

GPs' awareness of patients' preference for place of death

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ABSTRACT

Background

Being able to die in one's place of choice is an indicator of the quality of end-of-life care. GPs may play a key role in exploring and honouring patients' preferences for place of death.

Aim

To examine how often GPs are informed about patients' preferred place of death, by whom and for which patients, and to study the expressed preferred place of death and how often patients die at their preferred place.

Design of study

One-year nationwide mortality retrospective study.

Setting

Sentinel Network of GPs in Belgium, 2006.

Method

GPs' weekly registration of all deaths (patients aged ≥ 1 year).

Results

A total of 798 non-sudden deaths were reported. GPs were informed of patients' preferred place of death in 46% of cases. GPs obtained this information directly from patients in 63%. GP awareness was positively associated with patients not being hospitalised in the last 3 months of life (odds ratio [OR] = 3.9; 95% confidence interval [CI] = 2.8 to 5.6), involvement of informal caregivers (OR = 3.3; 95% CI = 1.8 to 6.1), use of a multidisciplinary palliative care team (OR = 2.5; 95% CI = 1.8 to 3.5), and with presence of more than seven contacts between GP and patient or family in the last 3 months of life (OR = 3.0; 95% CI = 2.2 to 4.3). In instances where GPs were informed, more than half of patients (58%) preferred to die at home. Overall, 80% of patients died at their preferred place.

Conclusion

GPs are often unaware of their patients' preference for place of death. However, if GPs are informed, patients often die at their preferred location. Several healthcare characteristics might contribute to this and to a higher level of GP awareness.

Keywords

advance care planning; end-of-life care; general practitioner; palliative care; preferred place of death; terminal care.

INTRODUCTION

In Western society, the importance of patient-centered care is increasingly recognised,¹ and personal autonomy and respect for patients' preferences at the end of life have become increasingly important.^{2,3} More specifically, being able to die in one's place of choice is considered a key indicator of the quality of end-of-life care and of a good death.^{4,5}

GPs may play a key role in exploring and honouring a patient's preference for place of death. In many countries, including Belgium, GPs have built up long-term relationships with their patients over the course of many years.^{6,7} They also play a central role at the end of life, as patients spend most of their time at home or in care homes in the final months before death, where GPs are their primary professional caregivers.⁸ As a result of their pivotal position, GPs can be the expert caregivers, initiating advance care planning, identifying where people would prefer to die, and coordinating care in accordance with the patient's preference.⁹ As many patients might lack the competence to make decisions at the end of life,¹⁰ timely communication between the GP and patient is of particular importance.¹¹

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How this fits in

GPs may play a major role in coordinating care at the end of life and in exploring patients' preferences for place of death. However, it is unknown how often GPs are aware of patients' preferences for place of death. Results of the current study show that less than half (46%) of GPs are informed about their patients' preferred place of death. However, if GPs are aware, patients often die in their place of choice. GP awareness is also positively associated with not being hospitalised, the involvement of informal caregivers, the use of a multidisciplinary palliative care team, and the presence of more than seven contacts between the GP and the patient or a significant other regarding the patient, all during the last 3 months of the patient's life.

Empirical data on how often GPs are informed about such preferences are lacking. Previous research has focused mainly on studying how many patients would like to die at home,¹²⁻¹⁴ but has not explored how often GPs are informed of this and about which patients they are informed. Also, it is unknown how often GPs are informed about patients' preferences by patients themselves or by proxies, which can also provide insights regarding patient autonomy. In addition, many previous studies have shown large variations in the proportion of patients preferring home death, or the proportion of patients dying at their place of choice. This is mostly due to differences in design or methodology, where studies have focused only on specific patient groups or care settings; for example, cancer patients or hospitalised patients.¹² Studies measuring across settings and patient groups are lacking.

This study focuses on the following research questions:

1. How often and by whom are GPs informed about their patients' wish for place of death, and what are the associated patient, disease, and healthcare characteristics?
2. What are the preferences of those patients about whom GPs are informed?
3. How often do those patients die in their place of choice and what are the associated patient, disease, and healthcare characteristics?

