

# Low confidence among general practitioners in end-of-life care and subcutaneous administration of medicine

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## ABSTRACT

**INTRODUCTION:** Most terminally ill patients prefer to die at home, and the general practitioner (GP) is central in making this possible. However, knowledge is needed about the GP's level of confidence in assuming this task and with subcutaneous (SC) administration of medicine in end-of-life care. The aim of this study was to determine if GPs used SC needle and medication in end-of-life care, if they felt confident about being principally responsible for palliative trajectories and whether such confidence was associated with GP characteristics.

**MATERIAL AND METHODS:** This was a cross-sectional questionnaire survey of all 332 GPs practising in Copenhagen, Denmark. Questions covered the GPs' use of SC medication/needle and their confidence in being principally responsible for palliative trajectories.

**RESULTS:** The survey response rate was 61%. 43% of the respondents had been principally responsible for a minimum of one palliative trajectory, and only 11% of these GPs had used a SC needle during this process. 57% felt very or somewhat confident being principally responsible and 27% felt very or somewhat confident administering SC medicine. Confidence as principally responsible was positively associated with the number of palliative trajectories for which the GP had been responsible, but no significant associations with the GPs' age, gender or practice organisation were found.

**CONCLUSION:** We found that few GPs in Copenhagen feel very confident about being responsible for terminal care and that very few used SC needles. Hence, more education and training in this field is warranted. Further research is needed into how GPs may best become involved and supported in end-of-life care.

**FUNDING:** Danish General Practitioners' Educational and Development Fund.

**TRIAL REGISTRATION:** not relevant.

Dying at home is important to most terminally ill patients [1, 2], and GPs seem to play an important role achieving this, as evidenced by previous research which has shown that dying at home is associated with GP home visits [3, 4]. Furthermore, interview studies suggest that 24-hour back-up and GP involvement are im-

portant elements in the bereaved relatives' evaluation of palliative trajectories [5-7].

However, a previous study found no variables as far as the GPs' services were concerned to be significantly associated with a successful palliative trajectory evaluated by the bereaved relatives [8]. Furthermore, former studies have identified considerable dissatisfaction with symptom control in the primary care setting [9].

In the last days and hours of life, SC administration of medicine, preferably via a fixed SC needle, is considered the best practice for relieving symptoms [10, 11]. However, we know very little about the GPs' confidence with subcutaneous administration of medicine and if they use a fixed SC needle.

Formal pre- and postgraduate education in palliative care in Denmark is scarce, and no academic faculty positions in palliative medicine have yet been established [12]. Postgraduate day-courses for GPs are available, but GP interest and involvement in palliative care varies [4, 13].

With hardly any palliative care education and often only sporadic experience with terminally ill patients, GPs are facing a challenge when having to take responsibility for these trajectories. We need to know whether GPs feel confident with assuming main responsibility for palliative care and whether some GPs are more confident than others if we gear focus future education and support efforts to GPs' needs. We may speculate that GP characteristics such as age, gender, experience or size of the general practice are associated the GPs level of confidence. Furthermore, as previously stated, there is only little knowledge about GPs' confidence with regard to SC administration of medicine and their use of fixed SC needles, which is an important tool in the management of symptom control during the last days of the patients' lives.

The aim of the present study was therefore to determine the extent to which GPs used fixed SC needles in the last days of patients' lives, to establish whether GPs felt confident being principally responsible for palliative trajectories and whether their confidence was associated with GP characteristics.

## ORIGINAL ARTICLE

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Dan Med J  
2012;59(4):A4407

 TABLE 1

General practitioner attitude and use of subcutaneous medicine in end-of-life care (n = 204). Not all sums equal 100% because of rounding off.

