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ORIGINAL ARTICLE

Associations between successful palliative trajectories, place of death and GP involvement

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Abstract

Objective. General practitioner (GP) involvement may be instrumental in obtaining successful palliative cancer trajectories. The aim of the study was to examine associations between bereaved relatives' evaluation of palliative cancer trajectories, place of death, and GP involvement. **Design.** Population-based, cross-sectional combined register and questionnaire study. **Setting.** The former Aarhus County, Denmark. **Subjects.** Questionnaire data on GPs' palliative efforts and relatives' evaluations of the palliative trajectories were obtained for 153 cases of deceased cancer patients. **Main outcome measures.** A successful palliative trajectory as evaluated retrospectively by the relatives. **Results.** Successful palliative trajectories were statistically significantly associated with home death (PR 1.48 (95% CI 1.04; 2.12)). No significant associations were identified between the evaluations of the palliative trajectory at home and GP involvement. "Relative living with patient" (PR 1.75 (95% CI: 0.87; 3.53)) and "GP having contact with relatives" (PR 1.69 (95% CI 0.55; 5.19)) were not significantly associated, but this may be due to the poor number of cases included in the final analysis. **Conclusion.** This study indicates that home death is positively associated with a higher likelihood that bereaved relatives will evaluate the palliative trajectory at home as successful. No specific GP services that were statistically significantly associated with higher satisfaction among relatives could be identified, but contact between GPs and relatives seems important and the impact needs further investigation.

Key Words: Denmark, family practice, neoplasm, palliative care, primary health care, terminally ill

Most terminally ill cancer patients and relatives wish for patients to die at home [1–3]. However, home death is not necessarily a proxy for a successful palliative trajectory, and many patients spend most of their palliative period at home even though they die in institutions [4]. Furthermore, the numerous professionals involved, e.g. general practitioners (GPs) and community nurses (CNs), and their services may influence patients' and relatives' views [5].

The fact that a large proportion of cancer patients die in hospital has been linked to the presumed poor services of primary health care professionals [3]. However, satisfaction with GPs is high in spite of dissatisfaction with symptom control [6]. Also, interview studies suggest that 24-hour back-up and GP involvement are important elements in bereaved relatives' evaluation of palliative trajectories [7–9]. Studies have also shown that GP home visits are positively associated with home

death [4–10]. However, it remains unclear what constitutes particularly important GP contributions in achieving successful palliative trajectories. This knowledge could be important for guiding GPs to provide the best possible palliative care.

The aim of the study was to examine associations between bereaved relatives' evaluation of palliative trajectories, place of death, and GP involvement.

Material and methods

Setting

The survey was conducted on 599 deceased cancer patients in the former Aarhus County (approximately 640 000 inhabitants, 12% of the Danish population) from January to July 2007. Questionnaire and health register data were linked using the

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GP home visits are associated with death at home in palliative trajectories. However, home death does not necessarily mean a successful palliative trajectory.

- Home death is positively associated with a higher likelihood that the bereaved relative will evaluate the palliative trajectory as successful.
- Interpersonal relationships, which are difficult to quantify, may be of greater importance than structural services in terms of perceived quality.

unique personal identification number allocated to all Danish citizens [11].

Some 98% of Danes are registered with GPs and receive free tax-financed medical care [12]. Danish GPs are responsible for frontline care 24 hours a day and act as gatekeepers for access to specialist treatment. Palliative specialist teams are available during daytime hours and provide support through home visits and telephone advice to other professionals.

Study population and sampling

We included adults in Aarhus County who died of cancer from 1 March to 30 November 2006 and who

received palliative home care, and sampled patients by combining official register data.

From the county hospital discharge register we identified 29 043 individuals aged 18 years and over who were registered with at least one cancer diagnosis (ICD-10) (excluding non-melanoma skin cancers) from November 1996 to November 2006. Using The Centralized Civil Register (CRS), we identified 813 individuals among the 29 042 who died between 1 March and 30 November 2006. From the regional health service register we identified their GPs. Eight (1.0%) were not registered with a GP and 18 (2.2%) had moved from the county, leaving 787 patients. Questionnaires were sent to the GPs asking if palliative home care had been provided and whether it was acceptable to contact the bereaved relative. In most cases GPs identified the relative, but if not relatives were identified according to the following priority: spouse, child over 18 years, oldest sibling, parent (CRS).

