

Obstacles to the delivery of primary palliative care as perceived by GPs

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Introduction: In order to facilitate GPs in their work and increase the possibilities for patients to remain at home, it is important to identify the obstacles which hinder the delivery of primary palliative care. From previous research we learned about some of the problems experienced by GPs. In this survey we aimed to identify the prevalence of such problems in providing palliative care and its determinants. **Methods:** The prevalence of obstacles and its determinants were identified by a questionnaire to 320 GPs in three regions of the Netherlands. Obstacles were grouped as follows: communication, organisation & co-ordination of care, knowledge & expertise, integrated care, time for relatives. The potential determinants were GP characteristics and expertise development activities. **Results:** The response rate was 62.3%. GPs experienced considerable obstacles in all aspects of palliative care. The most prevalent were: problems with bureaucratic procedures (83.9%), the time necessary to arrange home care technology (61.1%) and the difficulties accompanied with the wish or necessity to obtain extra care (56.3%). In general, more years of GP experience and the participation in (multidisciplinary) case discussions were associated with less perceived obstacles. **Discussion:** Based on the results of our survey policymakers and practitioners can plan and set priorities in handling the obstacles. There is a high necessity of firstly overcoming the barriers within organisation and coordination of care. Furthermore, our study can help in choosing the (additional) expertise needed in the future and in the realisation of the preferred expertise advancement activities. *Palliative Medicine* 2007; **21**: 697–703

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Introduction

General practitioners (GPs) increasingly encounter patients requiring palliative care. Medical developments, an ageing population and a primary-care oriented government policy all contribute to the growing need for palliative care in primary practice.^{1,2} GPs value the care provision highly,³ some even describe it as the epitome of their work.⁴ Palliative care can be described as complex care in terms of both content and organization; consequently, GPs perceive many barriers in daily practice.^{4–7}

Good primary palliative care is essential, as it allows patients to remain at home as long as possible. It is known that most patients wish to do so and would eventually prefer to die at home among family and friends.^{8–13} Nevertheless, as in many industrialized countries with a strong hospital sector, many patients in the Netherlands still die in hospital despite the emphasis on and preference for primary palliative care.^{8,14–16}

There are several ways to support GPs in their primary palliative care, for example by means of the development of good practice frameworks like the Gold Standards Framework (GSF)¹⁷ or the Liverpool Care Pathway (LCP).¹⁸ In the Netherlands a sizable palliative care developmental programme was launched in the last decade. Part of this programme was the establishment of Palliative Care Consultation teams (PCC teams) all over the country; teams of experienced professional care providers from different settings giving advice and support to their healthcare

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colleagues when they encountered problems in daily practice. Knowledge of barriers could contribute to an effective PCC team service provision as well as to the development of other quality improvement activities in palliative care. In order to support GPs in their care of these patients and increase the opportunities for patients to remain at home whenever they so wish, it is important to identify the barriers that hinder palliative care in daily practice.^{19,20}

From a previous qualitative study using focus groups, we learned that GPs experienced barriers on three different levels, namely: personal, relational and organizational.⁴ However, we still do not know the prevalence of the barriers and neither do we have information on the determinants of the barriers. So, with reference to this focus group study, we carried out a survey of the barriers in palliative care as perceived by GPs. It is hypothesized that GP characteristics and expertise developmental activities will influence the occurrence of several barriers. Therefore, the present article describes the results of this survey that aimed to identify the frequency of the various barriers and its determinants.

Methods

Study design and participants

A survey was conducted in three regions in the Netherlands. All the GPs practising in these regions (220, 167 and 127, respectively) received written questionnaires together with a covering letter explaining the aims of the study and a stamped addressed return envelope. Reminder letters were sent after one month.

