

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.¹ 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.^{2,3} Awareness of preferences is key to be able to tailor care to the patients' wishes, minimize decision-making burdens on relatives and carers,² 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.⁴⁻⁷

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.^{5,8,9} Although it is known that most patients prefer to die at home,¹⁰⁻¹³ studies clearly suggest that significant proportions would rather die in care homes,^{12,14,15} in hospices,^{16,17} and in hospitals.¹⁸⁻²¹ 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.^{22,23} Although dying in a preferred place may not be feasible in every case,^{17,24,25} an awareness by the GP of what is preferred is fundamental⁷ 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,^{6,22,23} and to a patient's ability to die in a preferred place.^{9,25-28}

A basic prerequisite for GP awareness of patients' care preferences is communication.^{26,29-32}

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.^{7,30} However, purposeful exploration of patient preferences, particularly when done in a sensible and caring manner, is key to improving the overall care process.^{2,3} 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.³

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.³³⁻³⁶ 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.^{35,36} It is evenly distributed in terms of the number of patients per GP, both in population and degree of urbanization.^{35,36}

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.³⁶ 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

closely scrutinized for errors, duplicated, and then sent to the researchers for analyses. Approval from the Dutch Ethical Review Board was not required because our data were collected from deceased patients. Patient and physician anonymity was preserved throughout the registration process, and NIVEL maintained its standardized protocol for monitoring the scale and continuity of case reporting per practice.^{35,36}

Before commencing this research, the authors, after a review of the literature, had developed a registration form along themes relevant to end-of-life care. The contents were reviewed for validity by multidisciplinary team members, and pretested by some GPs for readability and comprehensibility. This method of monitoring end-of-life care by means of a Sentinel Network of GPs (SENTI-MELC) was developed and successfully applied in Belgium, and the protocol of the study design has been published.³³

Research Instrument

The research instrument, a 15-item registration form, included multiple-choice and open-response questions for exploring, from a nonsudden death population, characteristics of patients, and the care they received in specified time frames (second to third month/second to fourth week/last week) within the last three months of life. Patient characteristics included basic sociodemographic information, cause of death, and preferred place of death (POD); care characteristics included locations of care in the last three months of life, GP awareness of POD, involvement of specialist (multidisciplinary) palliative care services, the main goal of the patient's treatment (curative/life prolonging/palliative), the main focus of care (physical/psychosocial/spiritual), the place of care (three months to weeks before death), and the actual POD.

To eliminate those patients who in principle were not eligible to have received end-of-life care, a routine question was asked: "Was the patient's death sudden and totally unexpected?" With regard to the GPs' awareness of the patient's preferred POD, they were asked "Were you aware (verbally or in writing) of where this patient preferred to die?," "Who informed you?" (patient/family member/specify, if other), and "Where did this patient wish to

die?" (at home or with family/in a care home/in a hospital/in a hospice or palliative care unit).

Statistical Analysis

Using SPSS 14.0, the nonsudden deaths were selected ($n = 637$), and logistic regression analyses were used to identify the variables that were associated with a GP being aware of where his patient preferred to die. Associated patient and care characteristics (variables) were analyzed using univariate logistic regression. Next, all variables having significant relationships were included in a stepwise backward logistic regression to make a predictive model. Variables were removed if $P > 0.05$.

Place of Death in the Dutch Context

Places for receiving terminal care and dying in The Netherlands include patients' own homes or with family members; care homes otherwise known as "verzorgingshuizen;" hospices or palliative care units; hospitals; and nursing homes, otherwise known as "verpleeghuizen." These places offer a variety of care packages. The care homes provide basic formal assistance to patients and are considered "home" by many, because patients reside there in the last phase of their lives. Care home patients remain under the care of their GPs.⁴ Hospices and palliative care units exist independently, but could also operate from private homes, hospitals, care homes, and nursing homes.³⁷ They provide more specialized end-of-life-care options, for which reason some units have GPs attached to them. However, patients usually continually maintain contact with their GPs.³⁷ Therefore, GPs are the physicians with the best overview of care received and place of care in the last phase of life. The nursing homes provide care predominantly for the elderly, and are unique in the sense that they have their own (nursing home) physicians.^{4,38} Care trajectories that involve long-term stay in nursing homes are essentially outside the purview of the GPs.