In late 2008, data on cancer deaths from 2006 were available. After merging with our initial database, 188 patients who did not die of cancer were excluded, reducing our study population to 599 (Figure 1).

Data collection

Questionnaires included themes identified through literature studies, clinical experience, and group interview studies with bereaved relatives [7] and involved professionals [13,14].

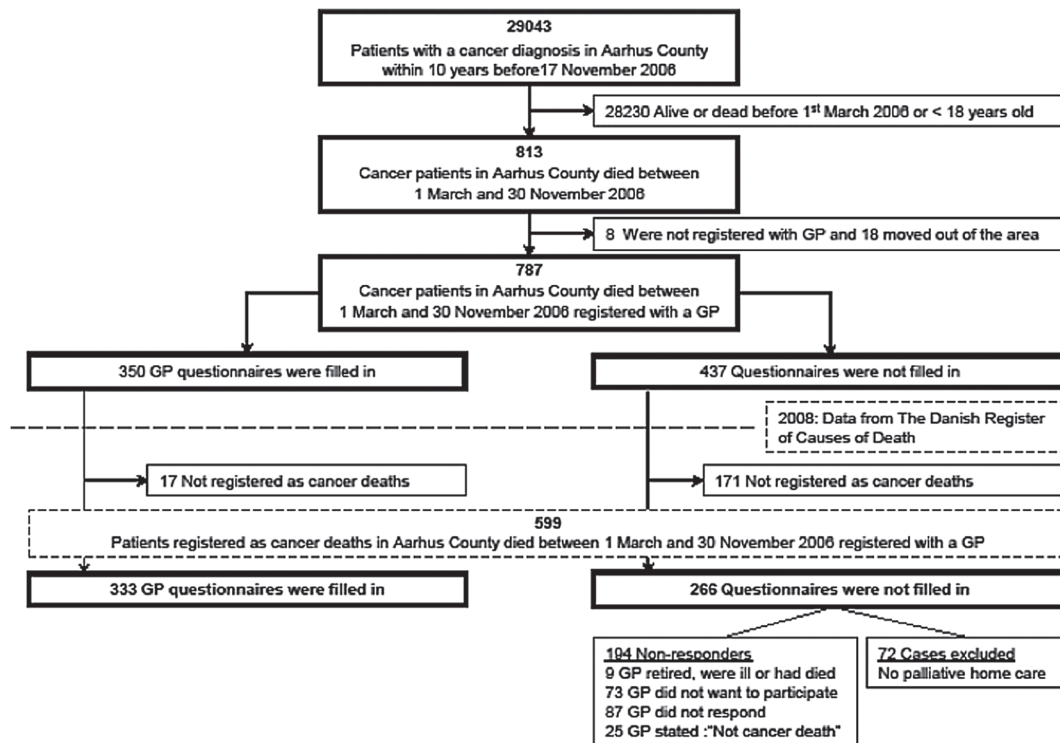


Figure 1. Flow-chart of sampling and GP questionnaire: Responders and non-responders.

The GP questionnaire was pilot-tested among 30 GPs. GPs received small financial compensation, and non-responders were sent two reminders. Relevant GP questionnaire data can be seen in Table I. Furthermore, GPs were asked about duration of the palliative period at home. The palliative period was defined as the patient's last period of life in which all curative treatment was stopped and care and treatment were solely palliative. Data on duration of the palliative period are given in a separate paper [4].

The relative questionnaire was pilot-tested among 14 bereaved relatives. Non-responders were sent one reminder. Relevant relative questionnaire data and register data can be seen in Table I. To examine "A successful palliative pathway at home" the relatives were asked to evaluate the palliative pathway, answering the following question: "How, in your own words, was the entire period at home during which the deceased was dying compared with how you felt it should have been?" (Dichotomized into unsuccessful ["Fairly well", "Bad", "Very bad"] and successful ["Very well", "Well"]).

Analysis

"A successful palliative trajectory" was defined as outcome measure, and unadjusted and adjusted associations were calculated. The multivariate model consisted of the variables seen in Table III and "the duration of the palliative period spent at home" (number of weeks as a categorical variable), since it may be associated with the GPs' ability to provide palliative care. Estimates were adjusted for clustering of patients within practices [15]. Prevalence ratios (PRs) with 95% confidence intervals (95% CI) were used as measure of association. Due to high prevalence of outcome measure (more than 20% of relatives evaluated the palliative trajectory as successful), odds ratios may tend to overestimate the association [16,17]. PRs were calculated using generalised linear models (GLM) with log link and the Bernoulli family and, because the model failed to converge, we used a Poisson regression model [16,18].

