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DJA Janssen, MA Spruit, EFM Wouters and JMGA Schols
Palliat Med 2008 22: 938 originally published online 18 September 2008
DOI: 10.1177/0269216308096906

The online version of this article can be found at:
http://pmj.sagepub.com/content/22/8/938
Daily symptom burden in end-stage chronic organ failure: a systematic review

DJA Janssen Central Department of Treatment and Care, Proteion Thuis, Horn, MA Spruit Staff functionary of Department of Research, Development and Education, Centre for Integrated Rehabilitation of Organ failure (CIRO), Horn, EFM Wouters Department of Respiratory Medicine, MUMC, Maastricht; Director of Centre for Integrated Rehabilitation of Organ failure (CIRO), Horn and JMGA Schols Faculty of Health Medicine and Life sciences, Department of General Practice, University Maastricht, Maastricht

Chronic diseases are nowadays the major cause of morbidity and mortality worldwide. Patients with end-stage chronic organ failure may suffer daily from distressful physical and psychological symptoms. The objective of the present study is to systematically review studies that examined daily symptom prevalence in patients with end-stage chronic organ failure, with attention to those that included patients with either congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD) or chronic renal failure (CRF). Thirty-nine articles (8 CHF, 7 COPD, 2 CHF and COPD, 22 CRF) have been included. The included studies used various study designs. There was a wide range of daily symptom prevalence that may be due to the heterogeneity in methodology used. Nevertheless, findings suggest significant symptom burden in these patients. This review highlights the need for further prospective and longitudinal research on symptom prevalence in patients with end-stage CHF, COPD and CRF to facilitate the development of patient-centred palliative care programs. Palliative Medicine (2008); 22:938–948

Key words: chronic obstructive pulmonary disease; congestive heart failure; chronic kidney failure; palliative care; symptom burden

Introduction

Chronic diseases are presently a major cause of morbidity and mortality worldwide. The prevalence of congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD) and chronic renal failure (CRF) is expected to rise over the next years. The prognosis of survival for patients with chronic organ failure is even poorer than that for many common malignant diseases.

To date, several authors have suggested that palliative care may have an important role in chronic non-malignant diseases. Indeed, previous research has shown that both patients with end-stage malignant and non-malignant diseases may suffer from many distressful physical and psychological symptoms such as fatigue, pain, dyspnoea, cough, lack of appetite, sadness and sleep disorders. Moreover, previous studies have shown that quality of life in patients with CHF, COPD or CRF is equally or even more greatly affected by their disease than those with cancer. However, until now palliative care has been reserved mostly for patients with malignant disease as evidenced by the limited access to palliative care for patients with non-malignant disease. Even with the increasing recognition of the need for palliative care for these patients, current clinical guidelines on the management of chronic disease offer little guidance on end-of-life care issues and care for patients with end-stage disease is presently prioritised by diagnosis rather than need. The disparity in care, despite evidence to the contrary, likely reflects the uncertainty in the prognosis in terms of survival in patients with chronic organ failure. The course of end-stage chronic organ failure is marked typically by a gradual decrease and punctuated by acute deteriorations in health status and daily functioning, especially in COPD and CHF. These deteriorations can be life threatening and increase the risk of hospital admission and intensive treatment. Thus, although there is a gradual decrease in health status and daily functioning in patients with CHF, COPD or CRF, timing of death remains uncertain and choosing the right moment for starting palliative care is a continuous challenge for the treating physician. Essential to any patient-centred palliative care program is an understanding of the self-perceived daily symptoms of patients with end-stage CHF, COPD or CRF.

In the present systematic review, we have critically appraised the currently available peer-reviewed literature that addresses daily symptom burden of patients with CHF, COPD or CRF at the end of their life.
Methods

Data sources and searches
A computerised literature search was performed to identify relevant articles. Several databases were used: MEDLINE/PubMed (timespan: 1966 to April 2007) and Web of Science (timespan: 1988 to April 2007) with the following three groups of keywords:

1) COPD, pulmonary disease chronic obstructive, end-stage lung failure, end-stage lung disease, heart failure congestive, end-stage heart disease, kidney failure chronic, dialysis, end-stage renal disease;
2) symptoms, pain, dyspnoea, breathlessness, cough, fatigue, anorexia, weight loss, depression, anxiety, delirium, confusion, insomnia, oedema, dizziness, nausea, mouth problems, pruritus, constipation.