Variables

The dependent variables in our survey were the perceived barriers in palliative care. After a rigorous procedure consisting of a qualitative focus group study, a pilot study ($n = 10$ GPs) of the first version of the questionnaire and preliminary analyses to determine the relevance of items and the underlying factor structure, the perceived barriers featured in our survey were grouped as follows:

- Communication scale (5 items, Cronbach's α 0.73)
- Organization and coordination of care scale (4, Cronbach's α 0.66)
- Knowledge and expertise scale (5, Cronbach's α 0.63)
- Integrated care¹ items (7)
- Time-for-relatives item (1).

Answers could be given on a 5 -point Likert scale ranged from 'totally disagree' to 'totally agree'. Most items were formulated negatively; originally, only seven of the 22 items were formulated positively, for instance as 'it is easy to...'. At the end of the questionnaire there was room to add further

comments. We asked the GPs to answer the questions with their general palliative care experiences in mind.

The survey of GPs in our study population was arranged according to the following possible determinants:

- *Expertise development.* We ascertained whether GPs had undertaken any activities to develop their expertise in palliative care, had attended any specific educational meetings, (multidisciplinary) case discussions, consultation or had read the current literature (yes/no).
- *GP characteristics.* We ascertained and classified the number of years of experience (<1 , 1–5, 6–10, >10), the mean annual number of palliative care patients (≤ 2 , 3–5, 6–9, ≥ 10), region (Nijmegen, Arnhem, Gelderse Valley), and we dichotomized gender, practice setting (country or rural town versus (big) city) and practice type (solo practice versus duo- or group practice). We also gathered data on the region, gender and practice setting of the nonresponders.

Analysis

Descriptive analyses were made of the characteristics of the respondents and nonrespondents, the items on expertise development and the questionnaire scores for the perceived barriers in palliative care (Tables 1, 2 and 3). We reversed the rank responses of the positively phrased questions in the barriers questionnaire so that responses with a similar meaning have a similar magnitude.

Table 1 Characteristics of respondents

Respondents ($N = 320$)		
Gender		
Women	89	(27.8%)
Men	229	(71.6%)
Missing	2	(0.6%)
Region		
Nijmegen	144	(45.0%)
Arnhem	104	(32.5%)
Gelderse Valley	72	(22.5%)
Practice setting		
Country/rural town	165	(51.5%)
(big) city	149	(46.6%)
Missing	6	(1.9%)
Practice type		
Solo	90	(28.1%)
Duo/group	159	(49.7%)
Missing	71	(22.2%)
Number of years of experience		
<1	2	(0.6%)
1–5	27	(8.4%)
6–10	62	(19.4%)
>10	184	(57.5%)
Missing	45	(14.1%)
Yearly number of palliative care patients		
≤ 2	39	(12.2%)
3–5	141	(44.1%)
6–9	67	(20.9%)
≥ 10	21	(6.6%)
Missing	52	(16.3%)

