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Original Study

One-Year Stability of Care Dependency in Patients With Advanced Chronic Organ Failure

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A B S T R A C T

Objectives: Care dependency is a determinant of quality of life and survival among patients with advanced chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), or chronic renal failure (CRF). The objectives of this study were to explore the profiles of care dependency in patients with advanced COPD, CHF, or CRF; to study the changes in care dependency during 1-year follow-up; and to study whether 1-year changes in care dependency are comparable between patients with advanced COPD, CHF, or CRF.

Design: Longitudinal observational study.

Participants: Clinically stable patients with advanced COPD (n = 105), CHF (n = 80), or CRF (n = 80) were recruited at outpatient clinics of 7 Dutch hospitals.

Measurements: Patients were visited at home at baseline, and at 4, 8, and 12 months to assess demographic and clinical characteristics, comorbidities (Charlson comorbidity index), care dependency (Care Dependency Scale), mobility, health status, and symptom burden.

Results: COPD and CHF patients reported a higher baseline level of care dependency than patients with CRF. Care dependency differed between patients with COPD, CHF, or CRF in the items 'getting (un) dressed,' 'hygiene,' 'contact with others,' and 'sense of rules/values.' One-year follow-up was completed by 206 patients (77.7%). Patients with COPD were more likely to experience an increase in care dependency. An increase in care dependency was associated with higher age, higher number of hospital admissions, decrease in health status, and worsening of Charlson comorbidity index score.

Conclusions: Care dependency profiles differ between patients with COPD, CHF, or CRF. Patients with advanced COPD are at risk for a 1-year increase in care dependency. Regular assessment of care dependency and addressing care dependency in palliative care programs for patients with advanced COPD, CHF, or CRF are needed.

Nowadays, the importance of palliative care for patients with advanced chronic organ failure, such as chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), and chronic renal failure (CRF) has been recognized.[1,2,3] The aim of palliative care is to improve quality of life of patients and their families facing the problem associated with life-threatening illness.[4] Previous studies have shown that care dependency is an important determinant of quality of life among patients with advanced COPD, CHF, or CRF.[5,6] A cross-sectional study has shown that a higher level of care dependency was associated with worse generic and disease-specific health status in outpatients with advanced COPD or CHF.[5] A study in patients on dialysis has shown that functional status was associated

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Trial registration: NTR 1552 Dutch Trial Register.

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with generic health status three and 12 months after the start of dialysis.[6]

Patients with advanced chronic organ failure often experience impairment in performing normal daily tasks.[7,8,9,10] Hospitalized patients with COPD or CHF reported to need assistance with instrumental activities of daily living, such as grocery shopping, doing house work, doing laundry, and traveling, but also with basic activities of daily living, such as bathing and dressing.[8] The initiation of dialysis in older patients is associated with a substantial decrease in functional status.[11,12] The inability to perform normal daily tasks may lead to feelings of frustration, and adaptation to functional limitations may be difficult for patients as well as for family caregivers.[7] Knowledge concerning the profile of care dependency among clinically stable outpatients with advanced COPD, CHF, or CRF is scarce. A cross-sectional study in patients admitted to the hospital suggested that patients with COPD experience more impairment in outdoor mobility than patients with CHF.[8] Moreover, care dependency may change during the course of the disease. Indeed, a qualitative study of bereaved relatives of COPD patients suggested that patients with COPD became increasingly dependent on their loved ones toward the end of life.[13] Finally, care dependency is an independent predictor of worse prognosis of survival among patients with advanced COPD, CHF, or CRF.[14]

Therefore, optimal management of care dependency is an important component of palliative care programs for patients with advanced COPD, CHF, or CRF. Insight in care dependency profiles and changes in care dependency over time are needed for the development of such programs. To date, changes in care dependency in patients with advanced COPD, CHF, or CRF have not been studied prospectively.

Objectives of the present longitudinal observational study were: (1) to study the profile of care dependency in patients with advanced COPD, CHF, or CRF; (2) to study the changes in care dependency during 1-year follow-up; and (3) to study whether changes in care dependency over 1 year are comparable between patients with advanced COPD, CHF, or CRF after correction for possible confounding variables. We hypothesized a priori that differences will be present in care dependency profiles and changes in care dependency over time between patients with COPD, CHF, or CRF.