The three groups were combined using ‘and’. Within each group the keywords were combined using ‘or’. In addition, reference lists of original articles were searched by hand to identify articles that may contain information on the topic of interest and may have been missed by the search strategy. Finally, corresponding authors of articles were contacted at least twice in an effort to include all available studies.

Study selection
Articles were included that reported original data on daily symptoms in adult patients with CHF, COPD or CRF at the end of their life and if the presence of one or more of the aforementioned symptoms in patients with CHF, COPD or CRF at the end of their life was reported in the abstract. Articles not written in English were excluded. The authors included observational studies with various study designs, such as cross-sectional, longitudinal, retrospectively and/or prospectively. Abstracts, reviews, editorials, qualitative studies and case reports were considered ineligible.

Data extraction and quality assessment
Two reviewers (D.J.A.J. and M.A.S.) assessed the methodological quality of the included studies. A predesigned data extraction form was used to obtain data on study design and relevant results. For each study, authors, journal, year of publication, country of origin and studied disease(s) were recorded. For quality assessment, studies were evaluated on the following items: design of the study (prospective or retrospective, cross-sectional or longitudinal, patient reporting, proxy reporting or chart review), number of patients, response rate and patient characteristics (severity of the disease, prognosis, age, gender, setting). For each of the symptoms, the definition of the symptom, method of measurement (if reported) and the reported prevalence was noted. Finally, the limitations of each study were considered.

Data synthesis and analysis
The use of meta-analytic techniques for data-analysis was not possible, because of variability of design, patient characteristics, and definition and measurement of symptoms that were used. Therefore, for each symptom, minimum, maximum and median prevalence numbers are reported for each chronic disease. Prevalence numbers are reported for patients who were not identified as terminally ill and patients who were, often retrospectively, identified as terminally ill, for example, the last 2 weeks of life, the last week of life, the last 3 days of life or the last 24 h of life. For CRF, discontinuation or declining of dialysis was also terminal illness defining event.

Results
In total, 595 articles were identified in the electronic searches, 515 were written in English. Of these articles, 79 were considered eligible after reading the abstract. Five case studies, letters and editorials, seven qualitative studies and 27 reviews were excluded. In addition, 14 articles were selected from reference lists of the remaining 40 articles. In total, 54 articles were reviewed in detail. Six articles were excluded because prevalence numbers were only reported for a combined group of diseases (e.g., CHF, COPD and liver disease) and three studies because symptom prevalence numbers were not mentioned. Six studies were excluded for other reasons. In total, 39 articles were considered eligible. Eight studies included patients with end-stage CHF, seven included patients with end-stage COPD, two included both patients with end-stage CHF and patients with end-stage COPD and 22 studies included patients with end-stage CRF (Figure 1).

A cross-sectional design was used in 32 studies and a longitudinal design in 7 studies. Thirteen studies were retrospective, mostly bereavement studies, and 23 were prospective. Retrospective and prospective information was combined in three studies. Patient reporting was used in 19 studies, proxy reporting in 10 studies, chart review in four studies and six studies combined patient and proxy reporting or chart review (Table 1).

Severity of the disease and prognosis of survival varied and was sometimes unknown. Therefore, the estimated prognosis for survival and, if this was unknown, the description of disease severity have been reported in Table 1. CHF patients with New York Heart Association (NYHA) class III or IV were included. In the studies...
that included patients with COPD, forced expiratory volume in the first second (FEV₁) was only reported in two studies (mean FEV₁: 34% of predicted\textsuperscript{24}; median FEV₁ 26.3% of predicted).\textsuperscript{25} All CRF studies included patients who needed dialysis or became terminal after discontinuation or declining of dialysis. When reported, estimated prognosis of survival ranged from 24 h to 1 year.

Reported mean age ranged from 67 to 86 years (CHF); 65 to 75 years (CHF/COPD); 67 to 77 years (COPD) and 38 to 85 years (CRF). In the studies included in this sys-

**Figure 1** Abbreviations: CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; CRF, chronic renal failure.
CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; CRF, chronic renal failure.