	GPs' answers
<i>Question 6: How confident are you with being the principally responsible?<sup>a</sup> n (%)</i>	
Not at all	38 (18.7)
Not very	49 (24.1)
Somewhat	78 (38.4)
Very	37 (18.2)
Don't know	1 (0.5)
In all	203 (100)
<i>Question 7: How confident are you with administering medicine subcutaneously?, n (%)</i>	
Not at all	106 (52.0)
Not very	43 (21.1)
Somewhat	39 (19.1)
Very	16 (7.8)
Don't know	0 (0.0)
In all	204 (100)
<i>Question 8: How confident are you with switching from orally to subcutaneously administered medicine?, n (%)</i>	
Not at all	114 (55.9)
Not very	46 (22.6)
Somewhat	32 (15.7)
Very	11 (5.4)
Don't know	1 (0.5)
In all	204 (100)
<i>Question 9: How many completed palliative trajectories have you been principally responsible for in 2009?<sup>a</sup></i>	
Mean (95% CI), n = 202	1.0 (0.7-1.3)
n (%)	
0	115 (56.9)
1	43 (21.3)
2	22 (10.9)
3	7 (3.5)
4	8 (4.0)
> 4	7 (3.5)
In all	202 (100)
<i>Question 10 A: Did you use a subcutaneous needle?<sup>a</sup> n (%)</i>	
No	83 (89.3)
Yes	10 (10.7)
In all	93 (100)
<i>Question 10 B: In how many cases did you use a subcutaneous needle?<sup>a</sup></i>	
Mean (95% CI), n = 8	1.9 (0.9-2.8)
<i>Question 11: How much does using a subcutaneous needle contribute to a good palliative trajectory?<sup>a</sup> n (%)</i>	
Not at all	4 (2.0)
Not very	5 (2.5)
Somewhat	44 (21.9)
Very	42 (20.9)
Don't know	106 (52.7)
In all	201 (100)

CI = confidence interval; GP = general practitioner.

a) Not all answered this question.

## Setting

By the end of 2009, the City of Copenhagen had 528,208 inhabitants (which equals approximately 10% of the Danish population), 332 GPs and a total of 4,694 deaths occurred in 2009 (figures from the municipality: City of Copenhagen).

Danish health care is tax-financed and more than 98% of Danes are registered with a GP and receive free medical care. Danish GPs are gatekeepers for access to specialist treatment and responsible for frontline care 24 hours a day, while large GP associations provide out-of-hours services.

Community nurses employed by the municipalities are often involved in palliation and visit patients on a 24-hour basis. Specialized outgoing palliative teams based at major hospitals are available during daytime hours, and GPs or community nurses can obtain specialist advice from these teams by telephone.

## Study population and sampling

We included all 332 GPs from 208 different practices in The City of Copenhagen. Their names and addresses were retrieved by means of The Quality Development and Continued Medical Education for GPs in the Capital Region.

## Data collection

Since no validated questionnaire on the issue was available, an 11-item purpose-designed questionnaire was developed. The five initial questions concerned the GP's age, gender, years serving as a GP and questions about the size of the practice. Questions 6-11 are presented in **Table 1**. Questions 6-9 were used in a former study on GPs and the implementation of a safety-box with SC medication and found applicable [14]. Two ad hoc questions (questions 10 and 11) about how often the GP had used SC needles and the GP's view on the SC needle were added. The questionnaire was pilot-tested on five GPs to evaluate the clarity of the questions and this resulted in only minor changes in the wording of the questions.

GPs received no economic compensation for their efforts. Non-responders were sent one reminder four weeks after they had received the initial questionnaire.

We retrieved questionnaire data on GPs' age (min-49, 50-59, 60+ years), gender, number of years in general practice (min-4, 5-9, 10-19, 20+ years), number of GPs per practice (single or group practice) (1, 2, 3+), number of patients per practice (0-1500, 1501-2500, 2501+ patients) as presented in **Table 2**. Questions six to 11 are shown in Table 1. In questions 6-8 and 11, the answer categories were "Very", "Somewhat", "Not very" and "Not at all". Furthermore, we retrieved register data on GPs' age, gender and practice organisation

## MATERIAL AND METHODS

In this cross-sectional survey, we mailed a self-administered questionnaire to 332 GPs in The City of Copenhagen during April and May 2010.

(single or group practice) from Sundhed.dk, which is a public database with information on Danish Health Care.

### Analysis

Descriptive statistics were calculated. "Being confident as the principally responsible" was defined as outcome measure, and associations with GP variables were calculated. All variables included in the full model can be seen in **Table 3**. The answers to question six were dichotomised into "Confident" ("Very", "Somewhat") and "Not confident" ("Not very", "Not at all").

Unadjusted and adjusted associations were calculated. Using robust variance estimates, the estimates were adjusted for clustering of GPs in practices [15]. Prevalence ratios (PRs) with 95% confidence intervals (CI) were used as a measure of association. Due to the high prevalence of the outcome measure (more than 20% were confident), odds ratios would overestimate the association [16]. Associations were therefore calculated with generalised linear models (GLM) with log link and the Bernoulli family, and whenever the model did not converge, we used the Poisson regression model [16].