METHOD

Study design

A 1-year nationwide retrospective mortality study was carried out in 2006 in Belgium. Data were collected within the SENTI-MELC study: re¹⁵ the Study on Monitoring End-of-Life Care via the nationwide Sentinel Network of General Practitioners in Belgium. This GP network has been operational since 1979 and proved to be a reliable surveillance system for health-related epidemiological data.¹⁵⁻¹⁹ It covers 1.75% of the total Belgian population and is representative of all GPs in the country in terms of age, sex, and geographical distribution.^{19,20} In 2006, the network

counted 174 regularly participating GP practices.

Data collection

Each week all participating GPs reported, on a standardised registration form, every deceased patient in their practice aged 1 year or older. For each patient, GPs were asked whether the death had occurred 'suddenly and totally unexpectedly'; those deaths were excluded in order to identify a sample of dying persons for whom the provision of end-of-life care is a relevant consideration.^{15,21,22}

Several quality control measures (such as data entry with consistency, range, and skip checks, possibility of contacting GPs by phone, double data entry) were used to ensure optimal data quality.

Registration form

For all deaths, the registration form surveyed: age at death, sex, region of Belgium where the patient resided, living status (for example; living with regular partner at time of death), level of education, cause of death, and place of death. For all non-sudden deaths it further measured:

- whether the GP was informed, verbally or in writing, of the patient's preference regarding place of death. If yes, by whom the GP was informed (patient him/herself, patient's family or significant other, someone else) and where the patient preferred to die: at home or living with family, in a care home (home for older people or nursing home), in a hospital (excluding palliative care unit), in an inpatient palliative care unit, or elsewhere;
- main treatment goal in the last 3 months of life: cure, prolonging life, comfort/palliation;
- presence of a multidisciplinary palliative care service in the last 3 months of life (multidisciplinary home care or care home teams, mobile hospital teams, inpatient palliative care units, or palliative day care centre);
- involvement of informal caregivers during the last 3 months of life: not/sometimes/often;
- extent to which physical, psychosocial, and spiritual (existential/religious) care was provided in the last 3 months of life (1 = not/to a very small extent, to 5 = to a very large extent);
- number of contacts (consultations, home visits, excluding telephone contact) with the patient or with significant others regarding the patient in the last 3 months of life; and
- whether or not the patient was hospitalised during the last 3 months of life.

The number of GP contacts, the main treatment goal, and the extent to which physical, psychosocial, and spiritual care was provided were measured in three

separate time frames: final week of life, second to fourth week, and second to third month before death.

The registration form was originally developed in Dutch and translated via a forward-backward procedure into French, as the study covered both language regions of Belgium. The full registration form and more details on the SENTI-MELC study's methodology have already been published.¹⁵

Analyses

Fisher's exact tests were conducted to explore bivariate associations between patient, disease, and healthcare characteristics, and whether or not: (1) the GP was informed about the preference for place of death; and (2) there was congruence between the preferred and actual place of death. A multivariate logistic regression analysis was also used to investigate these associations while controlling for the other factors. All analyses were performed using SPSS (version 16.0).

RESULTS

Study population

In total, 1305 deceased patients were registered, of which 20 cases were excluded from further analysis because of too many missing data. Of the remaining 1285 patients, 62.1% ($n = 798$) died non-suddenly; these are described in Table 1.

Age, sex, and place of death of those who died in the Dutch-speaking part of Belgium were compared with the non-sudden deaths identified in another study representative of all deaths in the same part of the country ($n = 2128$).²³ There were no significant differences for these characteristics between studies (binomial 95% confidence interval [CI], exact method). No comparison data were available for the French-speaking part of Belgium.

GPs' awareness of patients' preferred place of death

GPs knew patients' preferred place of death in 363 (46%) of all 798 non-sudden deaths. They were informed directly by the patient in about 63% of cases: 40% (40.4%) by the patient only and 22% (22.2%) by both the patient and a family member or a significant other. Thirty-six per cent were informed by the patient's family or significant other only, and less than 2% by someone else.