Table 1  Design of the included studies and (estimated) prognosis of survival or disease severity

<table>
<thead>
<tr>
<th>Disease</th>
<th>Design of the study</th>
<th>(Estimated) prognosis of survival or disease severity of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHF, n = 8</td>
<td>Longitudinal, n = 3</td>
<td>Proxy reporting, n = 2</td>
</tr>
<tr>
<td></td>
<td>Retrospective, n = 3</td>
<td>Last 3 days, ( n = 1^{22} )</td>
</tr>
<tr>
<td></td>
<td>Cross-sectional, n = 5</td>
<td>Chart review, n = 1</td>
</tr>
<tr>
<td></td>
<td>Prospective, n = 2</td>
<td>Patient reporting, n = 2</td>
</tr>
<tr>
<td>CHF/COPD, n = 2</td>
<td>Cross-sectional, n = 2</td>
<td>Proxy reporting, n = 2</td>
</tr>
<tr>
<td>COPD, n = 7</td>
<td>Longitudinal, n = 1</td>
<td>Chart review, n = 1</td>
</tr>
<tr>
<td></td>
<td>Retrospective and retrospective, n = 1</td>
<td>Patient reporting, n = 1</td>
</tr>
<tr>
<td></td>
<td>Cross-sectional, n = 6</td>
<td>Proxy reporting, n = 1</td>
</tr>
<tr>
<td></td>
<td>Prospective, n = 2</td>
<td>Patient/proxy reporting, n = 3</td>
</tr>
<tr>
<td></td>
<td>Retrospective, n = 1</td>
<td>Patient/proxy/chart reporting, n = 1</td>
</tr>
<tr>
<td>CRF, n = 22</td>
<td>Longitudinal, n = 3</td>
<td>Chart review, n = 1</td>
</tr>
<tr>
<td></td>
<td>Retrospective, n = 1</td>
<td>Proxy reporting, n = 1</td>
</tr>
<tr>
<td></td>
<td>Cross-sectional, n = 16</td>
<td>Chart review, n = 1</td>
</tr>
<tr>
<td></td>
<td>Prospective and retrospective, n = 2</td>
<td>Proxy reporting, n = 1</td>
</tr>
<tr>
<td></td>
<td>Patient/proxy/chart reporting, n = 3</td>
<td>Terminal after discontinuation of dialysis, ( n = 1^{42} )</td>
</tr>
<tr>
<td></td>
<td>Patient reporting, n = 13</td>
<td>Terminal after discontinuation of dialysis, ( n = 1^{34} )</td>
</tr>
<tr>
<td></td>
<td>Retrospective, n = 3</td>
<td>Proxy reporting, n = 2</td>
</tr>
<tr>
<td></td>
<td>Chart review, n = 1</td>
<td>Patient/proxy/chart reporting, n = 1</td>
</tr>
<tr>
<td></td>
<td>Longitudinal, n = 3</td>
<td>Terminal after discontinuation of dialysis, ( n = 1^{152} )</td>
</tr>
<tr>
<td></td>
<td>Prospective and retrospective, n = 1</td>
<td>Terminal after discontinuation of dialysis, ( n = 1^{148} )</td>
</tr>
</tbody>
</table>

CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; CRF, chronic renal failure.

systematic review, response rate of patients with CHF, COPD and CRF ranged from 40% to 100%. Although response rate was often not reported and if reported varied in definition, it did not seem to relate to certain diseases or study designs.

For measurement of most of the symptoms, different study designs were used. This is shown for the frequently reported daily symptoms fatigue, dyspnoea, pain and insomnia (Figure 2).

Despite the fact that there is a wide range in the reported prevalence of symptoms, some patterns are apparent (Table 2). Patients with CHF, COPD and CRF are likely to experience a high daily symptom burden, with fatigue being the most common symptom. Dyspnoea, insomnia and pain are frequently reported in all three diseases (Figure 3).

Discussion

The present systematic review of observational studies of symptom prevalence in chronic organ failure shows that there is great heterogeneity in study designs used for studying symptoms in end-stage CHF, COPD and CRF. Daily symptom burden is likely to be high in end-stage chronic organ failure, irrespective of the underlying disease. However, to our knowledge, a comparison of symptom prevalence between patients with CHF, COPD and CRF at the end of life has not been made. The most frequently reported symptoms in CHF, COPD and CRF were fatigue, dyspnoea, insomnia and pain. As many of the symptoms were not included in studies of patients who were terminally ill, a comparison of symptomatology of the terminally ill with those who were not was not possible.