The variables were assessed for co-linearity (Pearson's correlation coefficient > 0.4) and as shown in **Table 3**, "Number of years in general practice" had to be excluded due to co-linearity with "GP's age". "Number of GPs per practice" and "Number of patients in practice" had to be excluded due to co-linearity with "Practice organisation". Data were analysed using STATA 10.

*Trial registration:* not relevant

### RESULTS

Among the 332 questionnaires sent, a total of 204 GPs from 141 different practices filled in a questionnaire (response rate 61%). The characteristics of the GPs in the study are presented in **Table 2**. The 128 non-responding GPs were both significantly older and had a larger percentage of male GPs than the 204 participating GPs.

#### Descriptive data

The answers are presented in **Table 1** and **Figure 1**. More than half (57%) of the GPs stated that they had not been the principally responsible for any palliative trajectories in 2009 (question 9, **Table 1**), and on average the GPs had been principally responsible for one palliative trajectory (mean: 1.0, 95% CI: 0.7; 1.3). Only 10 (11%) of the 93 GPs who had had one or more palliative trajectories had used an SC needle (question 10A, **Table 1**) and, finally, 43% stated that using an SC needle contributed to a good palliative trajectory (categories "Very" and "Somewhat") (question 11, **Table 1**).

Less than a fifth (18%) of the GPs felt very confident about being principally responsible with palliative care

**TABLE 2**

General practitioner characteristics. Data on responders are taken from the general practitioner questionnaire. Data on non-responders were collected from the public register Sundhed.dk.

	Responders (n = 204)	Non-responders (n = 128)
GP's age, years, mean (95% CI)	54.4 (53.3-55.5)	56.1 (54.6-57.6) <sup>a</sup>
<i>GP's gender, n (%)</i>		
Male	98 (48.0)	78 (60.9) <sup>a</sup>
Female	106 (52.0)	50 (39.1) <sup>a</sup>
In all	204 (100.0)	128 (100.0)
Time in general practice <sup>b</sup> , years, mean (95% CI), n = 203	15.9 (14.7-17.2)	-
<i>Practice organisation</i>		
Single	128 (62.8)	89 (69.5)
Group	76 (37.2)	39 (30.5)
In all	204 (100.0)	128 (100.0)
Patients in practice <sup>b</sup> , n, mean (95% CI), n = 201	2,571.1 (2,340.9-2,801.2)	-
Patients per GP, n, mean (95% CI), n = 201	1,671.3 (1,623.0-1,719.7)	-

CI = confidence interval; GP = general practitioner.

a) Significantly different from responders; b) Not all general practitioners answered this question.

trajectories (question 6, **Table 1**). Only a few GPs felt very confident administrating SC medicine (8%) (question 7, **Table 1**) and switching to SC from orally administered medicine (5%) (question 8, **Table 1**).

Associations with GPs feeling confident about being the principally responsible for palliative trajectories.

A total of 200 GPs were included in the final multivariate analysis, since only 202 GPs stated a value in the question about confidence being principle responsible, and two GP did not answer the question concerning their number of palliative trajectories.

There was a positive association between the GP's feeling of confidence about being the principally responsible for palliative trajectories and the number of palliative trajectories for which the GP had been principally responsible (**Table 3**). The more palliative trajectories the GP had been the responsible for, the more confident the GP reported to be (e.g. five or more palliative trajectories in 2009; prevalence ratio (PR): 2.5 (95% CI: 1.9; 3.2). Being a male GP seemed also to be associated with a higher level of confidence about being the principally responsible for palliative trajectories in the unadjusted analysis, but this finding failed to show significance in the adjusted analysis.

### DISCUSSION

#### Summary of main findings

Our study showed that only 11% of the GPs who had had one or more palliative trajectories had used an SC needle, and in general the GPs did not feel confident about switching from orally to SC administered medicine. Very few of the GPs felt very confident with being the principally responsible. Being confident about being the principally responsible for palliative trajectories was

positively associated with the number of palliative trajectories for which the GP had been responsible in 2009. We found no significant association between being confident about being the principally responsible for palliative trajectories and GP characteristics.

### Strengths and limitations of the study

Our 61% response rate is in line with other Danish GP questionnaire studies [4]. Responders did not differ from the non-responders in terms of practice organisation, but in terms of age and gender (Table 2). If male and older GPs are more confident with being the principally responsible, as seen in the present study, such trends would have been a clearer if all GPs had answered. Furthermore, it is possible that a significant association between these characteristics and confidence would have been found, had the response rate been higher.

