

Danish general practitioners' self-reported competences in end-of-life care

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ABSTRACT

Objective: General practitioners (GPs) are pivotal in end-of-life (EOL) care. This study aimed to assess GP-reported provision of EOL care and to assess associations with GP characteristics.

Design: Population-based questionnaire study.

Setting: Central Denmark Region with approximately 1.3 million inhabitants.

Subjects: All 843 active GPs in the Central Denmark Region were sent a questionnaire by mail.

Main outcome measures: Responses to 18 items concerning four aspects: provision of EOL care to patients with different diagnosis, confidence with being a key worker, organisation of EOL care and EOL skills (medical and psychosocial).

Results: In total, 573 (68%) GPs responded. Of these, 85% often/always offered EOL care to cancer patients, which was twice as often as to patients with non-malignancies (34–40%). Moreover, 76% felt confident about being a key worker, 60% had a proactive approach, and 58% talked to their patients about dying. Only 9% kept a register of patients with EOL needs, and 19% had specific EOL procedures. GP confidence with own EOL skills varied; from 55% feeling confident using terminal medications to 90% feeling confident treating nausea/vomiting. Increasing GP age was associated with increased confidence about being a key worker and provision of EOL care to patients with non-malignancies. In rural areas, GPs were more confident about administering medicine subcutaneously than in urban areas.

Conclusion: We found considerable diversity in self-reported EOL care competences. Interventions should focus on increasing GPs' provision of EOL care to patients with non-malignancies, promoting better EOL care concerning organisation and symptom management.

KEY POINTS

- GPs are pivotal in end-of-life (EOL) care, but their involvement has been questioned. Hence, GPs' perceived competencies were explored.
- GPs were twice as likely to provide EOL care for patients with cancer than for patients with non-malignancies.
- EOL care was lacking clear organisation in general practice in terms of registering palliative patients and having specific EOL procedures.
- GPs were generally least confident with their skills in terminal medical treatment, for example, using medicine administered subcutaneously.

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Introduction

The end of life (EOL) can be defined as “*the period a patient, the family and health professionals are aware of the life-limiting nature of their illness*”.[1] This time is often characterised by an extensive need for support and comprehensive care. General practitioners (GPs) have a crucial role in providing optimal EOL care as GPs are responsible for at-home care, and their involvement in EOL care is generally highly valued by patients and relatives.[2,3] Several studies have found that most patients prefer to be cared for and die at

home.[4,5] Thus, the GPs' awareness of these patients and their needs, involvement in palliative trajectories and knowledge about medical treatments must be ensured and maintained.

Cancer patients have been shown to receive EOL care more often than patients with non-malignant diseases, although the last group have similar poor prognosis and equal symptom burden.[6,7] However, patients suffering from non-malignant diseases (e.g. heart failure or COPD) have unpredictable disease trajectories that make prognostication of survival time

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challenging.[7] As these patients are often regularly seen by their GPs as part of chronic disease management, more knowledge is needed if GPs provide EOL care to these patients.

As EOL care often involves many health care professionals, a well-defined key worker is important to ensure cooperation and distribution of tasks.[8,9] Along with a coordinating role, the key worker should take a proactive care approach,[8] initiate EOL discussions[10] and be aware of the individual patient's EOL preferences.[11,12] A revised guideline on palliative care developed by the Danish College of General Practitioners states that GPs are expected to assume the role of key worker.[13] To take on this role, the GPs must have an overview of their relevant patient population to ensure necessary care is provided. Nevertheless, little is known about if GPs' register these patients and have specific procedures in their organisation to ensure of EOL care to patients.

Previous studies looked into symptom control and home care provided by GPs as a part of EOL care and found room for improvement.[9,14–16] Therefore, training of skills is needed and requested by GPs.[16,17] Knowledge about how the GPs' perceive their abilities to provide EOL care is a prerequisite for development of successful EOL education in primary care.

Hence, the aim of this study was to assess to which degree GPs report to provide EOL care with regard to patients with different diseases, their confidence with being a key worker, their organisation of EOL care and their medical and psychosocial EOL care skills. Furthermore, we aimed to analyse if specific characteristics of the GPs and their practices were associated with their perceived abilities to provide EOL care.