The variables were assessed for *collinearity* (Pearson's correlation coefficient >0.4) and *multicollinearity* (variance inflation factor <10) [19,20]. Due to collinearity, one variable was not included. We adjusted for duration of the palliative period spent at home since it could be associated with GP involvement. Data were analysed using STATA 10 [21].

Results

Of 599 GP questionnaires, 333 questionnaires (231 general practices) were completed. Some 72 were excluded because GPs stated that no home care had been provided (response rate 63.2%) (see Figure 1).

General practices completed questionnaires for 1–6 patients (mean: 1.9 (SD 1.1)). Non-responding practices were not statistically significantly different from participating practices with respect to practice organization, patients, and the number of questionnaires we sent per practice. Comparison of the 194 cases from non-responding GPs with included cases are given in Table II.

In 106 (31.8%) of 333 cases, GPs advised against contacting the relative (Figure 2). Among 227 relative questionnaires, four cases were excluded since relatives stated that the questionnaire was not relevant at all, and 153 relative questionnaires were completed (response rate 68.6%) (Figure 2). Comparison of included cases with cases where relatives did not respond and cases where GPs advised against sending the relative a questionnaire are given in Table I.

Important factors for a successful palliative trajectory

"A successful palliative trajectory" was statistically significantly associated with home death compared with institutional death (PR 1.48 (95% CI 1.04; 2.12)) (Table III). The positive association with "Relative living with the patient" (PR 1.75 (95% CI 0.87; 3.53)) and "GP having contact with the relatives" (PR 1.69 (95% CI 0.55; 5.19)) did not reach statistical significance and should therefore be interpreted with caution. No other associations were found between the relatives' evaluation and GP services ("GP knowledge prior to palliative period", "GP home visits", "Unplanned home visits by GP", "GP gave private number to patient to use in out-of-office hours", "GP had made a plan with the patient for whom to contact in out-of-office hours").

Discussion

Principal findings

In a population who died from cancer having had a palliative trajectory at home, we found that relatives' positive evaluation of the palliative trajectory was associated with home death. However, we identified no statistically significant associations between evaluations and specific GP services.

Strengths and weaknesses of the study

Strengths of this study are sampling procedure and comprehensive data collection in a field difficult to study. To eliminate differential misclassification, we used official health registers identifying the study population. However, in 25 of 599 cases, GPs returned the questionnaires stating that the patient did not die from cancer. These cases were registered as GP non-responders, which may have introduced bias (including confounding by indication), but direction and importance of this bias are difficult to

Table I. Characteristics of 153 included cases, the 70 cases not included because the relative did not respond and the 106 cases where the GP advised against sending the relative a questionnaire. Case data in study arise from the GP and relative-questionnaires and from formal health registers. Case data of relative-non-responders and of the group where the GP advised against sending the relative a questionnaire stem from GP-questionnaires and formal health registers.