Bivariate analyses showed that GPs were more often informed about preferred place of death for patients who died of cancer, for home deaths, and for patients who had never been hospitalised in the final 3 months of life (Table 2). GPs were also more often informed if they had had more than seven contacts with the patient or family over the last 3 months of life, if informal care was given, or if treatment had a

Table 1. Patient characteristics of the study population of non-sudden deaths ($n = 798$).^a

| Characteristic | <i>n</i> (%) |
|-------------------------------|--------------|
| Age at death, years | |
| 1–64 | 99 (12.5) |
| 65–79 | 275 (34.6) |
| ≥80 | 421 (53.0) |
| Sex | |
| Male | 404 (50.6) |
| Female | 394 (49.4) |
| Level of education | |
| Elementary or lower | 313 (43.5) |
| Lower secondary | 221 (30.7) |
| Higher secondary | 124 (17.2) |
| Higher education/university | 62 (8.6) |
| Cause of death ^{b,c} | |
| Cancer | 362 (45.8) |
| Non-cancer | 428 (54.2) |
| Place of death | |
| Home | 187 (23.4) |
| Care home ^e | 220 (27.6) |
| Hospital | 308 (38.6) |
| Palliative care unit | 83 (10.4) |

^aMissing values for age $n = 3$; level of education $n = 78$; and cause of death $n = 8$. ^bEncoded into ICD codes (coding by International Statistical Classification of Diseases and Related Health Problems). ^cCare homes include homes for older people and nursing homes.

palliative aim. The involvement of multidisciplinary palliative care services and the provision of psychosocial or spiritual care also contributed to a greater awareness by the GPs.

After multivariate logistic regression analysis (Table 2), four factors remained significant: GPs were almost four times more likely to be informed if patients were never hospitalised, more than three times more likely if informal care was provided, two and a half times more likely if a multidisciplinary palliative care initiative was involved, and three times more likely if they had had more than seven contacts with the patient or family, all in the last 3 months of life.

Preferred and actual place of death

If the GP was informed, then in more than half of cases (58%) the patient preferred to die at home (Table 3): 31% in a care home, and far less in other settings. For 72% of all patients who preferred to die at home, their preference was fulfilled. Patients who preferred to die elsewhere died at their place of choice in 83% or more of cases. Overall, for 80% of patients, congruence between the actual and the preferred place of death was attained.

Factors associated with congruence between the preferred and actual place of death

For those patients who wished to die at home, congruence was more often achieved if patients were not hospitalised in the last 3 months of life (86%

Table 2. Factors associated with GP awareness of the patient's preferred place of death (n = 796).

| Characteristics | Total n ^a | % Being informed | Bivariate P-value ^b | Multivariate OR (95% CI) ^c |
|--|----------------------|------------------|--------------------------------|---------------------------------------|
| Patient and disease characteristics | | | | |
| Age at death, years | | | | |
| 1–64 | 99 | 53.5 | 0.18 | ns |
| 65–79 | 274 | 42.7 | | |
| ≥80 | 420 | 45.7 | | |
| Sex | | | | |
| Male | 403 | 43.9 | 0.36 | ns |
| Female | 393 | 47.3 | | |
| Level of education | | | | |
| Elementary or lower | 313 | 44.1 | 0.48 | ns |
| Lower secondary | 221 | 46.2 | | |
| Higher secondary | 124 | 50.0 | | |
| Higher education/university | 62 | 53.2 | | |
| Cause of death | | | | |
| Cancer | 362 | 53.6 | <0.001 | ns |
| Non-cancer | 426 | 39.0 | | |
| Residence characteristics | | | | |
| Place of death | | | | |
| Home | 186 | 81.2 | <0.001 | — ^d |
| Care home | 219 | 50.7 | | |
| Hospital | 308 | 18.5 | | |
| Palliative care unit | 83 | 53.0 | | |
| Hospitalised in last 3 months of life | | | | |
| Not | 314 | 69.1 | <0.001 | 3.91 (2.78 to 5.56) |
| At least once | 474 | 30.2 | | ref |
| Region of Belgium | | | | |
| Dutch-speaking | 499 | 44.5 | 0.71 | ns |
| French-speaking | 225 | 47.6 | | |
| Brussels capital | 72 | 47.2 | | |
| Degree of urbanisation | | | | |
| Core of large city | 433 | 48.7 | 0.14 | ns |
| Average | 214 | 40.7 | | |
| Low or rural | 148 | 43.9 | | |
| Living with regular partner at time of death | | | | |
| Yes | 370 | 47.8 | 0.28 | ns |
| No | 420 | 43.8 | | |
| Healthcare variables | | | | |
| Number of GP contacts over last 3 months of life ^a | | | | |
| 0–7 | 402 | 27.9 | <0.001 | ref |
| >7 | 394 | 63.7 | | 3.04 (2.16 to 4.28) |
| Informal care over last 3 months of life | | | | |
| None or very little | 78 | 25.6 | <0.001 | ref |
| Sometimes/often | 676 | 49.4 | | 3.30 (1.78 to 6.12) |
| Treatment goal over last 3 months of life | | | | |
| Curative/life-prolonging | 121 | 24.8 | <0.001 | ns |
| Palliative | 230 | 61.3 | | |
| From curative/life-prolonging to palliative in last month | 361 | 46.3 | | |
| Other combinations | 37 | 27.0 | | |
| Specialist palliative care initiative delivered over last 3 months of life | | | | |
| Yes | 317 | 62.1 | <0.001 | 2.50 (1.78 to 3.52) |
| No | 439 | 35.8 | | ref |
| Physical care over last 3 months of life | | | | |
| Not or to a (very) small extent | 9 | 33.3 | 0.51 | ns |
| Average/to a (very) large extent | 702 | 47.3 | | |
| Psychosocial care over last 3 months of life | | | | |
| Not or to a (very) small extent | 122 | 33.6 | <0.001 | ns |
| Average/to a (very) large extent | 533 | 52.7 | | |
| Spiritual care over last 3 months of life | | | | |
| Not or to a (very) small extent | 276 | 45.3 | <0.001 | — ^f |
| Average/to a (very) large extent | 229 | 62.9 | | |