Methods

Design

This study was a population-based questionnaire study among all 843 active GPs on 1st March 2014 in the Central Denmark Region comprising approximately 1.3 million inhabitants.

Setting

The Danish health care system provides free tax-financed access to health care. More than 98% of Danes are registered with a general practice. The GPs are remunerated for their services by the Danish Regions based on a nationally negotiated scheme. GPs are responsible for providing basic palliative care for

patients at home listed in their practices.[18] GPs have access to advice from palliative care specialists and can refer to specialist treatment if a patient develops complex palliative needs either physically, psychosocially or spiritually. Specialist palliative care in Denmark is based on outgoing teams, palliative wards and hospices.

The questionnaire

The 27-item questionnaire with eight predefined themes included both previously used questions and ad hoc items based on experience and existing literature. It was pilot tested among 20 GPs. Eighteen items focused on the four aspects in focus of this study, whereas the remaining nine items dealt with issues outside the scope of this paper. These four aspects were as follows: (1) GPs' provision of EOL care to patients with cancer, heart failure and chronic obstructive pulmonary disease (COPD), respectively (items 1–3), (2) GPs' confidence with being a key worker and performing tasks related to this role (proactive approach, initiating talks about dying and knowing where the patients preferred to die) (items 4–7), (3) organisation of EOL care (having specific EOL procedures and keeping a register of patients with palliative needs) (items 8–9) and (4) GPs' medical and psychosocial skills (nine different skills ranging from medical to psychosocial elements to embrace the holistic approach to EOL care) (items 10–18) (see Appendix A for wording of the items).

All items were answered on a five-point Likert scale. The questionnaire was sent to all GPs in the Central Denmark Region with a pre-paid postage envelope. If unanswered, a reminder was sent three weeks later. Participation was compensated with 122 DDK (€16).

The GPs

Register-based information about the GPs was retrieved from the Central Denmark Region. The data comprised information about the GP's age, gender, organisation of practices (solo or partnership practice) and list size (number of listed patients). Age and list size were changed into categorical data based on quartiles.

As a proxy for degree of urbanization, the general practices were divided into three groups based on geographic location: municipality with a university hospital (urban areas), municipality with a regional hospital or municipality with no hospital (rural areas).

Analysis

Descriptive statistics were used to characterise respondents and non-respondents as well as the GPs' perception of their EOL care. Estimates were given with 95% confidence intervals (CI). Differences between groups were tested with chi-square test, Mann–Whitney *U*-test or Kruskal–Wallis test. Weighted kappa coefficients were used to test for consistency in the GP's answers for each of the four themes.[19] The coefficients were interpreted as suggested by Landis et al: "poor" (< 0.0), "slight" (0.01–0.20), "fair" (0.21–0.40), "moderate" (0.41–0.60), "substantial" (0.61–0.80) and "almost perfect" (0.81–1.00).[20]

Answers to self-reported confidence in EOL care were dichotomised (agree/strongly agree vs. neither nor/disagree/strongly disagree), and associations with GP characteristics were calculated using a logistic regression model. Five items were chosen to examine the following four aspects of EOL care: (1) whether palliative care would be offered to patients with COPD (representing non-malignant diseases), (2) confidence about being key worker (key worker role), (3) whether the GP had specific EOL procedures (organisation) and (4) confidence with treating pain and administering medicine subcutaneously (i.e. one of the skills with the

highest and lowest proportions of reported GP confidence).

The variables used to characterise the GPs (age, gender, list size, organisation and urbanisation) were tested for collinearity, but none was found (in all cases, the Pearson's correlation coefficient was <0.4). To account for possible cluster effects on practice level robust variance estimation was performed. The level of statistical significance was 5% or less. Stata 13 was used for processing data (www.stata.com).

Results

A total of 573 (68%) GPs participated. Respondents were significantly younger, more often female and more often listed in a group practice compared to non-respondents (Table 1).

The GPs' provision of EOL care to patients with different diagnosis is shown in Table 2. The frequency of offering EOL care was considerably higher for cancer patients compared to patients with COPD or heart failure (*kappa*: 0.21 and 0.17 (data not shown)), whereas the frequency for offering EOL care to patients with COPD and heart failure were fairly similar (*kappa*: 0.740).