	Cases in the study (n=153)	Cases of relative non-responders (n=70)	Cases where the GP advised against sending the relative a questionnaire (n=106)
Data from formal health registers			
Patient's age at time of death (mean years (SD))	68.2 (12.8)	69.6 (12.2)	70.9 (12.5)
Patient's gender (n (%))			
Male	95 (62.1)	33 (47.1)*	50 (47.2)*
Female	58 (37.9)	37 (52.9)*	56 (52.8)*
Primary cancer diagnosis (n (%))			
Bronchus/lung	25 (16.3)	18 (25.7)	22 (20.8)
Colon/Rectum	22 (14.4)	12 (17.1)	15 (14.2)
Breast	17 (11.1)	7 (10.0)	10 (9.4)
Prostate	22 (14.4)	6 (8.6)	11 (10.4)
Other	67 (43.8)	27 (38.6)	48 (45.2)
Place of death (n (%))			
Home	76 (49.7)	25 (35.7)	18 (17.0)*
Nursing home	23 (15.0)	11 (15.7)	34 (32.0)*
Hospital / Hospice	53 (34.6)	33 (47.2)	52 (49.1)*
Other(e.g. other institution)	1 (0.7)	1 (1.4)	2 (1.9)
Number of GP home-visits during the last 3 months (Median (IQR))	3 (2;6)	4 (2;7)	2 (0;5)
(mean (SD))	4.2 (3.2)	4.4 (3.0)	3.2 (3.3)*
GP home-visits during the last 3 months (n (%))			
No	11 (7.2)	5 (7.1)	27 (25.5)*
Yes	142 (92.8)	65 (92.9)	79 (74.5)*
Data from relative- questionnaires			
Gender of relative (n (%))			
Male	42 (27.4)	—	—
Female	111 (72.6)		
Relation to deceased (n (%))			
Spouse	106 (69.3)		
Girlfriend or Boyfriend	1 (0.7)		
Daughter or son	39 (25.4)		
Sister or brother	2 (1.3)	—	—
Parent	2 (1.3)		
Friend	1 (0.7)		
Daughter-in-law	2 (1.3)		
Relative lived with patient (n (%))			
No	27 (18.2)	—	—
Yes	121 (81.8)		
Relative's vocational education (n (%))			
3 years or less	94 (64.4)	—	—
> 3 years	52 (35.6)		
Relative's evaluation of palliative trajectory (n(%))			
Really well	50 (35.5)		
Well	47 (33.3)		
Acceptable	28 (19.9)	—	—
Bad	12 (8.5)		
Really bad	4 (2.8)		
Data from GP-questionnaires			
GP-involvement (n (%))			
No	11 (7.3)	5 (7.3)	20 (19.4)*
Yes	140 (92.7)	64 (92.7)	83 (80.6)*
GP knowledge of patient prior to palliative period (n (%))			
Poor	14 (9.5)	7 (10.0)	23 (22.6)*
Well	133 (90.5)	63 (90.0)	79 (77.4)*

(Continued)

Table I. (Continued)

	Cases in the study (n = 153)	Cases of relative non-responders (n = 70)	Cases where the GP advised against sending the relative a questionnaire (n = 106)
Unplanned home-visits by GP (n (%))			
No	58 (43.9)	27 (43.6)	46 (61.3)*
Yes	74 (56.1)	35 (56.4)	29 (38.7)*
GP gave private number to patient to use in out-of-office hours (n (%))			
No	68 (50.7)	33 (53.2)	61 (75.3)*
Yes	66 (49.3)	29 (46.8)	20 (24.7)*
GP had made a plan with the patient for whom to contact in out-of-office hours (n (%))			
No	92 (68.2)	43 (68.3)	43 (52.4)*
Yes	43 (31.8)	20 (31.7)	39 (47.6)*
GP had contact with relatives (n (%))			
No	8 (5.8)	5 (7.8)	26 (34.2)*
Yes	131 (94.2)	59 (92.2)	50 (65.8)*
Home care nurse involvement (n (%))			
No	42 (27.5)	18 (25.7)	48 (45.3)*
Yes	111 (72.5)	52 (74.3)	58 (54.7)*
Specialist team-involvement (n (%))			
No	85 (55.6)	43 (61.4)	74 (69.8)*
Yes	68 (44.4)	27 (38.6)	32 (30.2)*

*Statistically significantly different from the 153 cases in the study (p-value < 0.05)

determine. To minimize recall bias, questionnaires were sent in January 2007 instead of awaiting update of the Danish Registry of Causes of Death. Furthermore, electronic patient records used in general practice help GPs to remember the patients [22].

Selection bias is possibly this study's weakness. We found differences between included cases and cases which were excluded because GPs advised against contacting relatives. Hence, we may have excluded

cases where GPs were not as involved and known to the patient as well as in included cases. In excluded cases relatives may evaluate the trajectory as less successful. Thus, we would tend to overestimate associations between successful trajectories and GP-related variables. This would also be the case if GPs excluded unsuccessful cases (which they might have done for several reasons) despite a high level of involvement. As home death is associated with GP involvement

Table II. Characteristics of 333 included cases and 194 cases not included because the GP did not respond. Case data obtained from formal health registers.

	Cases of GP responders (n = 333)	Cases of GP non-responders (n = 194)
Patient's age at time of death (mean (SD))	69.4 (12.7)	73.5 (12.7)*
Patient's gender (n (%))		
Male	181 (54.4)	113 (58.3)
Female	152 (45.6)	81 (41.7)
Primary cancer diagnosis (n (%))		
Bronchus/lung	65 (19.5)	37 (19.1)
Colon/rectum	50 (15.1)	32 (16.5)
Breast	34 (10.2)	22 (11.3)
Prostate	39 (11.7)	31 (16.0)
Other	145 (43.5)	72 (37.1)
Place of death (n (%))		
Home	120 (36.0)	70 (36.1)
Nursing home	69 (20.7)	51 (26.3)
Hospital/hospice	140 (42.0)	70 (36.1)
Other (e.g. other institution)	4 (1.2)	3 (1.5)
Number of home visits by GP during the last 3 months (median (IQI))	3 (1;6)	3 (1;5)
(mean (SD))	3.9 (3.2)	3.6 (3.1)

Notes: *Statistically significantly different from cases of GP responders (p-value < 0.05). Not percentages total 100.0% because of round-offs.