Our findings are in line with the findings of Solano, et al.26 systematic review of symptom prevalence in far advanced cancer, AIDS, CHF, COPD and CRF. They also found a great heterogeneity in prevalence of symptoms and a high rate of prevalence for almost all symptoms. Pain, breathlessness and fatigue were the most common reported symptoms in the diseases they reviewed.26 A recent systematic review of symptoms in end-stage CRF also found a wide variation in the prevalence of symptoms although the overall symptom burden seemed to be high, comparable with the findings in the present study.27
Limitations and methodological considerations

Because it is difficult to accurately determine the prognosis for survival in patients with end-stage CHF, COPD or CRF, authors who used prospective study designs may not have identified their patients as being at the end of life. Therefore, our search strategy may have failed to identify some relevant articles. Furthermore, some authors focused on a limited number of symptoms, and thereby our review may be underreporting some of the less commonly examined symptoms.

The variability in symptom prevalence we observed is likely the result of the heterogeneity in study design. Therefore, four causes probably contributing to the great variability will be discussed.

First, in this systematic review, studies of various designs, such as cross-sectional, longitudinal, retrospectively and/or prospectively, patient reporting, proxy reporting and chart review have been included. The reported symptom prevalence could probably be influenced by the design of the study. For example, some of the studies included in this systematic review relied on bereaved family members to act as proxies to report on the daily symptoms experienced by the patient. These proxies included relatives (partners and children), friends, neighbours or professional caregivers. In general, proxy respondent agreement on health symptoms is better for proxies living with the patient compared with proxies not living with the patient. Children of patients have been shown to report more symptoms than partners of patients. Caregivers, like physicians, may report depression less frequently than relatives. This is true not only for depression but also for pain, anxiety and other symptoms. Bereaved family members and medical staff have shown poor agreement. Previous research in patients with cancer and their relatives has shown a low agreement between family members’ ratings and the patients’ own ratings of their experienced symptoms. The low and inconsistent agreement brings into question the use of family members’ or professional caregivers’ views as proxies for the views of patients. Whether the study is prospective or retrospective can also have an impact. In retrospective assessment of symptoms, family members rate problems as mild or severe and avoid the mid-points of a rating scale, in contrast to what is seen in prospective assessment.

Timing of the interview is an important consideration in post-bereavement studies because passage of time may change the perception of daily symptom burden by relatives. Studies included in this review conducted interviews within 1 month, within 5–10 months or until 10 months after death. It has been shown that pain and