Table 1. Characteristics of the 843 GPs in the central Denmark region divided into respondents and non-respondents.

	Respondents <i>N</i> = 573	Non-respondents <i>N</i> = 270	Statistical test of difference ^a
Age (years, median (IQR ^b))	53.5 (14.5)	55.1 (14.8)	<i>p</i> = 0.030^c
Sex (<i>n</i> (%))			
Male	279 (48.7)	155 (57.4)	
Female	294 (51.3)	115 (42.6)	<i>p</i> = 0.002^d
List size (number, median (IQR ^b))	1502 (387)	1514 (341)	<i>p</i> = 0.110^c
Organisation of practice (<i>n</i> (%))			
Solo practice	119 (21.0)	74 (27.5)	
Group practice	447 (79.0)	195 (72.5)	<i>p</i> = 0.024^d
Urbanisation, municipality with (<i>n</i> (%))			
University hospital	164 (28.6)	77 (28.5)	
Regional hospital	250 (43.6)	127 (47.0)	
No hospital	158 (27.6)	63 (23.3)	<i>p</i> = 0.612^e

^aStatistically significant differences shown in bold text.

^bIQR: Interquartile range.

^cMann–Whitney test.

^dFisher's exact test.

^eKruskal–Wallis test.

Table 2. Frequency of GP-reported provision of 'end of life care' to three different patient groups (*N* = 573 GPs).

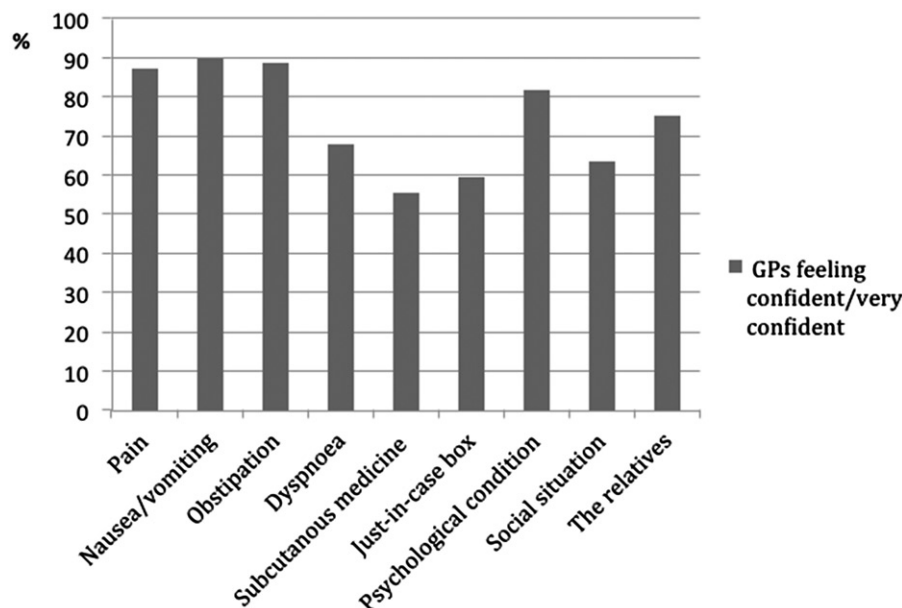
	Cancer		COPD		Heart failure	
	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)
Always	215	38.7 (34.7; 42.8)	41	7.4 (5.2; 9.6)	36	6.5 (4.5; 8.6)
Often	256	46.1 (42.0; 50.3)	182	32.9 (28.9; 36.8)	153	27.7 (24.0; 31.5)
Now and then	79	12.6 (9.8; 15.4)	225	40.6 (36.5; 44.7)	215	39.0 (34.9; 43.0)
Rarely/never	14	2.5 (1.2; 3.8)	106	19.1 (15.8; 22.4)	148	26.8 (23.1; 30.5)
Total ^a	555	100	554	100	552	100

^aMissings excluded.

Table 3. The distribution of answers according to confidence and different elements about being a key worker ($N = 571$ GPs).

