

## Original Article

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# Increased rate of home-death among patients in a Danish general practice

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**ABSTRACT**

**INTRODUCTION:** Most terminally ill patients wish to die at home. The aim of this study was to investigate whether the home-death rate was higher than the Danish average in a general practice with a systematic approach to palliative care and to examine if the number of clinical contacts between the practice and its patients was associated with place of death.

**METHODS:** In a large (6,500 patients) four-doctor general practice outside of Copenhagen, adult patients who died between 2015 and 2018 were identified. Accidental or suicidal deaths were excluded. Data on age, gender, diagnosis, place of death, the primarily responsible physician and the number of clinical contacts during the last four months of life were retrieved from the patients' medical files.

**RESULTS:** A total of 201 patients were included (mean age at time of death = 82.4 years) of whom 99 patients (49%) died at home/in a nursing home and 93 patients (46%) died in hospital/hospice. Compared with regional data, the proportion of home-death was higher in the study population (national (43%,  $p = 0.09$ ), regional (39%,  $p = 0.01$ ), municipal (44%,  $p = 0.18$ )). The odds of death in hospital were nine times higher if no GP was directly involved in the palliative phase ( $p = 0.001$ ). However, no significant difference in the number of contacts with the GP between patients who died at home or in hospital/hospice was observed.

**CONCLUSIONS:** The proportion of home-death in the studied general practice was higher than home-death recorded in regional data. Having a GP involved in the palliative phase was associated with home-death independently of the number of GP contacts in the trajectory.

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When asked at the beginning of the palliative period, most patients wish to die at home [1-4].

Even so, less than half of Danish deaths are home-deaths. In 2017, 47% died at home or at a nursing home [5].

The GP has a key role in providing home care for patients. However, prior studies have shown that many GPs have few continuous palliative trajectories and often feel insecure in the role of primary medical caregiver [6-8]. Therefore, studies are warranted that investigate whether optimising the care of patients with palliative needs in general practice may increase the home-death rate.

The aim of the study was therefore to investigate the number of home-deaths in a Danish general practice that systematically has focused on patients with palliative needs for a five-year period. We hypothesised that a higher number of patients would achieve home-death compared with municipal, regional and national data. Another aim of the study was to investigate whether the GP was primarily involved in the palliative trajectory and also to

investigate the patients' number of clinical contacts with the practice during their last four months of life in order to reveal any differences associated with place of death.

## METHODS

### Population

Patients who died between 1 January 2015 and 31 July 2018 in a large (6,500 patients) Danish four-doctor general practice located in a Copenhagen suburb were identified retrospectively by review of the register of patients affiliated with the practice. The age- and gender distribution among patients was comparable to the regional average. All patients  $\geq 18$  years were evaluated for study eligibility. Patients with no available information on either hospital or general practice treatment in the medical file and patients who died by accident or suicide were excluded.

### Setting

All Danish citizens are assigned a GP in their local community who serves as a gatekeeper to specialist treatment. The average Danish GP has approximately 1,600 patients, and practices typically count one or more doctors plus a varying number of healthcare staff, mostly nurses and secretaries.

Patients with palliative needs may be followed primarily by their GP and municipal home-care team, or they may also be affiliated with an outgoing hospital-based specialist palliative care unit in case of complex palliative needs.

### Palliative care in the general practice studied

Four permanent doctors are employed at the general practice, of whom one doctor completed the Nordic Specialist Course in Palliative Medicine. Therefore, the practice has focused on palliative care for the past five years through:

- systematic follow-up when the patient is initially referred to the hospital with a suspected cancer diagnosis
- identifying palliative needs using the Supportive and Palliative Care Indicators Tool and "the surprise questions" (i.e., "Would you be surprised if the patient died within one year?") [9, 10]
- systematic registration in the medical file that the patient has palliative needs
- early follow-up during the disease trajectory
- talking to patients about their end of life preferences, if possible
- assigning each palliative patient, a medically responsible team consisting of a doctor and a nurse
- ensuring that each patient always has a future appointment with the GP or nurse

### Data

From the medical files, information about age, gender, diagnoses (listed as cancer or other), place of death, number and type of clinical contacts (consultation (both home visits and practice consultations) or phone calls with a doctor, nurse or secretary) during the last four months of life was retrieved. In patients with several diagnoses, the most serious diagnosis was listed as the primary diagnosis.