Figure 2  Study design and prevalence of the reported symptoms fatigue (left upper quadrant), dyspnoea (right upper quadrant), pain (left lower quadrant) and insomnia (right lower quadrant) in patients with end-stage congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD) or chronic renal failure (CRF). ■, prospective patient reporting; ▲, retrospective proxy reporting; ▼, chart review; ●, mixed patient or proxy reporting and retrospective or prospective.
<table>
<thead>
<tr>
<th>Symptom</th>
<th>CHF</th>
<th>CHF terminal</th>
<th>COPD</th>
<th>COPD terminal</th>
<th>CRF</th>
<th>CRF terminal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>42–82% (69%)(n=212)</td>
<td>75–80% (78%) (n=323^a)</td>
<td>49–96% (68%)(n=353)</td>
<td>80% (n=222^a)</td>
<td>5–100% (82%)(n=557)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>18–88% (72%)(n=804)</td>
<td>42–79% (62%) (n=1131)</td>
<td>56–98% (94%)(n=619^b)</td>
<td>89–91% (90%) (n=726)</td>
<td>5–82% (52%) (n=196)</td>
<td>18–46% (n=34^a,41,42,68)</td>
</tr>
<tr>
<td>Insomnia</td>
<td>36–48% (45%)(n=726)</td>
<td>Not reported</td>
<td>55–77% (65%) (n=359^b)</td>
<td>51% (n=87^b)</td>
<td>14–82% (47%) (n=419)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Pain</td>
<td>20–78% (41%)(n=878)</td>
<td>14–63% (42%) (n=964)</td>
<td>21–77% (68%) (n=1038^b)</td>
<td>34–63% (49%) (n=400)</td>
<td>21–64% (52%) (n=292)</td>
<td>30–73% (49%) (n=33,34,41,42,48,68)</td>
</tr>
<tr>
<td>Mouth problems</td>
<td>9–45% (27%)(n=146)</td>
<td>Not reported</td>
<td>59–67% (63%) (n=150^b)</td>
<td>48% (n=29)</td>
<td>46–58% (52%) (n=30)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Cough</td>
<td>24–44% (35%)(n=739)</td>
<td>Not reported</td>
<td>59–80% (70%) (n=359^b)</td>
<td>52% (n=30)</td>
<td>46–47% (47%) (n=30)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Anorexia</td>
<td>11–43% (31%)(n=797)</td>
<td>Not reported</td>
<td>11–81% (51%) (n=440^b)</td>
<td>64% (n=425)</td>
<td>21–64% (48%) (n=87^b)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Depression</td>
<td>6–59% (23%)(n=814)</td>
<td>Not reported</td>
<td>17–77% (59%) (n=648^b,39)</td>
<td>55% (n=79)</td>
<td>21–64% (26%) (n=87^{2,9})</td>
<td>25% (n=79)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>2–49% (30%)(n=737)</td>
<td>Not reported</td>
<td>32–57% (53%) (n=353)</td>
<td>Not reported</td>
<td>20–41% (27%) (n=161)</td>
<td>25% (n=35)</td>
</tr>
<tr>
<td>Constipation</td>
<td>12–42% (37%)(n=667)</td>
<td>Not reported</td>
<td>27–44% (36%) (n=150^b)</td>
<td>25% (n=502)</td>
<td>18–63% (28%) (n=39,12)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Delirium/confusion</td>
<td>29% (n=80)</td>
<td>15–48% (17%) (n=481^a)</td>
<td>13–33% (23%) (n=387^{2,9})</td>
<td>Not reported</td>
<td>13–68% (26%) (n=196)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Nausea</td>
<td>2–48% (25%)(n=792)</td>
<td>20% (n=60)</td>
<td>4% (n=81)</td>
<td>Not reported</td>
<td>30–44% (39%) (n=362)</td>
<td>13–34% (13%) (n=196)</td>
</tr>
<tr>
<td>Edema</td>
<td>33–44% (39%)(n=146)</td>
<td>43% (n=90)</td>
<td>Not reported</td>
<td>Not reported</td>
<td>42–73% (55%) (n=198)</td>
<td>21% (n=35)</td>
</tr>
<tr>
<td>Dizziness</td>
<td>21% (n=80)</td>
<td>35% (n=60)</td>
<td>Not reported</td>
<td>Not reported</td>
<td>37–50% (44%) (n=256)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Pruritus</td>
<td>12% (n=80)</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Not reported</td>
<td>49–73% (62%) (n=392)</td>
<td>22% (n=35)</td>
</tr>
<tr>
<td>Weight loss</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Not reported</td>
<td>18–32% (25%) (n=30)</td>
<td>Not reported</td>
</tr>
</tbody>
</table>

Minimum–maximum prevalence, median (%), total number of patients in the included studies for each symptom (n) and references are shown. CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; CRF, chronic renal failure.

Terminal: last 2 weeks of life, last week, last 3 days, last 24 h or for CRF after discontinuation/declining of dialysis

\(a\)'n' can be under or overestimated because 'n' is not exactly reported for each disease and each symptom.

\(b\)5 patients with chronic lung disease other than COPD.

cPersistent thirst.

dDry mouth or thirst.

eDry mouth.

fConstipation or diarrhoea.
Figure 3  Minimum, maximum and median prevalence of reported daily symptom burden in patients with end-stage congestive heart failure (CHF, left upper panel), terminal congestive heart failure (CHF terminal, right upper panel), end-stage chronic obstructive pulmonary disease (COPD, left middle panel), terminal chronic obstructive pulmonary disease (COPD terminal, right middle panel), Chronic renal failure (CRF, left lower panel) or terminal chronic renal failure (CRF terminal, right lower panel). NR, not reported.
depression are reported as less severe and occurring less frequently the later the interview is conducted.38