	I feel confident about being key worker in palliative trajectories		I am proactive in identifying patients with palliative needs		I take the initiative to talk to my patients about dying		I know where my patients suffering from severe disease want to die	
	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)
Strongly agree	141	25.3 (21.7; 28.9)	82	14.7 (11.7; 17.6)	69	12.3(9.6; 15.1)	50	9.0 (6.6; 11.3)
Agree	284	51.0 (46.8; 55.2)	252	45.1 (40.9; 49.2)	256	45.8 (41.7; 50.0)	260	46.6 (42.4; 50.7)
Neither nor	114	20.6 (17.1; 23.8)	170	30.4 (26.6; 34.2)	187	33.5 (29.5; 37.4)	202	36.2 (32.2; 40.2)
Disagree/strongly disagree	18	3.2 (1.8; 4.7)	55	9.8 (6.3; 10.9)	47	8.4 (6.1; 10.7)	46	7.5 (5.3; 9.7)
Total ^a	557	100	559	100	559	100	558	100

^aMissings excluded.

**Figure 1.** Percentage of GPs who reported to feel confident/very confident taking care of nine different elements of EOL care ($N = 571$ GPs).

The proportion of GPs who felt confident about being a key worker was 76%. This proportion was larger than the proportions of GPs (56–60%) who agreed to carry out tasks of importance for the role as a key worker, that is, having a proactive approach, talking to patients about dying and knowing the individual patient's EOL preferences (Table 3). The GPs differed in their agreement with these different elements, which is shown by the weighted *kappa* coefficient comparing the items on a pairwise basis showing values between 0.21 and 0.41 (data not shown).

Concerning the organisation of EOL care, 9% (95% CI: 6.3; 11.0) of GPs kept a register of their patients with palliative needs, and 19% (95% CI: 15.9; 22.5) had specific EOL procedures.

The majority of GPs felt confident about providing EOL care, but the results also revealed substantial variations (56–89%) across specific palliative skills (Figure 1). The task that most GPs felt least

confident about was medical treatment in the terminal phase (56–59%) (i.e. use of “just-in-case box” (anticipatory medicine) and administration of medicine subcutaneously), whereas 64% of GPs felt confident about dealing with social issues, and 82% of GPs felt confident about dealing with psychological issues (Figure 1).

Table 4 shows associations between different aspects of EOL care and GP characteristics. The oldest GPs reported offering EOL care to COPD patients significantly more often than reported by the youngest GPs. The same trend was seen regarding confidence about being a key worker. No significant associations were found between GP characteristics and organisation of EOL care or EOL care skills with exception from administration of medicine subcutaneously. Female GPs and GPs working in rural areas felt significantly more confident about administering medicine subcutaneously than male GPs and GPs working in urban areas, respectively.

Table 4. Associations between GP characteristics and five different questions about EOL care clustered on provider number.

	EOL care to COPD patients			Confidence about being the key worker			Having specific EOL procedures			Confidence with treatment of pain			Confidence with s.c. medicine			
	Unadjusted		Adjusted	Unadjusted		Adjusted	Unadjusted		Adjusted	Unadjusted		Adjusted	Unadjusted		Adjusted	
	OR	p	OR	p	OR	p	OR	p	OR	p	OR	p	OR	p	OR	p
Age, years	1		1		1		1		1		1		1		1	
-45.5	1.52	0.084	1.56	0.08	1		1		1		1		1		1	
45.5-53.5	1.22	0.443	1.20	0.510	1.72	0.024	1.74	0.023	1.81	0.055	1.69	0.096	0.83	0.599	0.80	0.536
53.5-60	1.77	0.032	1.77	0.050	1.70	0.041	1.59	0.077	1.65	0.093	1.32	0.378	1.44	0.352	1.34	0.469
60 -					1.77	0.039	1.62	0.087	1.65	0.130	1.19	0.615	0.91	0.798	0.76	0.475
Gender	1		1		1		1		1		1		1		1	
Male	0.95	0.770	1.02	0.905	0.81	0.292	0.88	0.547	0.63	0.025	0.67	0.067	0.65	0.094	0.64	0.104
Female	1		1		1		1		1		1		1		1	
Organisation	1		1		1		1		1		1		1		1	
Group	1.27	0.274	1.25	0.352	1.81	0.030	1.68	0.065	1.52	0.115	1.40	0.240	1.12	0.525	1.16	0.644
Solo	1		1		1		1		1		1		1		1	
List size	1		1		1		1		1		1		1		1	
≤1299	1.47	0.120	1.52	0.111	0.79	0.411	0.755	0.333	1.12	0.772	1.13	0.750	0.60	0.167	0.57	0.117
1299-1510	1.44	0.150	1.51	0.116	1.17	0.553	1.09	0.758	0.93	0.834	0.85	0.653	0.75	0.420	0.67	0.252
1510-1668	0.88	0.630	0.86	0.588	0.88	0.637	0.75	0.311	1.24	0.557	1.11	0.792	0.76	0.444	0.68	0.265
≥1668	1		1		1		1		1		1		1		1	
Urbanisation, type of hospital in the municipality	1		1		1		1		1		1		1		1	
University	1.02	0.910	1.07	0.747	0.81	0.379	0.91	0.691	0.76	0.389	0.79	0.458	0.95	0.843	0.97	0.918
Regional	0.85	0.500	0.82	0.411	1.08	0.782	1.08	0.758	1.17	0.621	1.20	0.568	1.56	0.191	1.55	0.204
No hospital					1		1		1		1		1		1	