Representativeness of the Data

To investigate the representativeness of the data for all deaths in The Netherlands, we compared gender and age of our sample per setting with figures for all deaths per setting in The Netherlands. The data on all deaths were derived from the Dutch national bureau

for statistics (Statistics Netherlands) for the year 2006. Table 1 shows no statistically significant differences for sex and age between our sample (both expected and unexpected) and all deaths, namely home deaths, care home deaths, and hospital deaths; that is, the percentages of the national death rates fall within the 95% confidence interval (CI) of this cohort. The hospital deaths were somewhat underrepresented (40% vs. 45% of all deaths excluding nursing home deaths), and for patients 80 years or older, somewhat overrepresented (47% vs. 41%), perhaps because of underreporting of some hospital deaths. However, the national value falls well within the 95% CI in our study data. The nursing home deaths were obviously infrequently reported, and given the Dutch situation, are clearly not comparable with all nursing home deaths in The Netherlands. These differences were to be expected, because nursing home physicians take over care from GPs once transferred, and subsequent monitoring of such patients by their GPs is nonexistent or irregular.³⁸ For this reason, we decided to exclude all nursing home deaths from our study and to weigh our data for POD. The resulting data are representative for all deaths, that is, excluding nursing home deaths, in The Netherlands.

Results

Of the 637 nonsudden deaths (aged one year or older) that the Sentinel GPs registered, 52% were men. Most of the deaths were of patients older than 80 years (53%), followed by patients 41–80 years (44%); death most commonly resulted from malignancies (43%) and cardiovascular diseases (29%). Excluding nursing homes, 34% of all the deaths occurred at home (private or with family), 16% in a care home, 40% in a hospital, and 9% in a hospice or palliative care unit.

Table 2 shows the incidence of GP awareness of patients' preferred POD within the last three months of life. Slightly more patients had GPs who were aware of their preferred POD than those unaware. Of GPs who were aware of their patients' preferred POD, 84% were informed by the patients themselves and 44% (also) by family members of the patients. Most of the patients preferred to die

Table 1
Demographics of Deceased People of One Year and Older per Setting^a for All Deaths (Sudden and Nonsudden) in the SENTI-MELC Study and for All Deaths in The Netherlands—Comparability of the 2005–2006 Dutch SENTI-MELC Study with 2006 National Death Statistics^b

Characteristics	Home		Care Home		Hospital		Nursing Home	
	SENTI-MELC (n = 321)	All Deaths (n = 36,467)	SENTI-MELC (n = 137)	All Deaths (n = 15,065)	SENTI-MELC (n = 300)	All Deaths (n = 42,076)	SENTI-MELC (n = 55)	All Deaths (n = 31,122)
	% (95% CI)	%	% (95% CI)	%	% (95% CI)	%	% (95% CI)	%
Sex								
Men	60 (54–66)	58	27 (19–35)	28	56 (50–62)	53	48 (33–63)	37
Women	40 (34–46)	43	73 (65–81)	72	44 (38–50)	47	52 (37–67)	63
Age (years)								
1–49	7 (5–11)	8	0	0	3 (2–6)	6	2 (0–10)	1
50–79	56 (51–62)	61	10 (5–16)	12	50 (44–55)	54	45 (32–60)	28
80 and older	37 (31–42)	31	90 (85–95)	88	47 (41–53)	41	53 (39–67)	71

^aThe group "other setting" was not included: 23.1% of all deaths and 5.7% of deaths in the MELC study.
^bDerived from Statistics Netherlands (2006) Central Death Registry.