Place of death was registered according to the following categories: home address (either own housing or nursing home), temporary stay at nursing home, hospital, hospice or unknown.

These groups were further categorised into two: *home*-death (death at the home address, nursing home or

during a temporary stay at a nursing home) and *out*-death (death in a hospital or hospice) with the first-mentioned group being accessible for palliative care by their GP.

For each patient, it was assessed whether a GP had been primarily responsible for the palliative trajectory. The GP was listed as being primary medically responsible if there had been a face-to-face palliative-oriented contact with the GP during the last 14 days of life. In case of longer illness, it was recorded if there had also been palliative-oriented consultations during the last four months of life (based on an objective review of the medical file). Otherwise, the primary medically responsible person would be listed as “not a GP”, which therefore covers the care of all hospital and hospice doctors including palliative specialists. The type of GP (GP palliative specialist or Other GP) was listed in order to detect differences regarding their palliative patients, expecting that the palliatively educated GP would see more patients and more (complex) patients with cancer.

All data were collected by the same person, who was, at the time, a resident in the clinic and the four permanent doctors were not involved in the data collection or initial data processing.

In order to compare study data on place of death with both national, regional and municipal data, statistics on death were obtained from the annual report from the Danish Health Data Authority (national data from 2017) and from the Danish Centre of Rehabilitation and Palliation (regional and municipal data were available from the 2012-2014 period).

## Statistics

Statistical analysis was performed, and patients were grouped based on place of death (home or out) and compared using the non-parametric Pearson's  $\chi^2$ -test. The patients were described according to age, gender and diagnosis. The home-death percentage was compared to national, regional and municipal data by a two-sample test of proportions. Logistic regression was used to predict the odds ratio for death in hospital/hospice, depending on which doctor had been medically responsible.

## Ethics

Due to the retrospective nature of the study of deceased patients, it was not possible to obtain informed consent, and this was approved by the Danish Patient Safety Committee (registration number 3-3013-2592/1). A local data safety protocol was performed in line with the rules of the Danish Data Protection Agency.

*Trial registration:* not relevant.

## RESULTS

During the study period, 229 patients died and were evaluated for study inclusion.

Two patients were < 18 years of age and were excluded. Among the remaining 227 adult patients, 26 patients were excluded due to death by accident (n = 3), suicide (n = 4), found dead without any further information available (n = 7), no information available (n = 11) and one patient died during surgery. Hence, 201 patients (112 female) were included in the study. The mean age at time of death was 82.4 years and demographic data are presented in **Table 1**.

**TABLE 1 /** Patient characteristics according to place of death.

	Place of death, n (%)			p-value <sup>a</sup>
	all	home	out	
Total	201 <sup>b</sup>	99	93	
<i>Gender</i>				0.09
Female	112 (56)	62 (63)	47 (51)	
Male	89 (44)	37 (37)	46 (49)	
<i>Age, yrs</i>				< 0.01
47-70	29 (14)	5 (5)	20 (21)	
71-80	44 (22)	15 (15)	26 (28)	
≥ 81	128 (64)	79 (80)	47 (51)	
<i>Diagnosis</i>				0.48
Cancer	62 (31)	28 (28)	31 (33)	
Other <sup>c</sup>	139 (69)	71 (72)	62 (67)	

a) Pearson's  $\chi^2$ -test.

b) For 9 patients place of death was missing.

c) For 1 patient data of diagnosis were missing.