The table shows both unadjusted and adjusted analyses; associations are adjusted for all other characteristics. Associations are given in odds ratios (ORs) and the associated p values (p) are shown. Statistically significant associations are in 'bold'.

Discussion

Principal findings

GPs were twice as likely to offer EOL care to cancer patients as to patients with non-malignancies. Even though the majority of GPs felt confident about being a key worker, only a small minority of GPs reported to have organised their EOL care. The GPs felt least confident about taking care of social issues and medical treatment in the terminal phase. GP age was positively associated with confidence about being a key worker and increased provision of EOL care to patients with COPD. Gender and degree of urbanisation was associated with confidence in administering medicine subcutaneously as more GPs in rural areas and more female GPs felt confident about this task.

Strengths and weaknesses

The strengths of this study were the population-based design, the relatively high response rate and the high validity register data on GPs. The register-based data made it possible to compare respondents and non-respondents to assess the external validity. As we found differences between respondents and non-respondents in terms of age and gender, the external validity might be impaired. We found age to be associated with confidence about being a key worker, but none of the items illustrating specific elements of being a key worker (e.g. proactive approach) were associated with age. Gender was only associated with confidence about administering medicine subcutaneously. Consequently, the extent of the aforementioned bias that might undermine the external validity seems limited concerning the overall results.

We used a non-validated questionnaire with ad hoc items. The pilot test established apparent face validity of the questions. However, there are well-known problems in palliative research with ambiguous understanding of "EOL care" and "palliative care",^[21] which can both be interpreted as terminal treatment of cancer patients and the broader holistic definition encompassing bio-psycho-social factors suggested by WHO.^[22] We tried to account for this inherent ambiguity by using the questions on palliative care related to patients with non-malignant diseases to get an idea of the understanding of palliative care. The data could indicate an ambiguous understanding of palliative care among GPs, where some GPs use the broader holistic approach and others see palliative care as care to cancer patients. Hence, when interpreting the confidence with skills, it might reflect confidence with providing "traditional" care. This might cause a lack of

understanding of EOL care provided to patients with non-malignant disease. The results on non-malignancies should, therefore, be interpreted cautiously. Another limitation in terms of content validity is the expression "key worker", which is often used although it is weakly defined. In a palliative context, there is no formal task distribution and hence no clear expectations of a key worker.^[8,9] Again, the results should be interpreted with this in mind.

Comparison with other studies

In this study, GPs reported that patients with non-malignant diseases were less likely to receive EOL care. This finding is consistent with other studies, where similar differences in access to palliative care were found between cancer patients and patients with non-malignant diseases.^[6,7] To our knowledge, no other study has assessed GPs' own view of their provision of EOL care to patients with COPD or heart failure. We found similar levels for provision of EOL care to patients with COPD and patients with heart failure. This suggests that GPs' provision of EOL care to patients with non-malignant disease reflects a more general awareness of EOL needs aside from cancer.

