

**Original Article**

# General Practitioner Awareness of Preferred Place of Death and Correlates of Dying in a Preferred Place: A Nationwide Mortality Follow-Back Study in The Netherlands

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**Abstract**

*To improve the quality of end-of-life care, general practitioner (GP) awareness of where their patients prefer to die is important. To examine GP awareness of patients' preferred place of death (POD), associated patient- and care-related characteristics, and the congruence between preferred and actual POD in The Netherlands, a mortality follow-back study was conducted between January 2005 and December 2006. Standardized registration forms were used to collect data on all nonsudden deaths (n = 637) by means of the Dutch Sentinel Network, a nationally representative network of general practices. Forty-six percent of patients had GPs who were not aware of their preferred POD. Of those whose GPs were aware, 88% had preferred to die in a private or care home, 10% in a hospice or palliative care unit, and 2% in a hospital. GPs were informed by the patients themselves in 84% of cases. Having financial status "above average," a life-prolongation or palliative care goal, and using specialist palliative care services were associated with higher GP-awareness odds. Four-fifth of patients with known preferred POD died there. There is a potential for improving GP awareness of patients' preferred POD. Such awareness is enhanced when palliation is an active part of end-of-life care. The hospital is the POD least preferred by dying patients. J Pain Symptom Manage 2009;38:568–577. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

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### Key Words

General practitioner awareness, GP, Sentinel Network, place of death, end-of-life care, The Netherlands

## Introduction

Approximately two-thirds of all deaths are nonsudden and protracted.<sup>1</sup> For these people, death can be anticipated, making the provision of end-of-life care a relevant consideration. General practitioners (GPs) play a vital role in ensuring that patients are carried along as they manage their care, because many patients are under their care in the final phase of their lives.<sup>2,3</sup> Awareness of preferences is key to be able to tailor care to the patients' wishes, minimize decision-making burdens on relatives and carers,<sup>2</sup> and effectively plan and execute end-of-life care programs. One important subject that GPs need to be aware of is where their patients would prefer to receive terminal care and die, across the multiple settings in which death would normally occur.<sup>4-7</sup>

Care settings at the time of death affect the philosophy of care and the types and intensity of services that can be delivered. Who controls these services, expectations for care, and the skill and availability of professional caregivers ultimately exerts an influence on the quality of a person's death.<sup>5,8,9</sup> Although it is known that most patients prefer to die at home,<sup>10-13</sup> studies clearly suggest that significant proportions would rather die in care homes,<sup>12,14,15</sup> in hospices,<sup>16,17</sup> and in hospitals.<sup>18-21</sup> Unfortunately, most of these studies were undertaken within specific patient populations (e.g., cancer patients) or specialized settings (e.g., old peoples' homes); hence, it is often difficult to generalize the results. Arguably, there is a distinction between preferences of patients and the choices actually available to them.<sup>22,23</sup> Although dying in a preferred place may not be feasible in every case,<sup>17,24,25</sup> an awareness by the GP of what is preferred is fundamental<sup>7</sup> in providing relevant care. It is likely that certain patient- or care-related characteristics are related, directly or indirectly, to GP awareness of patients' preference,<sup>6,22,23</sup> and to a patient's ability to die in a preferred place.<sup>9,25-28</sup>

A basic prerequisite for GP awareness of patients' care preferences is communication.<sup>26,29-32</sup>

Literature on GP-patient communication at the end of life shows that discussing "death and dying" could prove challenging for some GPs, especially those who have had close and/or prolonged relationships with their patients.<sup>7,30</sup> However, purposeful exploration of patient preferences, particularly when done in a sensible and caring manner, is key to improving the overall care process.<sup>2,3</sup> Moreover, some patients become incompetent as their illnesses progress, making GP awareness of their end-of-life care preferences, whether verbal or in writing, particularly useful.<sup>3</sup>

This study sought to examine GP awareness of the preferred place of their patients' death, and whether this awareness was related to patient and care characteristics. Furthermore, it assessed the extent to which those patients whose GPs knew their preferred places of death actually died there.

## Methods

### Study Design and Population

Patients were recruited by means of the Dutch Sentinel Network of GPs, an existing nationwide health surveillance instrument.<sup>33-36</sup> This network consists of 45 general practices (65-70 GPs) and covers approximately 1% of the entire 16 million registered patient population in The Netherlands.<sup>35,36</sup> It is evenly distributed in terms of the number of patients per GP, both in population and degree of urbanization.<sup>35,36</sup>

The data collection process was managed by The Netherlands Institute of Health Services Research (NIVEL). Within one week of reporting a patient's death, the participating Sentinel GPs were asked to fill in a short registration form on the care the deceased received in the last three months of life.<sup>36</sup> All sudden or totally unexpected deaths were excluded. Also excluded were deaths of patients less than one year of age to eliminate deaths that might have resulted from congenital causes. On completion, the registration forms were returned to NIVEL, where they were

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