^aMissing values for being informed n = 2; age at death n = 3; level of education n = 76; cause of death n = 8; hospitalised in last 3 months of life n = 8; degree of urbanisation n = 1; living with regular partner at time of death n = 6; informal care n = 42; treatment goal n = 47; specialist palliative care initiative delivered n = 40; physical care n = 85; psychosocial care n = 141; and spiritual care n = 291. ^bFisher's exact test. ^cOdds ratio (OR) with 95% CIs from multivariate regression analysis (not informed as ref), performed for all bivariate tested significant associations. ^dNot taken into account in multivariate analysis because of potential multicollinearity problems with being hospitalised in last 3 months of life. ^eTotal number of contacts dichotomised at its median value. ^fNot taken into account in multivariate analysis because of potential multicollinearity problems with psychosocial care. ns = not significant. ref = reference category.

compared with 49% for those hospitalised at least once) and for those with whom the GP had more than seven contacts over the last 3 months of life (78% compared with 58% of those with seven contacts or fewer). Both factors remained significant when tested multivariately (odds ratio [OR] 5.65; 95% CI = 2.9 to 11.1 and OR 2.35; 95% CI = 1.2 to 4.7 respectively). Significance was reached for none of the other patient, disease, residence, or healthcare characteristics included in the registration form. Because the number of patients choosing to die in places other than home but not doing so was small, no factors were associated with the congruence between these preferred and actual places of death.

DISCUSSION

Summary of main findings

In Belgium, less than half of GPs had been aware of their deceased patients' preferred place of death. In cases where they were aware, they had been informed mostly by the patients themselves but also often by proxies. GP awareness was higher if, during the last 3 months of life, the patient was not hospitalised, if informal caregivers were involved, if a specialist multidisciplinary palliative care team was consulted, or if there were more than seven contacts between the GP and the patient or family. The majority of patients expressed a wish to die at home or in a care home, although a minority preferred to die in a hospital or a palliative care unit. Most incongruence between the actual and preferred place of death occurred for those patients wishing to die at home.

Strengths and limitations of the study

As far as the authors know, this is the first study investigating GP awareness of preference of place of death on a nationwide and population-based level. An important strength of the study is the use of a representative sample of non-sudden deaths, not restricted to a specific setting, age group, or disease, due to the fact that most of the Belgian population (95%), including care home residents, have their own GP who is easily accessible and consulted on a regular basis (79% of the population have contact with their GP at least once a year).²⁴ Another strength is the use of the representative,^{19,20} nationwide Sentinel Network of GPs, which is a highly reliable surveillance system for a wide variety of health-related epidemiological data, including end-of-life care provision.^{15,16,18,23,25,26} Consequently, the high quality of the network's research procedures (for example, weekly registrations which may limit memory bias, leaving little time between death and registration) guarantees data of high scientific quality.

There are also some limitations to this study. First, due to the retrospective approach, a possible

memory bias cannot be excluded entirely; for example, a patient's wishes might not always be registered in their records. Second, by measuring preference for place of death only if GPs had been informed, these results cannot be generalised to all deaths. Third, it was not possible to explore cause and effect relationships, only associations between GP awareness and patient/healthcare factors. Finally, the timing of or changes in expressed preferences were not measured, which could have provided more in-depth interpretation.

