Original Article

Dynamic Preferences for Site of Death Among Patients With Advanced Chronic Obstructive Pulmonary Disease, Chronic Heart Failure, or Chronic Renal Failure

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Abstract

Context. To die at the preferred site is a key principle of a good death.

Objectives. To examine one-year stability of preferences for site of death among patients with advanced chronic organ failure, and to assess agreement between the actual site of death and the site patients indicated in advance as their preferred site.

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 their preferred site of death. One-year follow-up was completed by 77.7% of the patients. A bereavement interview was done with the closest relative of patients who died within two years after baseline ($n = 66$, 24.9%) to assess their actual site of death.

Results. During one-year follow-up, 61.2% of the patients changed their preference for site of death. During the home interview before their death, 51.5% reported to prefer to die at home. A considerable portion of the patients (57.6%) died in the hospital, and 39.4% of the patients died at the site they reported previously as their preferred site ($\kappa = 0.07$, $P = 0.42$).

Conclusion. Preferences for site of death may change in patients with advanced chronic organ failure. Future studies should explore whether and to what extent discussing the possibilities for the site of end-of-life care as a part of advance care planning can prepare patients and relatives for in-the-moment decision making and improve end-of-life care.

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Key Words
Terminal care, palliative care, advance care planning, pulmonary disease, chronic obstructive, congestive heart failure, kidney failure, chronic

Introduction

To die at the preferred site is one of the key principles of a good death.[1] Home is often seen as the most preferable site to die,[2,3] as it represents for patients the presence of loved ones, familiarity, and comfort.[4] Studies that mainly included patients with cancer showed a wide range in the proportion of patients who preferred to die at home (24–100%).[5–7]

Determining the preferred site of death may be an important component of advance care planning for patients with advanced chronic organ failure such as chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), or chronic renal failure (CRF).[8] Indeed, a previous study showed that approximately 90% of the clinically stable outpatients with advanced COPD or CHF were able to indicate their preferred site of death.[9] Studies in patients with cancer suggest that preferences for site of death may change during progression of the disease.[10–12] To date, stability of preferences for site of death is unknown in patients with chronic organ failure. Therefore, it remains unknown whether previously documented preferences for site of death can serve as a reliable proxy in situations when patients are too ill to participate in decision making.

In studies that mainly included patients with cancer, agreement between the preferred site of death and the actual site of death ranged from 30% to 91%.[5,6] Patients with a malignant disease may be more likely to die at home than patients who die because of nonmalignant diseases.[13,14] This may reflect the difficulty in predicting prognosis in patients with life-threatening nonmalignant diseases such as chronic organ failure.[15] Indeed, unexpected death occurs frequently in patients with advanced COPD, CHF, or CRF.[16–19] Therefore, it may be difficult to achieve dying at the preferred site for these patients. Currently, it is unknown how often patients with advanced chronic organ failure die at the site they prefer.

The objectives of the present study were to examine the stability of preferences for site of death during one-year follow-up among patients with advanced COPD, CHF, or CRF, and to assess the agreement between the actual site of death and the site these patients indicated in advance as their preferred site.

Methods

Study Design

The present study is a secondary analysis of a multicenter, prospective, longitudinal study concerning palliative care needs among patients with advanced COPD, CHF, or CRF.[9,20–25] Patients were visited in their home environment at baseline and every four months after baseline for a period of one year. If patients died during one-year follow-up, a bereavement interview was done with the closest relative. Two years after baseline, all patients, or their participating closest relatives, were contacted by telephone. For patients who died between one and two years after baseline, a bereavement interview was conducted with the closest relative two years after baseline. 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

Clinically stable outpatients with advanced COPD, CHF, or CRF were recruited by their physician specialist at the outpatient clinic of one academic and six general hospitals in The Netherlands. Patients were eligible if they had a diagnosis of severe to very severe