We consider selection bias to be present in this study, since those GPs who answered the questionnaire are probably those most interested in palliative care. Therefore, our results can be interpreted as “best possible” and the “real picture” concerning GPs’ use of SC medication and SC needle may be that SC needle administration is used even less commonly than our results would seem to indicate. All in all, because of the possible disparities in culture between rural and non-rural areas and because of selection bias, any generalization regarding Danish GPs must be made with caution. Furthermore, the questionnaire is not validated, which is warranted for further use.

### Discussion of results and comparison with existing literature

Many studies conclude that GPs and primary health care may not be sufficient in symptom control in palliative and end-of-life care [9, 17]; however, only few studies have actually studied the GPs’ knowledge and confidence in this area. In our study, very few GPs felt confident with administering SC medicine and with switching from orally to SC administered medicine; indeed, fewer felt confident than in another study in a provincial city in Denmark where this issue was examined to ascertain the basis for a possible subsequent educational intervention [14]. This difference may be due to cultural differences rather than to an actual lack of knowledge among GPs in Copenhagen. It is surprising that most GPs in our study did not use the SC route, even if many of them considered that using an SC needle would have contributed to a good palliative trajectory. Hence, there seems to be a mismatch between GPs’ use of SC medication and best practice. Likewise, a study from the UK in which 450 GPs answered questionnaires with concrete questions, e.g. about dose of conversion of oral morphine to subcutaneous diamorphine, concluded: “There is still some way to go before all dying patients receive high quality care” [18].

In another study, 92% Danish GPs in Jutland either definitely or probably agreed that “palliative care is a rewarding part of my work” and only 5% of the GPs agreed that “I would rather leave the care of terminally ill and dying patients to others” [13]. In a Dutch study, the GPs interviewed described their palliative care tasks as satisfactory and varied [19]. In our study, only a little more than 50% of the GPs in Copenhagen felt “very” or “somewhat” confident about being principally responsible for palliative trajectories – a result which leaves room for improvement and underlines the need for further education in end-of-life care.

Only a little more than half of the GPs had been the principally responsible doctor in one or more palliative trajectories in 2009. This may be due to the fact that pa-

TABLE 3

Associations between general practitioner confidence as the principally responsible for palliative trajectories (Question 6, Table 1)<sup>a</sup> and model variables. A total of 204 general practitioner answers were included in the analyses. The unadjusted and the adjusted prevalence ratios are shown (with 95% confidence intervals). In the adjusted analysis, 200 general practitioners were included because of missing values in four cases.

	Unadjusted		Adjusted	
	prevalence ratio	p-value	prevalence ratio	p-value
<i>Age of GP</i>				
Min.-49 years	1		1	
50 – 59 years	1.3 (0.8-1.6)	0.451	1.3 (1.0-1.7)	0.100
60+ years	1.1 (0.8-1.6)	0.512	1.2 (0.8-1.7)	0.402
<i>Gender of GP</i>				
Female	1		1	
Male	1.4 (1.1-1.8)	0.006 <sup>b</sup>	1.3 (1.0-1.6)	0.080
<i>Number of years in general practice</i>				
0-4	1		Not included because of co-linearity with “GP’s age”	
5-9	0.9 (0.5-1.5)	0.678		
10-19	0.9 (0.6-1.4)	0.741		
20+	1.2 (0.8-1.7)	0.480		
<i>Practice organisation</i>				
Single	1		1	
Group	1.0 (0.8-1.3)	0.929	1.2 (0.9-1.5)	0.202
<i>Number of GPs per practice</i>				
1	1		Not included because of collinearity with “Practice organisation”	
2	1.1 (0.8-1.4)	0.660		
3	0.8 (0.5-1.5)	0.520		
<i>Number of patients in practice</i>				
0-1,500	1		Not included because of collinearity with “Practice organisation”	
1,501-2,500	0.9 (0.7;1.3)	0.715		
2,501+	0.9 (0.7;1.3)	0.762		
<i>Number of palliative trajectories (question 9)</i>				
0	1		1	
1-2	1.7 (1.3-2.2)	0.000 <sup>b</sup>	1.7 (1.-;2.2)	0.000 <sup>b</sup>
3-4	2.1 (1.5-2.8)	0.000 <sup>b</sup>	2.1 (1.5-2.9)	0.000 <sup>b</sup>
5+	2.5 (2.0-3.1)	0.000 <sup>b</sup>	2.4 (1.8-3.1)	0.000 <sup>b</sup>