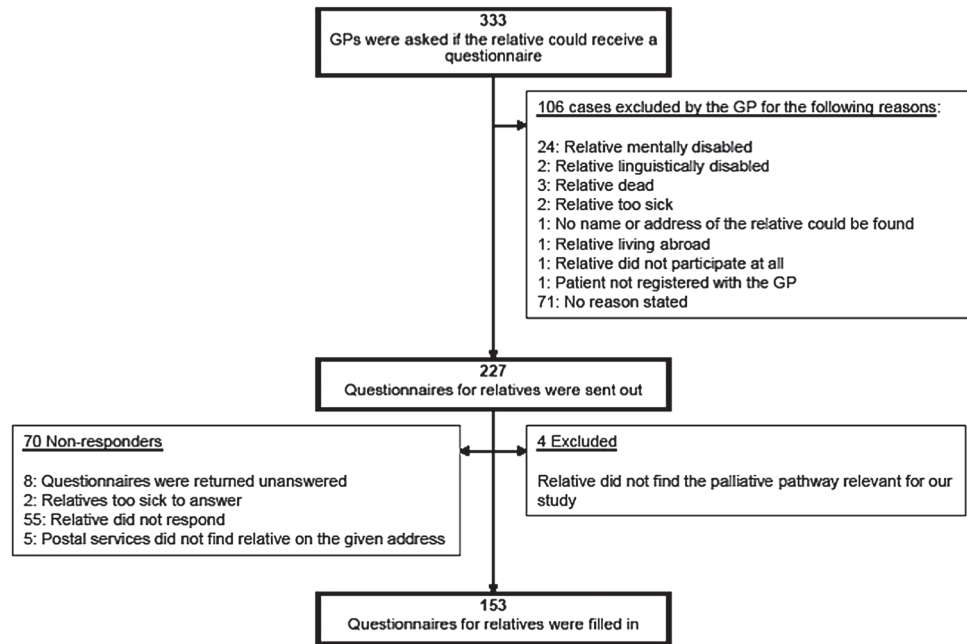


Figure 2. Flow-chart of questionnaire to bereaved relatives: Responders and non-responders.

[10,23–25], such selection bias would therefore tend to overestimate the association between home death and successful trajectories in this study.

Approximately 1680 patients died from cancer in Aarhus County in 2006, but we recruited only 599 cases during nine months. This may be because we excluded persons under the age of 18 years and persons with non-melanoma skin cancers, and we included only patients registered with cancer diagnoses in Aarhus County hospitals. Furthermore, 1 March–30 November does not include any winter months, which may account for some missing cases since mortality rates are higher during winter months.

Comparison with existing literature

We found a statistically significant association, although minor, between home death and relatives' positive evaluation of the palliative trajectory. In another study, using other and therefore different data from the same population focusing on CNs' role, we found a stronger association between relatives' positive evaluation and home death (PR 2.3 (95% CI 1.2;4.4)) [26]. Furthermore, other studies found home death to be associated with better bereavement response [10,24,25] and overall satisfaction with the palliative trajectory [27].

Some of the difference between bereaved relatives' evaluation in cases with home versus institutional death may be because patients with severe symptoms are forced into an institutional death, which would affect relatives' evaluation. However, by adjusting for patients' contact with palliative

specialist teams we may have adjusted for some of the confounding by symptom severity. Eliminating "specialist team involvement" from the model accordingly weakens the association between successful trajectories and home death. One may also argue that caring for dying patients at home in the last few days of life may be distressing for relatives and that institutional death may be preferable even if the palliative trajectory at home has been successful until then. It may even make the trajectory at home look even more successful in retrospect since the distressing and care-demanding last days of the patient's life did not take place at home. In this context, the weak association between a positive evaluation and home death is even more interesting.