In this study, 76% of GPs felt confident about being a key worker in palliative trajectories, which was more than in a previous study from 2012 from the Capital Region of Denmark, where only 57% of GPs felt confident.^[16] This could be due to geographical variation. However, in our study, the degree of urbanisation was not associated with confidence about being a key worker, but about administering medicine subcutaneously. The difference found between the two studies could also be due to EOL care improvements over time as palliative care has received increased focus in Denmark over the last years.^[23] Despite the GPs' confidence about being a key worker, a study revealed that many patients and relatives felt that they had to function as the key worker themselves although they also acknowledged the GP as the ideal key worker.^[9] Hence, we need to look into *how* GPs should assume the role and clarify expectations to the key worker.

Lack of organisation of EOL care was identified in our study as only few GPs had specific procedures for EOL care and even less kept register of patients with palliative needs. A national initiative in the United Kingdom focused on improvement in EOL care by increasing the proportion of GPs with specific EOL procedures to 39–82% depending on tasks.^[24] A review found that only GPs in Spain and the United Kingdom have a tradition for keeping register of palliative patients and that this did not necessarily result in

conversations about EOL care.[25] So whether keeping a register of patients is affecting clinical practice is uncertain. However, one could speculate that, without specific EOL procedures or register there might be an increased risk of overlooking patients with palliative needs and thereby reduced possibilities of taking a proactive approach. This could be especially important when caring for patients with non-malignant diseases.

Other studies examined if GP characteristics were associated with confidence in providing palliative care,[16] seeing palliative care as a central part of the GP's work [26] or involvement in palliative care.[27] They all found higher age of GPs to be positively associated with confidence concerning these aspects. In our study, age was only associated with confidence about being a key worker and increased provision of EOL care to COPD patients. Whether this higher confidence in being a key worker was actually reflected in the quality of care provided to patients is uncertain, and this needs further investigation using patient-related outcomes.

More GPs in rural areas felt confident about administering medicine subcutaneously than GPs in urban areas. In a substantial number of cases, the possibility to give medicine subcutaneously will be a prerequisite for optimal symptom relief and for the patient to die at home. Additionally, geographical variation has been found in Denmark with regard to number of home deaths in 2007-2011.[28] The Capital Region of Denmark had the lowest proportion of home deaths, and the North Denmark Region (more rural area) had the highest proportion.[28] Furthermore, a previous study found that patients in rural areas had more contact to their GP than patients living in urban areas prior to death.[29]

Implications

The identified lack of organisation in EOL care calls for introducing a systematic approach in EOL care among GPs. This could be inspired by ideas from the Chronic Care Model (CCM), which effectively has changed the care for chronic diseases in general practice from reactive to proactive.[30] The CCM has a population-based approach to care, where the care is organised for a disease group as well as for the individual patient. In a palliative context, implementing elements from the CCM may support GPs in their key-worker role and enhance a proactive approach. Furthermore, it may be a way to overcome the diagnosis-specific variation in access to EOL care.

None of the GP characteristics were associated with all examined aspects of EOL care, and low agreement

between the answers to the different EOL aspects was found. This indicates that confidence and EOL care skills vary considerably among GPs, which is important to consider when addressing GPs in future interventions.

Conclusions

We found diagnosis-specific variations in the GPs' provision of EOL care as they reported to be more likely to offer EOL care to cancer patients than to patients with non-malignancies. In addition, diversity in the GPs' self-reported EOL care competencies were found even though most GPs felt confident about being a key worker. A vast majority of GPs reported a lack of EOL care organisation. We identified a need to look further into the importance of geographical variation and to examine if the association between age and confidence about being a key worker is resulting in better EOL care for the patient.

Future interventions aiming to optimise EOL care in primary care should address the need to increase the provision of EOL care to patients with non-malignancies, facilitate better organisation of EOL care and ensure optimum medical treatment in the terminal phase.

Ethics approval

According to the Committee on Health Research Ethics in the Central Denmark Region, this study needed no approval from this committee (file no. 31/2013). The Danish Data Protection Agency (File. no. 2013-41-1965) and the Multi-Practice Committee of the Danish College of General Practitioners (MPU 02-2014) approved the study.

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