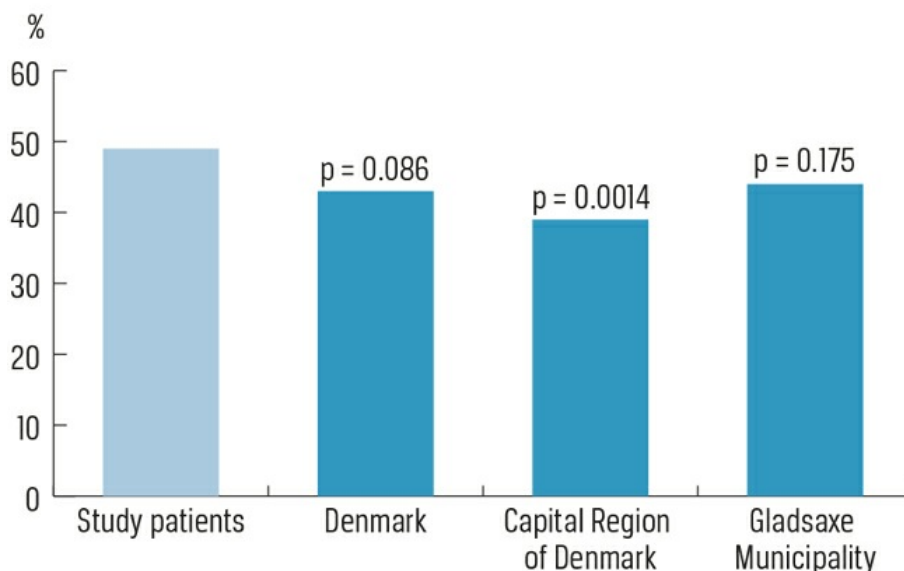
#### Place of death

A total of 99 patients (49%) died at home or in a nursing home (called *home*); 93 patients (46%) died in hospital or hospice (called *out*) (Table 1). The place of death was unknown for nine patients. (Table 1).

The age differed between patients who died at home and away from home (Table 1). Patients who died at home were older and, unsurprisingly, more often dying old of age. Diagnoses did not significantly differ between the groups (Table 1).

Compared with both national (43%,  $p = 0.086$ ), regional (39%,  $p = 0.014$ ) and municipal (44%,  $p = 0.175$ ) data from the 2012-2014 period, the proportion of home-death was higher in the study population. However, statistical significance was evident only when comparing study data with regional data (**Figure 1**).

**FIGURE 1 / Percentages of home death<sup>a</sup>**



a) p-value indicates comparison with study patients by two-sample test of proportions.

**Role of the general practitioner**

Patients were divided into three groups based on which doctor was responsible in the palliative phase. Odds ratio for death in hospital/hospice was found to be lower for the group of other GPs than for the GP palliative specialist, also after adjusting for patients' age, gender and diagnosis (Table 2); however, this difference was not statistically significant. The palliative GP had more cancer patients than the group of other GPs (22% versus 16%). If no GP was involved, the adjusted odds were nine times higher for death in hospital/hospice ( $p < 0.001$ ) than if the GP had been primarily responsible for the palliative trajectory.

**TABLE 2 / Place of death and odds ratio for death at hospital/hospice (out).**

	Place of death, n (%)			p-value (all physicians: $p < 0.01$ )	OR (95% CI)			
	all <sup>a</sup>	home	out		unadjusted	p-value	adjusted <sup>b</sup>	p-value
GP palliative specialist	49 (24)	35 (35)	12 (13)	0.087	Reference	-	Reference	-
Other GP	51 (25)	44 (45)	6 (6)	-	0.398 (0.14-1.17)	0.093	0.301 (0.07-1.5)	0.098
Not a GP	101 (50)	20 (20)	75 (81)	-	10.937 (4.8-24.49)	$< 0.001$	9.773 (2.45-38.93)	0.001

CI = confidence interval; OR = odds ratio

a) For 9 patients place of death was missing.

b) Adjusted for age, gender and diagnosis.

Regarding the number of clinical contacts with the healthcare staff at the practice (doctors, nurses, secretaries), both doctors and secretaries had significantly more contacts with the patient when a GP was the primary medically responsible person. However, there was no overall difference in the number of clinical contacts with the doctor between patients who died at home and in hospital/hospice (Table 3).

**TABLE 3 /** Median number of clinical contacts with healthcare staff: doctor, nurse or secretary, the last four months, by place of death (home or out) and primary medically responsible person in the palliative phase (GP or not GP).

	Place of death				Primary medical responsible					
	all <sup>a</sup>	home	out	p-value <sup>a</sup>	home			out		
					GP	not a GP	p-value <sup>a</sup>	GP	not a GP	p-value <sup>a</sup>
Patients, n	190 <sup>b</sup>	97	93		78	19		18	75	
<i>Clinical contacts, n, median (IQR)</i>										
Doctor	2 (1-4)	2 (1-4)	2 (1-4)	0.29	3 (2-4.3)	1 (0-2)	< 0.01	4 (2-4.25)	2 (1-3)	0.02
Nurse	0 (0-1)	0 (0-1)	0 (0-1)	0.09	0 (0-0.3)	0 (0-1)	0.04	1 (0-2)	0 (0-1)	0.15
Secretary	2 (0-3)	2 (1-4)	1 (0-3)	0.047	2 (1-4)	1 (0-2)	0.001	2 (1-4)	1 (0-3)	0.02

IQR = interquartile range.

a) Mann-Whitney U test.

b) Clinical contact data was missing for 3 patients and place of death was missing for 8 patients; thus, total number of patients is 190.

