Brief Report

Patient-Clinician Communication About End-of-Life Care in Patients With Advanced Chronic Organ Failure During One Year

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Abstract

Context. Patient-clinician communication is an important prerequisite to delivering high-quality end-of-life care. However, discussions about end-of-life care are uncommon in patients with advanced chronic organ failure.

Objectives. The aim was to examine the quality of end-of-life care communication during one year follow-up of patients with advanced chronic organ failure. In addition, we aimed to explore whether and to what extent quality of communication about end-of-life care changes toward the end of life and whether end-of-life care communication is related to patient-perceived quality of medical care.

Methods. Clinically stable outpatients ($n = 265$) with advanced chronic obstructive pulmonary disease, chronic heart failure, or chronic renal failure were visited at home at baseline and four, eight, and 12 months after baseline to assess quality of end-of-life care communication (Quality of Communication questionnaire). Two years after baseline, survival status was assessed, and if patients died during the study period, a bereavement interview was done with the closest relative.

Results. One year follow-up was completed by 77.7% of the patients. Quality of end-of-life care communication was rated low at baseline and did not change over one year. Quality of end-of-life care communication was comparable for patients who completed two year follow-up and patients who died during the study. The correlation between quality of end-of-life care communication and satisfaction with medical treatment was weak.

Conclusion. End-of-life care communication is poor in patients with chronic organ failure and does not change toward the end of life. Future studies should develop an intervention aiming at initiating high-quality end-of-life care communication between patients with advanced chronic organ failure and their clinicians. J Pain Symptom Manage 2015;49:1109–1115.

Key Words

End-of-life care, palliative care, communication, chronic obstructive pulmonary disease, chronic heart failure, chronic renal failure

Introduction

Patients with chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), and chronic renal failure (CRF) frequently die unexpectedly.[1–4] Early patient-clinician end-of-life care communication (EOLCC) can improve quality of communication[5,6] and the concordance between patient's preferences and end-of-life (EOL) care received.[7–9] Patients and their families identified communication as an important physician skill in EOL care.[10] Patients with advanced chronic organ failure are able to discuss preferences for EOL care with their treating physician. However, these discussions are uncommon in daily practice.[11,12] Most important, physician-reported

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barriers to EOLCC are lack of time and poor communication skills.[13] Patients are often not aware of the fact that their disease is life limiting and will not initiate EOLCC themselves.[13] Cross-sectional studies showed that death and dying were rarely or not discussed at all with patients with advanced chronic organ failure.[14,15]

Currently, it is unknown whether and to what extent the quality of EOLCC will change during the course of the disease or toward the end of life. The objective of this study was to examine the quality of EOLCC during a one year follow-up in patients with advanced chronic organ failure. In addition, we aimed to explore whether and to what extent the quality of EOLCC changes toward the end of life and whether EOLCC is related to patient-perceived quality of medical care.

Methods

Study Design

The present study is a secondary analysis of data from a multicenter, longitudinal study concerning palliative care needs among outpatients with advanced COPD, CHF, or CRF.[11,14,16–20] Home visits took place at baseline and four, eight, and 12 months after baseline. Two years after baseline, all patients, or their participating relatives, were contacted by telephone to assess survival status. If patients died within two years after baseline, a bereavement interview was conducted with the closest relative. The Medical Ethical Committee of the Maastricht University Medical Centre+, Maastricht, The Netherlands, approved this study (MEC 07-3-054). The study was registered at the Dutch Trial Register (NTR 1552).

Patients

Patients with advanced chronic organ failure and their closest relatives were recruited by their physician specialists at the outpatient clinic of one academic and six general hospitals in The Netherlands between January 2008 and June 2009. Patients were included if they had severe to very severe COPD (Global initiative for chronic Obstructive Lung Disease Stage III or IV),[21] end-stage CHF (New York Heart Association Class III or IV), or end-stage CRF (requiring dialysis). All participating patients provided written informed consent.

Instruments

The following outcomes were assessed at baseline: demographics; smoking history; hospital admissions in the previous year; previous admissions to the intensive care unit; previous mechanical ventilation and cardiopulmonary resuscitation; weight and height; current self-reported comorbidities (Charlson Comorbidity Index[22]); anxiety and depression (Hospital Anxiety and Depression Scale[23]); satisfaction with medical treatment patients received for their chronic organ disease, using a Visual Analogue Scale ranging from 0 (not satisfied) to 100 mm (very satisfied); general health status (Medical Outcomes Study 36-Item Short-Form Health Survey).[24]

Quality of EOLCC was assessed using the EOL subscale of the Quality of Communication (QOC) questionnaire.[25] In this questionnaire, patients are asked to rate how good the physician specialist primarily responsible for the management of their chronic disease is at each of the communication skills. The subscale EOL communication (QOC-EOL) comprises seven items, and each item is rated on a scale of 0 (“the very worst”) to 10 (“the very best”). In addition, patients were offered two additional response options: “My doctor didn’t do this” and “Don’t know.” The domain score was calculated from the average from all endorsed items and was calculated for patients who had at least four valid items. This score ranges from 0 (“worst”) to 10 (“best”). The answer “My doctor didn’t do this” was replaced by a score of 0, and “Don’t know” was replaced by the median domain score of the valid items for the individual, as suggested by the QOC questionnaire developers.[25,26] The QOC questionnaire is a validated instrument and meets the standards of scale measurement, including good construct validity and internal consistency (Cronbach’s $\alpha \geq 0.79$).[26]

Details of the study design and baseline data on EOLCC have been previously published.[11,12,14,17,27]

Statistical Analysis

Statistics were done using SPSS 21.0 (SPSS Inc., Chicago, IL). Categorical variables are described as frequencies, and continuous variables were tested for normality and are presented as mean and SD or median and interquartile range. Categorical variables were compared between patients who completed the study, patients who died during the study, and patients who withdrew from the study because of other reasons, using a one-way analysis of variances with independent sample t-tests as post hoc tests or Kruskal-Wallis followed by Mann-Whitney U-tests, as appropriate.

Quality of EOLCC at baseline and four, eight, and 12 months was compared using the Friedman test. Only patients who completed the study were included in this analysis. A Mann-Whitney U-test was used to compare the quality of EOLCC at baseline and four, eight, and 12 months between patients who completed a two year follow-up and patients who died between one and two year follow-up over one