	7.12	5.62

[a] Personal care.
[b] Motivational support.
[c] Emotional support.
[d] Practical support.

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Table 3
Items that were removed from the initial 50-item selection

In the previous 3 months, did you support your partner:

1. In preparing meals
2. In planning and organizing meals
3. With transportation to health care providers
4. With transportation to family and friends
5. In using the telephone
6. In preparing medication
7. In taking the medication
8. In evaluating the need for (extra) diuretics
9. In monitoring symptoms of deterioration
10. In contacting a professional when things get worse
11. In taking care of rest in daily life
12. When I am away, I have to arrange someone else to stay with my partner

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Validiteit

- Women are expected to perform more tasks than men

- A worse health status is expected to result in more caregiving tasks regarding personal care

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Table 5

Correlation coefficients between caregiving tasks and external variables

	Personal care	Practical care	Motivational	Emotional
Partner variables				
Gender	.13*	− .07*	− .18**	.01
Caregiver burden				
Disruption daily schedule	.50**	.35**	.37**	.32**
Lack of family support	.17**	.13*	.12*	.01
Financial problems	.18**	.06	.10	.14*
Loss of physical strength	.25**	.07	.19**	.11
Self esteem	.07	.05	.08	.18**
Patient variables				
NYHA class	.24**	.15*	.04	.08
RAND 36 physical functioning	− .43**	− .17**	−.19**	− .29**
RAND 36 mental functioning	− .26**	− .20**	−.13*	− .32**
CES-D Depressive symptoms	.13*	.05	.04	.16**

$* p \leq 0.05$ $**p \leq 0.01$.

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Betrouwbaarheid

- Interne consistentie
  - Cronbach's alpha scores between 0.81-0.84

Table 4
Mean scores (SD) for performed care giving tasks and task related burden

Performed care giving tasks [a]	Mean/median (SD)
Personal care	1.16/1.09 (0.3)
Motivational support	1.43/1.30 (0.4)
Emotional support	1.82/1.83 (0.5)
Practical related support	1.97/1.90 (0.5)

[a] Range 1–3.

Afsluiting

- Dutch Objective Burden Inventory (DOBI)
  - Self-reporting vragenlijst met 38 items, 4 domeinen
  - Ten behoeve van het inventariseren van taken uitgevoerd door partners van patiënten met HF
  - Retrospectief over afgelopen 3 maanden

The objective burden in partners of heart failure patients; development and initial validation of the Dutch Objective Burden Inventory.

Luttik ML[1], Jaarsma T, Tijssen JG, van Veldhuisen DJ, Sanderman R.

European Journal of
Cardiovascular
Nursing

The Dutch Objective Burden Inventory: validity and reliability in a Canadian population of caregivers for people with heart failure.

Makdessi A[1], Harkness K, Luttik ML, McKelvie RS.

Vragen en discussie