**DISCUSSION**

The finding of an increased home-death rate in the study compared with regional data is in accordance with previous findings showing that the propensity among GPs to pay home visits and to be actively involved and accessible in palliative disease trajectories is associated with an increased home-death rate. [11-13]

Achieving home-death is considered good quality in palliative care. Home-death is influenced by many factors besides GP involvement, and prior studies have found that the presence of close relatives, social networks, specialist palliative treatment and municipal home care service are important factors [14]. Home-death is also highly dependent on demographic and economic conditions along with patients’ preferences [15, 16]., Also, fear and stigma associated with death among healthcare staff, patients and relatives can serve as a barrier to home-death [7, 8, 17]. Hence, the endeavour towards achieving home-death is multidimensional, and a joint effort across sectors and professionals is essential. However, not all patients can or prefer to die at home and the optimal proportion of home-deaths is not yet agreed upon [18].

Training, communicating and systematically working with palliative care may potentially reduce fear or low confidence in performing palliative care among GPs and practice nurses [19] and this may have positively affected the study outcome. However, comparing the 49% study home-death rate with municipal (44%) and national (43%) home-death rates, there was no significant difference. Non-GP factors may have had a greater impact on the final outcome, or the number of study patients may have been too small to demonstrate an expected significant difference.

Talking with patients about their preferred place of death has been found to be associated with achieving home-death [3, 20], and this may also have affected the obtained home-death rates in our study. The odds of hospital-death were higher if a GP was not directly involved. The GP provides daily contact and home visits, which the outpatient clinics cannot offer in the same manner. Still, some patients may be more prone to aim for hospital death than elderly patients in nursing homes if they have an already well-established contact with the hospital system or have symptoms that require admittance [20].

Unexpectedly, the number of clinical contacts with the GP or the nurse did not differ between patients dying at home or away from home. The median number of GP contacts was only two among patients dying at home, indicating that achieving home-death was not associated with a higher work burden for the GP or the practice.

**Strengths and limitations**

To our knowledge, this study is the first to evaluate both place of death, physician responsibilities and the number and type of palliative patient contacts by review of the medical files in a general practice. The study included a relatively high number of patients over a three-year period, and almost all patients were treated by the same group of doctors. The study had some limitations. First, the study was purely observational, and no definitive conclusions can be drawn regarding causation. Second, the study was performed retrospectively on deceased patients; thus, bias from data collection and missing data may occur. Third, including data on symptom burden and admission history would have been optimal but such data were not available. Fourth, data extraction was based on an objective review of the patients' medical files conducted by a single person and some degree of subjective interpretation of the trajectories was necessary.

### Implications for the future

Enhanced education of GPs and GP staff may improve palliative care in primary healthcare to better accommodate patient and family wishes, increase home-death rates and thereby reduce hospital admission costs. However, for the proportion of home deaths to be even higher than was found in the present study, the practice's pro-active palliative approach and co-operation with all other involved healthcare professionals needs to be reconsidered. Future studies should include data on symptom burden, patient wishes regarding place of death and healthcare utilisation (hospital admissions and home care) along with comparison of ways to organise GP practices in order to conclude on the effect of GP involvement.

### CONCLUSIONS

This study showed an increased home-death rate as compared to regional data in a Danish general practice that has been focusing on palliative care for several years. However, no significant difference was found when compared to municipal and national data. The odds of dying in hospital were nine times higher if the GP was not involved in the palliative trajectory, indicating the importance of the GP's involvement. Despite this, numbers of clinical contacts between patients and GPs were not higher for patients achieving home-death, emphasising that a systematic approach does not necessarily lead to a higher use of healthcare resources in general practice. Future research should focus on how to strengthen general practice performing optimal palliative care in co-operation with the total healthcare system.

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