Table 2 Perceived obstacles in general palliative care ($N = 320$)*

Parts	Item	% (strongly) agree	% neutral	% (strongly) disagree
Communication with patients and relatives	I find it difficult to handle relatives' hidden agenda	58.8	29.7	11.5
	I have difficulties with a situation in which mutual disagreement within the relatives exist	56.6	23.7	19.6
	I have difficulties if a patient assumes that I automatically know about his problems	49.1	25.9	25.0
	I have difficulties with talking to a patient and his relatives, when they do not want to admit to each other how much grief they bear	35.6	19.9	44.5
	Discussing problems and needs of a patient costs me a lot of trouble when the patient does not start talking about them himself	12.6	18.0	69.4
Organisation & co-ordination of care	I have troubles with bureaucratic procedures within organizations	83.9	10.7	5.4
	Arranging home care technology ^a costs me too much time	61.1	20.6	18.4
	It is difficult organizing home care technology	37.5	34.7	27.8
	I need to invest too much time in co-ordinating tasks	28.6	43.2	28.3
Knowledge and expertise	I lack expertise to perform home care technology myself	42.3	20.2	37.5
	It is not easy to gain knowledge about the performance of home care technology	30.2	31.1	38.7
	I am short of knowledge concerning the possibilities within health- and social care	22.1	31.2	46.7
	It is not easy to gain knowledge about treatment possibilities**	20.3	32.4	47.3
Integrated care	I am short of knowledge concerning possible treatment options**	14.6	34.9	50.5
	Obtaining extra care for the patient is difficult**	56.3	20.3	23.4
	I have troubles with changes in the homecare professional workforce	44.8	23.5	31.7
	The transfer (of patient data) from the medical specialist to me is not going well**	35.7	34.7	29.6
	There are no clear appointments about who is the principal doctor in attendance during the palliative phase**	33.4	32.5	34.1
	I am not fully acquainted with the possibilities of other health- and social caregivers	28.8	36.1	35.1
	I am not fully acquainted with the activities performed by other health- and social caregivers concerned with my patients**	16.5	28.8	54.7
	I have difficulties with consecutive involvement of hospital staff when patient is discharged	10.8	25.4	63.8
Time-for-relatives	In my view I cannot give enough time and attention to the relatives**	23.5	23.8	52.7

Ad,* :Missing (between 3 – 9 per question) excluded.

Ad,** :Reversal of items.

^aHome care technology covers the whole scale from diagnostics, therapeutic aids and procedures. Examples are: a drip or pump for medication or blood, drip feed, oxygen, ascitespuncture

Nonresponse bias was assessed by comparing the respondents and nonresponders on three publicly-available GP characteristics; gender, region and the setting of the practice.

To determine the variation associated with the perceived barriers in palliative care, a General Linear Model univariate analysis was used to compare scale and item scores by GP characteristics and expertise information. The level of significance was set at $P < 0.05$. All statistical procedures were performed with the SPSS 12.0 program.

Results

Study sample and nonresponders

Of the 514 questionnaires mailed to the GPs in our study, 320 questionnaires were returned, an overall response rate of 62.3%. The respondents were from 31 to 62 years of age,

with a median of 46 years. Most (71.6%) of them were men. A substantial proportion (49.7%) worked in a duo- or group practice. More than half of the respondents had worked as a GP for more than 10 years and nearly half of the GPs reported an annual number of about 3–5 palliative care patients (Table 1).

An analysis of the nonresponders showed that they did not differ significantly from the respondents regarding gender, region or the setting of the practice.

Perceived barriers in primary palliative care

With regard to *communication* with patients and relatives, over 50% of the respondents experienced difficulties in situations featuring mutual disagreement among relatives and the handling of relatives' hidden agendas. With regard to the *organization and co-ordination of care*, more than 80% of the responding GPs reported problems with bureaucratic

Table 3 Expertise development items and scores

Activities	Yes (%)	No (%)	Missing (%)
Did you read articles about palliative care during the last year?	89.0	9.1	1.9
Did you get advice for palliative questions from one or more regular consultants in the region?	66.6	31.2	2.2
Did you participate in (multidisciplinary) case discussion?	58.4	39.7	1.9
Did you attend an educational meeting regarding palliative care or terminal care during the last year? (e.g., course, workshop, conference or network meeting)	52.2	45.9	1.9

procedures within organizations. Arranging homecare technology also seemed to be a source of problems. GPs' opinions were divided on the other two topics in this scale. The main problem regarding *knowledge and expertise* was the GPs' lack of sufficient expertise to enable them to deal with homecare technology themselves. GPs were most positive about their knowledge concerning possible treatment options; opinions differed when it came to gaining knowledge about the performance of homecare technology. Concerning *integrated care*, GPs reported obtaining extra care for the patient as the most problematic topic. The consecutive involvement of hospital staff and less than full knowledge of other professional care providers' activities involving the patient was seen as the least difficult problem. Nearly a quarter of the GPs thought that the *time and attention they gave to the relatives* was insufficient (Table 2).

