

# Self-perceived symptoms and care needs of patients with severe to very severe chronic obstructive pulmonary disease, congestive heart failure or chronic renal failure and its consequences for their closest relatives.

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Patients with moderate to severe COPD, CHF or CRF have been shown to suffer from exercise intolerance, muscle weakness and abnormal changes in body composition, irrespective of the degree of primary organ failure. Therefore, it seems reasonable to...

<b>Ethische beoordeling</b>	Positief advies
<b>Status</b>	Werving gestart
<b>Type aandoening</b>	-
<b>Onderzoekstype</b>	Observationeel onderzoek, zonder invasieve metingen

## Samenvatting

### ID

NL-OMON20513

### Bron

NTR

### Verkorte titel

N/A

### Aandoening

chronic obstructive pulmonary disease (COPD); congestive heart failure (CHF); chronic renal failure (CRF);

Chronisch obstructieve longziekte (COPD); chronisch hartfalen (CHF); chronisch nierfalen (CRF)

## Ondersteuning

**Primaire sponsor:** Proteion Thuis

**Overige ondersteuning:** This project was supported by: Proteion Thuis, Horn, The Netherlands;

Grant 3.4.06.082 of the Netherlands Asthma Foundation, Leusden, The Netherlands; Stichting Wetenschapsbevordering Verpleeghuiszorg (SWBV), Utrecht, The Netherlands.

## Onderzoeksproduct en/of interventie

## Uitkomstmaten

### Primaire uitkomstmaten

- self-perceived symptoms; <br>
- care needs;<br>
- daily physical functioning;<br>
- general health status;<br>
- relatives' perception of the patient's symptoms and needs;<br>
- care-giver burden;<br>
- end-of-life care treatment preferences;<br>
- quality of end-of-life care communication;

## Toelichting onderzoek

### Achtergrond van het onderzoek

Background:

Recent research shows that the prevalence of patients with very severe chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF) and chronic renal failure (CRF) continues to rise over the next years.

Scientific studies concerning self-perceived symptoms and care needs in patients with severe to very severe COPD, CHF and CRF are scarce.

Consequently, it will be difficult to develop an optimal patient-centred palliative care program for patients with end-stage COPD, CHF or CRF. The present study has been designed to assess the symptoms, care needs, end-of-life care treatment preferences and communication needs of patients with severe to very severe

COPD, CHF or CRF.

Additionally, family distress and care giving burden of relatives of these patients will be assessed.

#### Methods/design:

A cross-sectional comparative and prospective longitudinal study in patients with end-stage COPD, CHF or CRF has been designed. Patients will be recruited by their treating physician specialist. Patients and their closest relatives will be visited at baseline and every 4 months after baseline for a period of 12 months. The following outcomes will be assessed during home visits: self-perceived symptoms and care needs; daily physical functioning; general health status; end-of-life care treatment preferences; end-of-life care communication and care-giver burden of family caregivers.

Additionally, end-of-life care communication and prognosis of survival will be assessed with the physician primarily responsible for the management of the chronic organ failure. Finally, if patients decess during the study period, the baseline preferences with regard to life-sustaining treatments will be compared with the real end-of-life care.

#### Discussion:

To date, the symptoms, care needs, caregiver burden, end-of-life care treatment preferences and communication needs of patients with very severe COPD, CHF or CRF remain unknown. The present study will increase the knowledge about the self-perceived symptoms, care-needs, caregiver burden, end-of-life care treatment preferences and communication needs from the views of patients, their loved ones and their treating physician. This knowledge is necessary to optimize palliative care for patients with COPD, CHF or CRF.

### **Doel van het onderzoek**

Patients with moderate to severe COPD, CHF or CRF have been shown to suffer from exercise intolerance, muscle weakness and abnormal changes in body composition, irrespective of the degree of primary organ failure. Therefore, it seems reasonable to hypothesize that patients with end-stage COPD, CHF or CRF have comparable daily symptom burden and care needs.

### **Onderzoeksopzet**

Patients and their closest relatives will be visited at baseline and every 4 months after baseline for a period of 12 months.

## Onderzoeksproduct en/of interventie

Observational study

## Contactpersonen

### Publiek

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### Wetenschappelijk

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## Deelname eisen

### Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

Patients with severe COPD (Global initiative for chronic Obstructive Lung Disease (GOLD classification III); patients with end-stage COPD (GOLD classification IV) without long-term oxygen therapy (LTOT); patients with end-stage COPD (GOLD classification IV) with LTOT;

patients with end-stage CHF (New York Heart Association (NYHA) classification III and IV) and patients with end-stage CRF (requiring dialysis).

## Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

1. The patient is not clinically stable for at least 4 weeks preceding enrolment (no hospital admission or major change in medication, according to the treating physician specialist); pharmacological therapy is not optimal (according to the current available guidelines) and stable for at least 2 months preceding enrolment and patients in a nursing home.

## Onderzoeksopzet

### Opzet

Type: Observationeel onderzoek, zonder invasieve metingen  
Onderzoeksmodel: Anders  
**Controle:** N.v.t. / onbekend

### Deelname

Nederland  
Status: Werving gestart  
(Verwachte) startdatum: 01-01-2008  
Aantal proefpersonen: 350  
Type: Verwachte startdatum

## Ethische beoordeling

Positief advies  
Datum: 21-11-2008  
Soort: Eerste indiening

## Registraties

### Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

### Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

### In overige registers

Register	ID
NTR-new	NL1482
NTR-old	NTR1552
Ander register	07-3-054 : MEC
ISRCTN	ISRCTN wordt niet meer aangevraagd

## Resultaten

### Samenvatting resultaten

- Janssen, D.J., E.F. Wouters, J.M. Schols, and M.A. Spruit, Self-perceived symptoms and care needs of patients with severe to very severe chronic obstructive pulmonary disease, congestive heart failure or chronic renal failure and its consequences for their closest relatives: the research protocol. BMC Palliat Care, 2008. 7: p. 5.