Table 2
GP Awareness of Patients' Preferred Place
of Death ($n = 637^a$)

Characteristics	% ($n = 637$)
Not aware of patient's preferred place of death	46
Aware of patient's preferred place of death	54
The general practitioner was informed by ($n = 374$) ^b	
Patient himself/herself	84
A family member or a significant relative	44
Specialist, carer, or some other person	3
Preferred place of death for these patients ($n = 374$) ^b	
At home (private or with family)	69
In a care home	19
In a hospice or palliative care unit	10
In a hospital	2

^aWeighted percentages, excluding nursing home deaths.

^bMore than one answer possible.

at home, although some preferred to die in a care home, a hospice or palliative care unit, and in a hospital.

Table 3 shows patient and care characteristics of the patients, and their association with the GPs' awareness of patients' preferred POD. Of the patient characteristics assessed, only the patients' financial status remained associated with GP awareness in the multiple regression analysis; patients with a financial status above average (as estimated by the GP) had about a seven times higher chance of the GP awareness of their preferred POD than those financially below average. Having cancer, as opposed to other diagnoses, was positively associated univariately (odds ratio [OR]: 3.2), but did not remain so in the multivariate analysis.

Although all investigated care characteristics were univariately associated with GP awareness, five variables remained significant in the multivariate analysis. Those positively associated with GP awareness were being cared for at home, receiving care directed at palliation or life prolongation (rather than cure) in the last two to three months of life, using specialized palliative care services, receiving care that was focused on spiritual or psychosocial needs (rather than physical) in the last week of life, and dying elsewhere

than in a hospital (especially strong for dying at home; OR: 24).

Table 4 shows the relationship between preferred and actual POD in percentages for those patients whose GPs were aware of their preferred POD. The proportion of patients whose preferences were met was calculated, as per the actual POD. Overall, 84% of the patients died in the place they had preferred. When the patient's preference was for a hospital death, it was met in all cases. The lowest proportion of patients whose preferences were met died at home or in a hospice.

Discussion

This study provides information on GP awareness of their patients' preferred POD, dying in a preferred place, and factors that are related to them. It is the first study reporting on end-of-life care from a general end-of-life patient population in The Netherlands. Its methodology is akin to one previously used in Belgium,³³ and the nationwide collection of reliable data was made possible by the participation of committed Sentinel GPs.³³⁻³⁶

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. The GPs had been 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-fifths of patients with known preferred POD died there.

Our data were sourced by means of the Sentinel Network of GPs in The Netherlands. This network is well suited for reporting in retrospect, prospectively collected data through a continuous morbidity registration process, and its outcome is typically used for monitoring and harmonizing health information.³³⁻³⁶ The general practice milieu additionally suits our study, because in The Netherlands, registration with a GP is compulsory for access to health care.^{35,36} The Dutch primary care system is equally accessible to all sociodemographic subgroups.³⁶ Also, involving GPs ensured that the quality of registration was

Table 3
 Characteristics Associated with GP Awareness of Patients' Preferred Place of Death ($n = 637^a$)