To our knowledge, no other population-based study has examined the association between relatives' or patients' general evaluation of the palliative trajectory and GP-related factors. Surprisingly, we found no GP-related factors, not even GP home visits, to be statistically significantly associated with relatives' evaluation even though prior studies have reported that home visits are strongly associated with home death [10,24,25]. Other studies have found that bereaved relatives' satisfaction with GPs was statistically higher when GPs provided many home visits (> 20) or were willing to perform home-visits [28,29].

Associations between successful palliative trajectories and "relatives living with the patient" and "GPs' contact with relatives" did not reach statistical significance, which may be because only 100 cases were included in the adjusted analysis. However, the analysis indicates that relationships between

Table III. Associations between a successful palliative course and model variables. A total of 153 cases were included in the analyses. The unadjusted and the adjusted prevalence ratios (PRs) are shown with 95% confidence intervals (95% CIs).

	Unadjusted		Adjusted	
	Prevalence ratio (95% CI)	p-value	Prevalence ratio (95% CI)	p-value
Gender of relative				
Male	1		1	
Female	1.08 (0.83;1.41)	0.559	1.03 (0.72;1.47)	0.882
Age of relative				
18 – 64	1		1	
65+	1.29 (1.06;1.58)	0.013	1.00 (0.76;1.32)	0.988
Relative living with patient				
No	1		1	
Yes	1.88 (1.16; 3.06)	0.011	1.75 (0.87;3.53)	0.119
Relative's relation to diseased				
Not spouse	1		Not included because of collinearity with 'Relative living with patient'	
Spouse	1.59 (1.15;2.19)	0.005		
Relative's vocational education				
3 years or less	1		1	
> 3 years	0.80 (0.62;1.04)	0.102	0.88 (0.65;1.18)	0.397
GP knowledge prior to palliative period				
Poor	1		1	
Well	1.41 (0.82;2.42)	0.211	1.24 (0.74;2.08)	0.405
GP home-visits				
No	1		1	
Yes	1.11 (0.61;1.92)	0.719	0.97 (0.44;2.26)	0.951
Unplanned home-visits by GP				
No	1		1	
Yes	1.14 (0.87;1.49)	0.335	1.18 (0.89;1.57)	0.238
GP gave private number to patient to use in out-of-office hours				
No	1		1	
Yes	1.03 (0.80;1.33)	0.800	0.83 (0.62;1.11)	0.205
GP had made a plan with the patient for whom to contact in out-of-office hours				
No	1		1	
Yes	0.96 (0.71;1.28)	0.767	0.98 (0.66;1.44)	0.917
GP had contact with relatives				
No	1		1	
Yes	1.15 (0.55;2.39)	0.712	1.69 (0.55;5.19)	0.360
Community nurse involvement				
No	1		1	
Yes	0.92 (0.72;1.16)	0.470	0.89 (0.61;1.29)	0.524
Specialist team-involvement				
No	1		1	
Yes	1.01 (0.81;1.26)	0.917	1.04 (0.78;1.37)	0.808
Place of death				
Institution (hospital or hospice)	1		1	
Nursing home	0.89 (0.55;1.45)	0.636	1.03 (0.53;1.98)	0.940
Home	1.37 (1.05;1.80)	0.021	1.48 (1.04;2.12)	0.031

Note: Significant correlations with a p-value < 0.05 are in bold text.

specific persons (patient–relative, GP–relative) are important and it would be valuable to try and qualify these relations as they may be important for successful palliative trajectories by comparing with the structural factors we included. Personal relationships with patients and relatives may very well be one of GPs' strengths and explain why satisfaction with GPs is high despite dissatisfaction with symptom control [6]. Further knowledge on interpersonal relationships and reasons for GPs' involvement or non-involvement is needed [30].

Implications for future research

More research is needed on how to measure bereaved relatives' evaluation of palliative trajectories, how GP involvement and personal relationship with patients and families affect this evaluation and what constitutes well-delivered palliative care by GPs.

Conclusion

Our study indicates that home death is positively associated with a higher likelihood that bereaved relatives

will evaluate the palliative trajectory at home as successful. We could not identify any specific GP services that were statistically significantly associated with higher satisfaction among relatives, but contact between GPs and relatives seems important and the impact needs further investigation.

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Ethical approvals

According to the Regional Research Ethics Committee, the Biomedical Research Ethics Committee System Act does not apply to this study as no active intervention was involved. The study was approved by the Danish Data Protection Agency and the Danish National Board of Health.

Conflicts of interest: The authors have no conflicts of interest.

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