Comparison with existing literature

In cases where patients are hospitalised within the last 3 months of life, GPs appear to be less often informed of their wishes. This might mean that GPs, once informed, may actively contribute to preventing hospitalisations at the end of life, or that GPs more often set out to explore the patient's preference if the patient's situation allows the possibility of dying at home. However, it is more likely that GPs either lose track of their patient once hospitalised, or that it becomes much more difficult to communicate and to explore where these patients want to die. It probably also means that exploration or expression of wishes occurs relatively late in the dying process, as most hospitalisations take place close to the time of death.²⁶ This suggests that end-of-life care communication might best be started early in the progress of the illness, prior to the moment of possible hospitalisation. The Belgian guideline for GPs on end-of-life care communication ('Zorgzaam thuis sterven; een zorgleideraad voor huisartsen') could be a very useful instrument to deal with feelings of uncertainty and to initiate timely advance-care planning.²⁷

The positive association between the involvement of a multidisciplinary palliative care team and GP awareness might suggest that an expressed preference triggers GPs to get such a team involved so that the patient can die more easily at a preferred place, which is often at home. However, the association could also be explained conversely: involving such palliative care teams might also indicate that GPs recognise that the patient is in a terminal phase of life, making the exploration regarding their end-of-life care automatically more relevant.

Besides professional palliative care, the involvement of informal caregivers also increases the possibility of GPs being informed. Loved ones surrounding the patient may act as facilitators so that patients can more easily express their end-of-life wishes to their GP. Or GPs may discuss the patient's situation directly with the family, which is supported by the present results (58% informed by proxy). Studies have likewise shown that the presence of informal caregivers itself is strongly related to the possibility of staying at home

Table 3. Preferred and actual place of death of patients for whom the GP is informed of the preference (n = 363).^a

| Preferred place of death | n (%) | Actual place of death, % | | | |
|--------------------------|------------|--------------------------|-------------------|-------------------|----------------------|
| | | Home | Care home | Hospital | Palliative care unit |
| Home | 209 (57.7) | 71.8 ^b | 3.3 | 14.4 | 10.5 |
| Care home | 112 (30.9) | 0 | 92.9 ^b | 6.3 | 0.9 |
| Hospital | 17 (4.7) | 0 | 0 | 94.1 ^b | 5.9 |
| Palliative care unit | 24 (6.6) | 0 | 0 | 16.7 | 83.3 ^b |

^aMissing values preferred place of death n = 1. ^bPercentages of patients who eventually died at the expressed preferred place of death (of which the percentages are shown in the left part of the table).

(which is often the preferred place) until death.²⁸

The present finding that the majority of patients prefer to die at home in the presence of their loved ones fits well with other studies.^{12,13,29} Overall, the number of patients dying in their place of choice in Belgium is quite high compared with other studies, in which percentages between 30% and 94% are found, depending on the methodology used.^{12,13,30–38} Since congruence could only be measured for those patients whom GPs were informed about, it can be assumed that the high congruence found in the present study is probably an overestimation. The fact that patients died in hospital more often when GPs were not informed (58% as opposed to 16% where GPs were informed) confirms this hypothesis. Additionally, congruence may also be obtained less often in societies where the relationship between a GP and his/her patient is less stable, or where out-of-hours arrangements are not necessarily manned by local GPs, or are manned by teams in whom patients do not confide their hopes.

Implications for future research or clinical practice

Awareness by GPs of where their patients want to die is an important prerequisite if GPs aim to coordinate care in accordance with their patients' wishes. The relatively low figure found in this study leaves room for improvement for many GPs. Timely communication and involvement of palliative care teams and informal caregivers might contribute to a higher GP awareness. Congruence between the actual and preferred place of death is allied not only to the patient's choice, but also to social and structural healthcare availability as well, and may therefore not always be realistic to attain.³⁹ However, results of this study showing that the high positive association between GPs being aware and patients dying in their place of choice, might suggest that GPs, if aware, actively contribute to making it possible for patients to die where they want to. Care might be coordinated and directed by the GP in such a way that fulfilment of the patient's end-of-life wishes is maximally enhanced.

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Ethics committee

The study protocol and anonymity procedures were approved by the ethical review board of the University Hospital of the Vrije Universiteit Brussel (reference 2004045)

Competing interests

The authors have stated that there are none

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