Characteristics	% of Patients for Which GP Was Aware ^b		Logistic Regression ^c	
	No	Yes	Univariate	Multivariate ^d
	%	%	Odds Ratio (95% CI)	Odds Ratio (95% CI)
<i>Patient characteristics</i>				
Age (years)				
1–64	41	59	1.0	^e
65–89	50	50	0.7 (0.5–1.1)	
90–105	38	62	1.2 (0.7–2.1)	
Gender				
Male	43	57	1.0	^e
Female	46	54	0.9 (0.6–1.3)	
Relational status				
Having a regular partner	43	57	1.2 (0.9–1.6)	^e
Without regular partner	47	53	1.0	
Financial status				
Below average	54	46	1.0	1.0
Average	47	53	1.3 (0.9–2.0)	2.4 (1.3–4.7)
Above average	29	71	2.9 (1.7–4.7)	5.8 (2.2–15.1)
Primary cause of death				
Cancer	30	70	3.2 (2.3–4.4)	^f
Not cancer	57	43	1.0	
<i>Care characteristics</i>				
2–3 Months before death				
Location of care				
Home	44	56	1.0	1.0
Other	46	54	0.9 (0.6–1.5)	0.4 (0.2–1.0)
Main goal of treatment				
Curative	71	29	1.0	1.0
Life prolonging	37	63	4.0 (2.4–6.7)	3.5 (1.6–7.9)
Palliative	26	74	6.9 (4.4–10.9)	4.1 (2.0–8.4)
Main focus (domain) of care				
Physical	51	49	1.0	^f
Psychosocial	33	67	2.1 (1.3–3.3)	
Spiritual	43	57	1.3 (0.9–2.1)	
No. of care setting transitions				
None	18	82	3.3 (2.1–5.3)	^f
One	68	32	0.3 (0.2–0.5)	
Two or more	42	58	1.0	
Use of specialized PC services				
Present	23	77	1.0	1.0
Absent	54	46	0.3 (0.2–0.4)	0.4 (0.2–0.9)
7 Days before death				
Place of care ²				
Hospital	83	17	1.0	1.0
Home	10	90	40.1 (23.3–69.2)	27.4 (12.6–59.4)
Care home	33	67	9.5 (5.7–16.1)	13.9 (5.6–34.7)
Hospice	31	69	11.1 (5.9–20.9)	7.5 (2.6–21.2)
Main care domain				
Physical	62	38	1.0	1.0
Psychosocial	36	64	2.9 (1.8–4.7)	1.3 (0.6–3.0)
Spiritual	42	58	2.2 (1.4–3.5)	3.0 (1.3–6.9)

PC = palliative care.

^aBetween 1% and 9% of these values could not be provided by the GP (i.e., missing observations).

^bWeighted row percentages.

^cDependent variable: GP aware of patient's preferred place of death ($n = 374$); reference group: GP unaware ($n = 316$).

^dStepwise backward logistic regression (significant values in bold print).

^eNot entered in multiple backward logistic regression.

^fVariable removed within Steps 2–7 of the backward regression analysis.

Table 4
 Percentage Agreement Between Preferred and Actual POD for Patients Whose GPs Were Aware
 of Their Preferred POD (*n* = 374)

Preferred POD ^a	Actual POD ^a				
	% Home (95% CI)	% Care Home (95% CI)	% Hospital (95% CI)	% Hospice (95% CI)	% Total (<i>n</i> = 374)
Home	83 (78–88)	3 (1–6)	13 (9–18)	1 (0.1–3)	100 (<i>n</i> = 221)
Care home	6 (2–14)	92 (84–97)	1 (0.3–6)	0 (—)	100 (<i>n</i> = 79)
Hospital	0 (—)	0 (—)	100 (91–100)	0 (—)	100 (<i>n</i> = 41)
Hospice	6 (1–24)	0 (—)	11 (1–31)	83 (62–97)	100 (<i>n</i> = 20)

^aRounded percentages, weighted values, excluding 13 reported nursing home deaths.

high and virtually all the Sentinel deaths were captured, because GPs are routinely informed about the death of their patients, and Sentinel GPs are specially trained for this form of data collection.^{33–35} With the exclusion of all nursing home deaths, our sample was representative nationally. The lack of representativeness for nursing home patients is a limitation that was expected because nursing home physicians take over care from GPs once patients are admitted in nursing homes for long-term care.^{4,38} Another limitation was the use of information derived from GPs alone, rather than alongside information from the patients themselves—research demonstrates that “proxies” are not very accurate in representing patient needs.³⁹

This study portrays a patient’s financial (or social) status as being important in determining GP awareness of preferred POD. Although it is known that a higher socioeconomic status generally translates to more education and more access to information, Andersen’s model on the use of health services explains how a person’s financial status could determine his (or her) ability to cope with presenting problems and command resources to deal with them.³² Other patient characteristics, such as age and gender, were, however, not associated with GP awareness.

