

Original Article

End-of-Life Communication: A Retrospective Survey of Representative General Practitioner Networks in Four Countries

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Abstract

Context. Effective communication is central to high-quality end-of-life care.

Objectives. This study examined the prevalence of general practitioner (GP)-patient discussion of end-of-life topics (according to the GP) in Italy, Spain, Belgium, and The Netherlands and associated patient and care characteristics.

Methods. This cross-sectional, retrospective survey was conducted with representative GP networks. Using a standardized form, GPs recorded the health and care characteristics in the last three months of life, and the discussion of 10 end-of-life topics, of all patients who died under their care. The mean number of topics discussed, the prevalence of discussion of each topic, and patient and care characteristics associated with discussions were estimated per country.

Results. In total, 4396 nonsudden deaths were included. On average, more topics were discussed in The Netherlands (mean = 6.37), followed by Belgium (4.45), Spain (3.32), and Italy (3.19). The topics most frequently discussed in all countries were “physical complaints” and the “primary diagnosis,” whereas “spiritual and existential issues” were the least frequently discussed. Discussions were most prevalent in The Netherlands, followed by Belgium. The GPs from all

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countries tended to discuss fewer topics with older patients, noncancer patients, patients with dementia, patients for whom palliative care was not an important treatment aim, and patients for whom their GP had not provided palliative care.

Conclusion. The prevalence of end-of-life discussions varied across the four countries. In all countries, training priorities should include the identification and discussion of spiritual and social problems and early end-of-life discussions with older patients, those with cognitive decline if possible, and those with non-malignant diseases. *J Pain Symptom Manage* 2014;47:604–619. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Patient-physician communication, palliative care, terminal illness, patient participation, cross-national

Introduction

Palliative care involves the “identification and impeccable assessment of physical, psychosocial, and spiritual suffering.”¹ Such high-quality assessment requires the discussion of a range of end-of-life topics, such as diagnosis, prognosis, treatment preferences, and psychosocial and spiritual issues. These end-of-life discussions enable health care professionals to recognize their patients’ values and preferences and are an important step in the provision of care commensurate with patients’ wishes.²

Good end-of-life communication enhances patients’ understanding of their condition and care and treatment options,² facilitates informed participation in decision making,² and is repeatedly identified as important for patient and caregiver satisfaction with end-of-life care.^{3,4} Suboptimal communication, in contrast, may result in poor pain and symptom management,⁵ psychological and spiritual distress,^{6,7} and a lack of knowledge concerning patients’ preferences.⁶ Considering the centrality of communication in high-quality end-of-life care, it is important to understand how often physicians discuss different end-of-life issues with patients and the factors that influence discussions.

There is, however, little evidence concerning the topics that are discussed between physicians and patients at the end of life and even less from a cross-country perspective. International comparisons draw attention to factors that are universally important and those that are country specific, highlight examples of

“best practice,” and inform policy nationally and internationally.

Previous cross-national research has been mostly limited to attitudinal or prevalence studies focusing on diagnosis, prognosis, and treatment discussions.^{8–11} These studies revealed differences between countries, differences that were ascribed to cultural, social, and institutional influences.^{8–11} Furthermore, a study by Cartwright et al.¹² estimated the topics that, in principle, physicians from Australia and six European countries discuss with patients at the end of life.¹² However, Cartwright et al.¹² did not examine the topics that were actually discussed with individual patients. There is, therefore, no cross-country empirical research on the actual prevalence of physician-patient discussion of end-of-life topics in Europe.

This study examines the prevalence of general practitioner (GP)-patient discussion of different end-of-life topics in Italy, Spain, Belgium, and The Netherlands. The GPs were chosen because, although complex cases are often referred for a time to specialist care, much end-of-life care is provided in primary care settings.^{13,14} The GP’s role in end-of-life care provision, together with related laws, policy, and training in each country, is detailed in [Table 1](#). The study draws on data collected by representative GP networks as part of the European Sentinel Network Monitoring End-of-Life Care (EURO SENTIMELC) project, which aims to describe and compare care provided to patients in the last three months of life. Specific objectives of this study are: to estimate and compare the prevalence of GP-patient

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