Methods

Study Design

The current data are part of a multicenter prospective longitudinal study concerning palliative care needs in patients with advanced COPD, CHF, or CRF.[15] Cross-sectional data about symptom burden, family caregiving, care dependency, and longitudinal data on the influence of care dependency on survival were published before.[5,14,16,17,18] Patients were visited in their home environment at baseline and every 4 months after baseline for 1 year to assess palliative care needs, including care dependency. The Medical Ethical Committee of the Maastricht University Medical Center + (MUMC+), Maastricht, The Netherlands, approved this study (MEC 07-3-054). The study was registered in the Dutch Trial Register (NTR 1552).

Patients

A convenience sample of clinically stable outpatients with advanced COPD, CHF, or CRF was recruited by their physician specialist at the outpatient clinic of 7 hospitals in The Netherlands during 2008 and 2009. Patients were eligible if they had a diagnosis of severe to very severe COPD (Global Initiative for Chronic Obstructive Lung Disease grade III or IV)[19]; advanced CHF (New York Heart Association class III or IV)[20]; or advanced CRF (requiring dialysis) and were clinically stable for 4 weeks preceding enrolment. Patients were classified as COPD, CHF, or CRF according to the primary diagnosis made by their physician specialist. All patients provided written informed consent.

Measurements

The following outcomes were assessed at baseline, 4, 8, and 12 months in the patient's home environment: demographics; body mass index (BMI); current self-reported comorbidities using the Charlson comorbidity index[21]; smoking status; symptoms of anxiety and depression using the Hospital Anxiety and Depression Scale (HADS) consisting of an anxiety subscale (HADS-A) and a depression subscale (HADS-D)[22]; and generic health status using the EuroQol-5 Dimensions (EQ-5D).[23] The number of symptoms experienced in the previous 2 weeks was assessed using a symptom checklist consisting of 18 physical and psychological symptoms. The symptom checklist was described before[16,18] and is available from the authors upon request. In addition, the number of hospital admissions during 1-year follow-up was recorded.

Functional Status

Care dependency was assessed using the Care Dependency Scale (CDS)[24] at baseline, 4, 8, and 12 months. The CDS consists of 15 items regarding basic and instrumental activities of daily living, such as personal care, household activities, and social and recreational activities. (Table 1) For each item, patients rate their level of care dependency in 5 levels from completely care dependent (1 point) to independent (5 points). These items form the profile of care dependency, showing in which domain(s) a patient is care dependent. The total score ranges from 15 (worst) to 75 points (best). Patients with a CDS score $\leq$68 points are considered as care dependent. Using this cut-off results in a sensitivity of 0.85 and a positive predictive value of 0.90.[25]

Physical mobility was assessed during every visit using the Timed 'Up and Go' (TUG) test.[26] The TUG test measures in seconds the time needed to stand up from a chair, walk a distance of 3 m, turn, and walk back to the chair and sit down again.[26] Patients performed 3 tests, and the best score was used for analysis. If patients were unable to perform the test, the missing value was replaced by the highest score.[5]

Table 1
Care Dependency Scale items

Items	The extent to which the patient is able to…
1. Eating/drinking	satisfy his/her need for food and drink
2. Incontinence	control the discharge of urine and feces voluntarily
3. Body posture	adopt a position appropriate to a certain activity
4. Mobility	move about unaided
5. Day/night pattern	maintain an appropriate day/night cycle unaided
6. Getting (un)dressed	get dressed and undressed unaided
7. Body temperature	protect his/her body temperature against external influences unaided
8. Hygiene	take care of his/her personal hygiene unaided
9. Avoidance of danger	assure his/her own safety unaided
10. Communication	communicate
11. Contact with others	appropriately make, maintain and end social contacts
12. Sense of rules/values	observe rules by him/herself
13. Daily activities	structure daily activities unaided
14. Recreational activities	participate in activities outside unaided
15. Learning ability	acquire knowledge and/or skills and/or to retain that which was previously learned unaided