Among the various care characteristics analyzed, patients whose care focused on palliation (comfort) or prolongation of life appeared to have discussed their preferred POD with their GPs more often as opposed to those with care focused on cure. This could be related to the fact that many of these patients died from cancer-related causes, which have a more predictable trajectory toward death,⁴⁰ and that cancer patients are more

likely to discuss end-of-life issues with their caregivers than noncancer patients.^{16,17,26} Similarly, caregivers are more likely to refer cancer patients for specialist palliative care services.^{41,42} With respect to the focus of care, GP awareness of a patient’s preferred POD was realized more often when the care focus was on psychosocial or spiritual (religious and existential) needs. Both forms of care could be used as proxies for good GP-patient communication,⁴³ and for assessing a GPs orientation toward end-of-life care.⁴⁴

Again from this study, it comes as no surprise that patients with more chances of GP contact, or more communication (i.e., those at home, in care homes, and hospices, rather than hospitals) tended to die more often in a preferred place. Van Royen et al.,⁴⁵ using a theoretical framework of items showed that, aside from creating a closer GP-patient relationship, home visits actually allow for in-depth understanding of patient contextual information, and this might explain the higher congruence observed in these patients. Furthermore, GP awareness was relatively higher (82%) among patients who had experienced no transitions in location of care in the last three months of life, irrespective of the place of care, although only in the univariate analysis. Although it is known that some transitions in location or domain of care are inevitable,⁴⁶ it could again be suggested that patients who are transferred are less likely to have GPs who are aware of their preferred POD. This is because some transfers disrupt the flow of care and attention that patients receive from their GPs.^{7,46} It is also possible that, for some of these patients, the focus of care remained curative for a significant proportion of the illness time, resulting for instance, in recurrent

hospital transitions. This may explain why the care setting transitions were not significant in the multivariate analysis, as the aim of treatment was significant in this analysis.

Although previous studies from selected populations have shown that most patients wish to die at home,^{10–13} our study shows that about one in five patients prefer to die in a care home and one in 10 patients in a hospice or palliative care unit. More so, in the Dutch context, a care home is really “home” for most residents, and more people appear to be choosing care home deaths. Gott et al.,¹⁸ in a study of older people, demonstrated that although patients generally considered home as their ideal place of care during dying, others identified practical problems in achieving this. Hence, they prefer to die anywhere (other than home), but simultaneously strive for factors associated with home, such as the presence of family, familiarity, and comfort.¹⁸

Again from our results, GPs were twice as likely to have been informed of a patient’s preferred POD by the patients themselves rather than by family members, and far less by other carers or even specialists. Although the exact time these GPs became aware was not examined in this study, one would suggest the need for timely exploration of care preferences directly from the patients themselves. Patients are often more comfortable sharing personal information with their GPs,^{47,48} and this opportunity is sadly lost if they are no longer able to communicate or represent themselves.^{3,39} Having said that, GPs should be aware that care preferences could change in the course of an illness and, therefore, make allowances for this.^{22,48}

Given that this study focused on nonsudden deaths only, the proportion of patients whose GPs were aware of their preferred POD (54%) would appear low. Possibly, this was because some GPs did not find it important to ask, judged it too early to ask, or probably, the patients were simply too sick to provide such information. Also, it makes sense that some GPs would be less aware of their patients preferred POD if such patients had not been directly under their care for prolonged periods in the last months of their lives, for example, those in hospital or in a hospice. However, the positive association between GP awareness

and reception of care focused mainly on palliation and life prolongation, use of specialized palliative care services, and reception of spiritual or psychosocial care in the last week of life, suggests that imminent recognition of palliative needs is important for achieving GP awareness. Although such an association may best be described as that of the “chicken and the egg,” this study suggests that a timely focus on palliative care is needful.

Finally, to provide quality care at the end of life, GPs require a sizeable amount of patient detail, for which open and direct communication about diagnoses, prognoses, and related preferences is encouraged.^{47,48} On-time recognition of impending death allows for better management of dying patients.⁴⁹ This could prove challenging when planning care for noncancer patients (such as those with congestive heart failure or chronic obstructive pulmonary disease), whose illness trajectories are relatively more complicated, and oftentimes less predictable.⁴⁰ GPs should be taught to determine the last phase of all illnesses, and trained to discuss the dying process more openly with patients, including where the patients would prefer to die. Such conversations, with patients, their family members, and primary caregivers, will allow GPs to make sharper assessments of their patients’ situations, and simultaneously prepare patients for all possible eventualities.^{2,43,48} On the whole, we advocate the employment of a more holistic approach to end-of-life care, and this incorporates palliation while seeking to provide cure.