Expertise development

Nearly all the respondents had read some articles concerning palliative care during the previous year. Consultation with (expert) colleagues in palliative care was also a fairly common resource for expertise development. Half the GPs had participated in specific palliative care education (Table 3).

Determinants of perceived barriers

Gender, consultation and reading the literature were not associated with the quantity of barriers perceived in palliative care. The other variables were significant contributors to one or more of the three scales or eight separate item scores.

More years of experience as a GP and attending specific educational meetings were associated with the experience of fewer barriers in *communication* with patients and relatives. Having a larger number of palliative care patients per year was related with fewer barriers in *knowledge and expertise*. Similarly, participation in (multidisciplinary) case discussions was associated with fewer barriers on the knowledge and expertise scales. Table 4 also shows that GPs working in two regions and also in the cities reported more barriers

concerning knowledge and expertise and with regard to obtaining extra care for the patient. None of the independent variables in our model was related with the barriers within the *organization and co-ordination of care* scale. With regard to *integrated care*, participating in (multidisciplinary) case discussions and number of working years were also associated with the reporting of barriers. This association was however, contrary to what was expected; participating in (multidisciplinary) case discussions was related with more problems associated with 'changes in home care professional workforce' and 'consecutive involvement of hospital staff after discharge'.

Discussion

GPs encounter formidable barriers in all aspects of palliative care. The most frequent barriers are problems with bureaucratic procedures within organizations, the time required to arrange homecare technology and the difficulties accompanying the wish or the necessity to obtain extra care for the patient.

More years of experience as a GP and participation in (multidisciplinary) case discussions in general is associated with fewer perceived barriers. Several previous studies have shown that education sometimes has small or no effect at all.^{22–24}; our association, however, is not only at the level of ready knowledge, but more in terms of the better handling of problematic and complex situations. Furthermore, the positive relations mostly came from the participation in case discussions, a very specific form of education because of the high level of interaction between the participants and the fact that the topic directly comes out of daily practice. In general terms, the mean differences on the obstacle scales and items related with GP characteristics and expertise on the barriers experienced are relatively small. It might be interesting to examine whether other factors such as organizational aspects (adding specialized nurses to the primary palliative care team, for example) or legislation and regulation have any influence on the barriers experienced.

The practice has become established in our health-care system for professionals from different health-care institutions to collaborate on complicated care issues^{25,26} in order to facilitate care processes. Such collaboration could lead to a decrease in the number of barriers encountered. In one region we found fewer barriers, possibly as the result of such arrangements. Furthermore, the mutual disagreement about some barriers might also be attributable to these (multidisciplinary, integrated) care arrangements. Further exploration and specification of this problematic topic is needed.

The GP characteristics and expertise development activities of GPs had no significant influence on the organization and co-ordination of care barriers. This result seems to be logical for, say, the use of homecare technology; this is infrequently used, so the necessary skills are difficult to develop, even for experienced GPs. The same argument applies to