GP = general practitioner.

a) The answers to question 6 were dichotomised into “Confident” (“Very”, “Somewhat”) and “Not confident” (“Not very”, “Not at all”); b) Statistically significant.

tients in long-term specialist care (e.g. oncology) do not re-establish contact with their GP for many reasons [20]. The analysis in this study indicates that the confidence in being principally responsible increased with the number of palliative trajectories for which the GPs had been responsible. Not surprisingly, this implies a “learning by doing” tendency. However, it also points out a need for pre- and postgraduate education to make GPs more confident with end-of-life care from the outset in order to avoid problems with poor symptom control, because as it is now GPs mainly learn through experience in the field.

In a recent study in Jutland, Thellessen et al found an overall improvement in the GPs’ confidence, competence and knowledge about handling the last days of life for patients dying at home as a result of an intervention involving informative letters, access to a website, training, telephone specialist support, and peer-to-peer-based training [14]. This indicates that training in SC medication and focusing on end-of-life issues improves GPs’ confidence with the challenges of palliative care.

### Implications for future research

This survey suggests a need for systematic training in the practical medical treatment of terminal patients in general practice. However, further research is needed, especially on how the GPs are best motivated to seek further education and get involved in end-of-life care. We also need to find ways of reaching those GPs who may benefit from further education in palliative care, but who do not perceive the need themselves.

### CONCLUSION

We found that few GPs in Copenhagen feel very confident about being responsible for terminal care at home and that very few use SC needles in terminal care. The positive correlation between confidence and the number of experienced trajectories may reflect attitudes and a “learning by doing” approach. Hence, more systematic education and training in this field is warranted. Further research is needed on how GPs are best involved and supported in end-of-life care.

### Ethical approval

According to Scientific Committee for The Capital Region of Denmark, the Biomedical Research Ethics Committee System Act does not apply to our study (j.no. H-C-FSP-2009/15). The same applied for the Danish Data Protection Agency.

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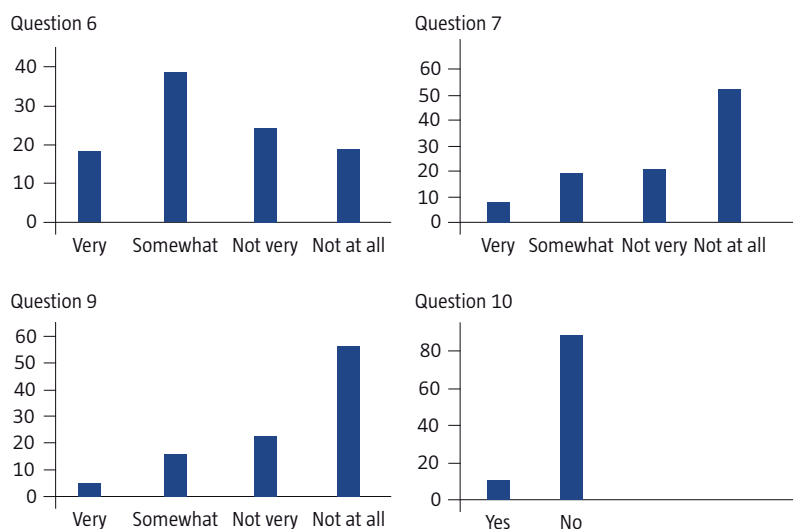
**ACCEPTED:** 11 January 2012

**CONFLICTS OF INTEREST:** Disclosure forms provided by the authors are available with the full text of this article at [www.danmedj.dk](http://www.danmedj.dk).

**ACKNOWLEDGEMENTS:** Our profound gratitude is extended to the partici-

**FIGURE 1**

Diagrams presenting answers to questions 6, 7, 9 and 10. Question 6: How confident are you being the principally responsible? Question 7: How confident are you administering medicine subcutaneously? Question 9: How confident are you converting from orally to subcutaneously administered medicine? Question 10: Did you use a subcutaneous needle?



pating GPs. Furthermore, we thank *Tove Vejlgård* and *Jacob Borggaard Thellessen* from The Palliative Team, Vejle Hospital, Denmark, for inspiration to the questionnaire from the project Implementation of a Safety Box in General Practice and The Danish General Practitioners’ Educational and Development Fund (PLU) for funding.

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