In conclusion, this study demonstrates that there is a potential for improving GP awareness of patients’ preferred POD in The Netherlands. This can be achieved if palliative care ideals are integrated into general end-of-life care. Also it shows that the hospital remains the POD least preferred by a general practice population of patients facing death.

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References

1. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003;362(9381): 345–350.
2. Winzelberg GS, Hanson LC, Tulsky JA. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc* 2005;53:1046–1050.
3. Nakanishi M, Honda T. Processes of decision making and end-of-life care for patients with dementia in group homes in Japan. *Arch Gerontol Geriatr* 2009;48:296–299.
4. Veerbeek L, van Zuylen L, Swart SJ, van der Maas PJ, van der Heide A. The last 3 days of life in three different care settings in the Netherlands. *Support Care Cancer* 2007;15:1117–1123.
5. Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? *Gerontologist* 2002;42(Spec No 3): 54–67.
6. Weitzen S, Teno JM, Fennell M, Mor V. Factors associated with site of death: a national study of where people die. *Med Care* 2003;41:323–335.
7. Michiels E, Deschepper R, Van Der Kelen G, et al. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin 472. *Palliat Med* 2007;21:409–415.
8. Evans WG, Cutson TM, Steinhauer KE, Tulsky JA. Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. *J Palliat Med* 2006;9:100–110.
9. Martineau I, Blondeau D, Godin G. Choosing a place of death: the influence of pain and of attitude toward death. *J Appl Soc Psychol* 2003;33: 1973–1993.
10. Brown M, Colton T. Dying epistemologies: an analysis of home death and its critique. *Environ Plan A* 2001;33:799–821.
11. Burge F, Lawson B, Johnston G, Cummings I. Primary care continuity and location of death for those with cancer. *J Palliat Med* 2003;6:911–918.
12. Foreman LM, Hunt RW, Luke CG, Roder DM. Factors predictive of preferred place of death in the general population of South Australia. *Palliat Med* 2006;20:447–453.
13. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332(7540):515–521.
14. Husebo BS, Husebo S. Nursing homes as arenas of terminal care: practical aspects. *Tidsskr Nor Laegeforen* 2005;125:1352–1354.
15. Klinkenberg M, Visser G, van Groenou MI, et al. The last 3 months of life: care, transitions and the place of death of older people. *Health Soc Care Community* 2005;13:420–430.
16. Davies E, Linklater KM, Jack RH, Clark L, Moller H. How is place of death from cancer changing and what affects it? Analysis of cancer registration and service data. *Br J Cancer* 2006;95:593–600.
17. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000;3: 287–300.
18. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. *Palliat Med* 2004; 18:460–467.
19. Gu D, Liu G, Vlosky DA, Yi Z. Factors associated with place of death among the Chinese oldest old. *J Appl Gerontol* 2007;26:34–57.
20. Candib LM. Truth telling and advance planning at the end of life: problems with autonomy in a multicultural world. *Fam Syst Health* 2002;20:213–228.
21. Searight HR, Gafford J. Cultural diversity at the end of life: issues and guidelines for family physicians. *Am Fam Physician* 2005;71:515–522.
22. Munday D, Dale J, Murray S. Choice and place of death: individual preferences, uncertainty, and the availability of care. *J R Soc Med* 2007;100: 211–215.
23. Wheatley VJ, Baker JL. "Please, I want to go home": ethical issues raised when considering choice of place of care in palliative care. *Postgrad Med J* 2007;83(984):643–648.
24. Cohen J, Bilsen J, Hoofst P, et al. Dying at home or in an institution using death certificates to explore the factors associated with place of death. *Health Policy* 2006;78(2–3):319–329.
25. Tang ST, Liu TW, Lai MS, McCorkle R. Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan. *Soc Sci Med* 2005;61: 1560–1566.
26. Beccaro M, Costantini M, Rossi PG, et al. Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *J Epidemiol Community Health* 2006;60: 412–416.
27. Gruneir A, Mor V, Weitzen S, et al. Where people die: a multilevel approach to understanding influences on site of death in America. *Med Care Res Rev* 2007;64:351–378.
28. Pritchard RS, Fisher ES, Teno JM, et al. Influence of patient preferences and local health system characteristics on the place of death. *SUPPORT*

- Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. *J Am Geriatr Soc* 1998;46:1242–1250.
29. Burge F, McIntyre P, Kaufman D, et al. Family medicine residents' knowledge and attitudes about end-of-life care, Errata 494. *J Palliat Care* 2001;17:85.
30. Burgess TA, Brooksbank M, Beilby JJ. Talking to patients about death and dying. *Aust Fam Physician* 2004;33(1–2):85–86.
31. Deschepper R, Bernheim JL, Stichele RV, et al. Truth-telling at the end of life: a pilot study on the perspective of patients and professional caregivers. *Patient Educ Couns* 2008;71:52–56.
32. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav* 1995;36:1–10.
33. van den Block L, van Casteren V, Deschepper R, et al. Nationwide monitoring of end-of-life care via the sentinel network of general practitioners in Belgium: the research protocol of the SENTI-MELC study. *BMC Palliat Care* 2007;6:6.
34. Busse R, Wagner HP, Krauth C, Klein-Lange M, Schwartz FW. Sentinel practices in evaluating longer periods of care: quality of life and drug therapy of terminally ill persons in Lower Saxony (Germany). *J Epidemiol Community Health* 1998;52(Suppl 1):56S–60S.
35. van der Zee S, Saskia C, Hoek G, Brunekreef B. Incidence of influenza-like illness, measured by a general practitioner sentinel system, is associated with day-to-day variations in respiratory health in panel studies. *Am Epidemiol* 2000;152:389–392.
36. Donker GA Continuous morbidity registration at Dutch sentinel stations, 2006. In Press.
37. Echteld MA, Deliens L, van der WG, Ooms ME, Ribbe MW. Palliative care units in The Netherlands: changes in patients' functional status and symptoms. *J Pain Symptom Manage* 2004;28:233–243.
38. Hoek JF, Ribbe MW, Hertogh CM, van der Vleuten CP. The role of the specialist physician in nursing homes: the Netherlands' experience. *Int J Geriatr Psychiatry* 2003;18:244–249.
39. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? *Soc Sci Med* 2003;56:95–109.
40. Murray AS, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330:1007–1011.
41. Field D, Addington-Hall J. Extending specialist palliative care to all? *Soc Sci Med* 1999;48:1271–1280.
42. Higginson IJ, Addington-Hall JM. Palliative care needs to be provided on basis of need rather than diagnosis [letter]. *BMJ* 1999;318(7176):123.
43. Breitbart W, Gibson C, Poppito SR, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Can J Psychiatry* 2004;49:366–372.
44. Hsiao CJ, Boulton C. Effects of quality on outcomes in primary care: a review of the literature. *Am J Med Qual* 2008;23:302–310.
45. Van Royen P, De Lepeleire J, Maes R. Home visits in general practice: an exploration by focus groups. *Arch Public Health* 2002;60:371–384.
46. Burge FI, Lawson B, Critchley P, Maxwell D. Transitions in care during the end of life: changes experienced following enrolment in a comprehensive palliative care program. *BMC Palliat Care* 2005;4:3.
47. Pink J, Jacobson L, Pritchard M. The 21st century GP: physician and priest? *Br J Gen Pract* 2007;57(543):840–842.
48. Deschepper R, van der Stichele R, Bernheim JL, et al. Communication about end-of-life decisions with patients wishing to die at home: the making of guidelines for GPs in Flanders, Belgium. *Br J Gen Pract* 2006;56:14–19.
49. Teno JM, Shu JE, Casarett D, et al. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage* 2007;34:120–125.