Table 4 Determinants of differences in perceived obstacles

Contributing variables		<i>B</i>	Mean	Significance
Communication scale				
Number of years of experience	<1	-3.5	11.0	ns
	1 tm 5	-2.0	12.8	0.00
	6 tm 10	-1.2	13.8	0.01
	>10		15.0	
Specific educational meetings	No	-0.8	14.0	0.04
	Yes		14.8	
Organisation and co-ordination of care scale				
No contributing variables.				
Knowledge and expertise scale				
Yearly number of palliative care patients	≤ 2	-2.8	14.0	0.00
	3 tm 5	-1.1	16.2	0.05
	6 tm 9	-1.4	16.2	0.03
	≥ 10		17.5	
Region	Nijmegen	-0.9	15.7	0.03
	Arnhem	-0.9	15.7	0.03
	Gelderse Valley		16.5	
Practice setting	country/rural town	0.9	16.4	0.01
	(big) city		15.3	
(Multidisciplinary) case discussions	No	-1.5	14.8	0.00
	Yes		16.7	
Integrated care				
<i>Changes in homecare professional workforce</i>				
(Multidisciplinary) case discussions	No	0.23	3.0	0.05
	Yes		2.7	
<i>Transfer (of patient data) from medical specialist</i>				
Number of years of experience	<1	-0.51	2.5	ns
	1 tm 5	-0.12	2.9	ns
	6 tm 10	-0.38	2.6	0.00
	>10		3.0	
<i>Consecutive involvement of hospital staff after discharge</i>				
(Multidisciplinary) case discussions	No	0.26	3.7	0.01
	Yes		3.5	
<i>Obtaining extra care</i>				
Region	Nijmegen	-0.7	2.4	0.00
	Arnhem	-0.5	2.6	0.00
	Gelderse Valley		3.0	
Practice setting	country/rural town	0.2	2.7	0.03
	(big) city		2.5	
<i>Acquainted with the possibilities of other caregivers</i>				
Number of years of experience	<1	-1.2	2.0	0.05
	1 tm 5	-0.3	2.9	ns
	6 tm 10	-0.2	3.0	ns
	>10		3.2	
<i>Acquainted with activities by other caregivers</i>				
(Multidisciplinary) case discussions	No	-0.3	3.2	0.00
	Yes		3.5	
Time-for-relatives				
Give enough time and attention to the relatives				
(Multidisciplinary) case discussions	No	-0.4	3.1	0.00
	Yes		3.5	

bureaucratic procedures within organizations. Procedures are often very complex and they change as legal or financial scope differs in the course of time. Decreasing these barriers seem to ask for other interventions. Focusing on organization and co-ordination of care barriers, however, is important given their magnitude.

A limitation of our survey is that it displays only the GPs' perspective of potential barriers in the daily practice of

palliative care. Professionals from other disciplines, and the patient and patient's family, may have different views about barriers. Notwithstanding the very important role in primary practice of, for instance, district nurses, usually GPs constitute the main stable, continuing factor. If primary practice remains the preferred place to be in the last phase of life and GPs continue to play a pivotal part in palliative care, keen observation of the problems experienced is important for

future developments. Developments in primary care (like the increase of GPs' out-of-hours-organizations and the boundaries concerning informal care)^{27,28} and the existence of the huge barriers like we found demand for a broad debate concerning the (near) future of primary palliative care and the ways in which this focus on primary care remains feasible.

The results of this study provide a basis for policymakers and practitioners to plan and set priorities in handling the barriers. Practice-oriented education, given by GPs experienced in palliative care on demand and at the bedside, combines a number of obstacle-decreasing factors. The provision of such support might be one of the actions capable of leading to a situation in which more patients remain at home to be cared for by GPs who are sufficiently equipped and supplemented by specialist backup.

Another way of coping with the barriers experienced might be the establishment of institutionalized consultation services. Following our survey, more than 20 Palliative Care Consultation teams (PCC teams) were set up to operate throughout the Netherlands, replacing the noninstitutionalized ad hoc arrangements current at the time of our survey. A recent study has shown that half of all requests for consultation with PCC teams come from GPs, who fairly frequently request advice concerning organizational problems (such as the use/availability of material and equipment).²⁹ Our survey refers to the consultation activities in the period preceding the establishment of these teams. The results reported in this PCC team study seem to be positive, although a repeated or complementary survey might yield more clarity concerning the possible contribution of PCC teams in the eradication of barriers.

A thoroughly considered palliative care action program for the coming years, accompanied by support in the sphere of (temporary) staff and finances, will improve palliative care in general. This would have a positive effect on the GPs who consider palliative care as the epitome of their work as well as the patients and their families who want to end their lives at home in a humane and personal way.

Note

¹ Integrated care: care attuned to the needs of the patient, provided on the basis of the cooperation and coordination of general and specialist care providers, with shared overall responsibility, and the specification of delegated responsibilities.²¹

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