Other studies relied on charts or medical records for identifying symptoms.39–42 These sources provide only indirect reporting of the daily symptom burden, potentially under representing symptoms that are not recognised by caregivers such as nurses and physicians. Moreover, these sources can also include interpretations. For example, in two of the studies, the presence of depression was based upon the use of anti-depressive medication. However, this will underestimate the prevalence of depression.24

Second, in the currently available literature, there is no clear and commonly accepted definition of end-of-life or end-stage43. We included studies that were found by searching for the keywords ‘palliative care’, ‘hospice care’, ‘terminal care’, ‘terminally ill’ or ‘end-of-life’. However, these labels signify varying degrees of prognosis. This could probably influence the reported daily symptom burden. For instance, in the study of Edmonds, et al., symptom burden of patients with COPD has been studied retrospectively in the last year and the last week of life. For all the studied symptoms, a lower prevalence has been reported in the last week compared with the last year of life.29 In patients with CRF who withdrew from dialysis, Chater, et al.42 have shown that in the last 24 h of life symptom prevalence decreased. On the contrary, in the Study to Understand Prognoses and Preferences for Outcome and Risk of Treatments (SUPPORT), it was found that the number of patients with CHF who reported symptoms such as severe pain or dyspnoea increased as death came nearer.22 This could probably be partly explained by the fact that symptom burden in the last 3 days of life has only been studied by proxy reporting and in the last 6 months symptom burden has been studied by patient and proxy reporting. Although the exact relationship is not known, it is highly plausible that symptom burden is related to prognoses.

Third, patient selection criteria varied between the studies, introducing variability in patient characteristics. Some studies included only patients who were hospitalised during an acute exacerbation,22,44,45 other studies selected only outpatients.25 Patients included in prospective studies, those recognised as being at the end of life, could conceivably have other characteristics than patients included in retrospective studies, patients who have died.40 In some studies, considerably co-existing morbidities were present,8,34,45,47–50 whereas in others co-morbidity was not reported.

Fourth, definition and measurement of symptoms varied across the studies. Depression for example was defined as neurotic depression (DSM-IIIR),51 major depression (DSM-IV),52 feelings of depression,21 low mood,30 feeling sad,8 a score of ≥8 points on the depression scale of Hospital Anxiety and Depression Scale (HADS),23 a score of ≥16 points on the Center for Epidemiologic Study-Depression survey (CES-D),25 a score of ≥11 points on the Geriatric Depression Scale (GDS)24 or Beck Depression Inventory (BDI).17 The criteria for determining when a symptom was present and to what degree also varied. A symptom was considered as present in the various studies, if it was experienced all the time or sometimes,30 if it was mild to very severe,24 if it was moderately severe or extremely severe at least half of the time,22 a little bit, moderately, much or very much present55 or the symptom was uncontrolled.23 The length of the recall period varied from 24 h to 1 year.

Conclusions and implications

The need for palliative care for patients with end-stage chronic organ failure has been previously asserted.7,8,10,56 The degree daily symptom burden of patients with end-stage CHF, COPD or CRF that we found in this systematic review adds to such an assertion. Unfortunately, the heterogeneity and limitations of the study designs we reviewed do not permit a comparison of symptom prevalence between patients with end-stage CHF, COPD or CRF.

This limitation highlights the methodological challenges of research in end-of-life care as have been previously described.46,57,58 The resulting limited understanding of daily symptom burden in patients with CHF, COPD or CRF at the end of their life hampers efforts to develop patient-centred intensive management program aimed at reducing suffering and/or improving quality of life of patients with end-stage chronic organ failure and their families by preventing, relieving or soothing self-perceived daily symptoms. Further prospective and longitudinal research in which the views of patients, their families and their treating physician are taken into account is needed. Only then it may be possible to optimise palliative care and symptom management in patients with CHF, COPD or CRF at the end of their life.

Acknowledgements

We are grateful to Prof. Dr J.R. Curtis for his useful comments on a preliminary version of this manuscript. We like to acknowledge the editing skills of Dr Scott S. Wagers. 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 Verpleeghuizorg (SWBV), Utrecht, The Netherlands. No funding source had any role in the design or conduct of the study; collection, management, analysis and interpretation of the data; or preparation, review, or approval of the manuscript. The authors have no conflicts of interest that are directly relevant to the content of this article.

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