Facilitators and barriers for GP–patient communication in palliative care:

a qualitative study among GPs, patients, and end-of-life consultants

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ABSTRACT

Background

Effective communication is considered to be essential for the delivery of high-quality care. Communication in palliative care may be particularly difficult, and there is still no accepted set of communication skills for GPs in providing palliative care.

Aim

To obtain detailed information on facilitators and barriers for GP–patient communication in palliative care, with the aim to develop training programmes that enable GPs to improve their palliative care communication skills.

Design of study

Qualitative study with focus groups, interviews, and questionnaires.

Setting

GPs with patients receiving palliative care at home, and end-of-life consultants in the Netherlands.

Method

GP (n = 20) focus groups discussing facilitators and barriers, palliative care patient (n = 6) interviews regarding facilitators, and end-of-life consultant (n = 22) questionnaires concerning barriers.

Results

Facilitators reported by both GPs and patients were accessibility, taking time, commitment, and listening carefully. GPs emphasise respect, while patients want GPs to behave in a friendly way, and to take the initiative to discuss end-of-life issues. Barriers reported by both GPs and end-of-life consultants were: difficulty in dealing with former doctors' delay and strong demands from patients' relatives. GPs report difficulty in dealing with strong emotions and troublesome doctor–patient relationships, while consultants report insufficient clarification of patients' problems, promises that could not be kept, helplessness, too close involvement, and insufficient anticipation of various scenarios.

Conclusion

The study findings suggest that the quality of GP–patient communication in palliative care in the Netherlands can be improved. It is recommended that specific communication training programmes for GPs should be developed and evaluated.

Keywords

communication; palliative care; physicians, family; physician–patient relationship; qualitative research.

INTRODUCTION

GPs play a central role in providing palliative care in the Netherlands, where palliative care is not a medical specialism. Many authors consider effective communication between healthcare professionals and patients as an essential requirement for the delivery of high-quality care. Effective communication has been shown to be beneficial to patient outcomes such as pain control, adherence to treatment,[1,2] and psychological functioning.[3,4] Conversely, ineffective communication has been associated with adverse effects on patient compliance with treatment.[5] Furthermore, poor communication can leave patients anxious, uncertain, and dissatisfied with the care they receive.[6] Communicating with patients in palliative care has been acknowledged to be more difficult than communicating with patients with less serious

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conditions.[7] Communication in palliative care involves a complex mix of physical, psychological, social, and spiritual issues in the context of impending death. Doctors, including GPs, often fail to communicate effectively with patients on these issues.[8,9] Many GPs have never received any training in communication skills with a specific focus on palliative care at any time throughout their career.[10,11]

It is still unclear what the most important barriers are for GPs in their communication with patients who need palliative care. Moreover, there is still no generally accepted set of essential communication skills for GPs providing palliative care. The aim of this study was to obtain detailed information about these facilitators and barriers, in order to develop a communication training programme for GPs, with a specific focus on palliative care. Previous studies have merely collected data on GP–patient communication in palliative care reported by doctors and patients separately.[8,12–17] One study involved patients as well as caregivers, but did not focus on palliative care provided by GPs.[18] The present paper reports on a qualitative study of facilitators and barriers for GP–patient communication in palliative care, based on data from GPs (who provide palliative care), patients (who receive palliative care), and end-of-life consultants (experts). GPs were asked which facilitators they considered to be most important for GP–patient communication in palliative care. They were also asked which barriers they experienced. To complement the information received from the GPs, some of their palliative care patients were also asked which of their GP's communication skills they appreciated most, and end-of-life consultants were asked which barriers in GP–patient communication they had observed in the previous year.

The research questions were: (1) which facilitators for GP–patient communication in palliative care are reported by GPs and/or their palliative care patients, and (2) which barriers for GP–patient communication in palliative care are reported by GPs and/or end-of-life consultants?

How this fits in

This qualitative study suggests that GP–patient communication in palliative care in the Netherlands could be improved. Palliative care patients want friendly and committed GPs who take the initiative in discussing end-of-life issues. End-of-life consultants advise GPs to clarify the patient's problems and concerns more explicitly and to pay attention to their own personal barriers. The results of this study can contribute to the development of training programmes that enable GPs to improve their communication skills in palliative care.

METHOD

GP focus groups discussing facilitators and barriers

The perspectives of GPs with regard to facilitators and barriers for GP–patient communication in palliative care were studied in 2004 in two 90-minute focus group discussions with 10 GPs in each. The choice for focus groups was made because this qualitative method capitalises on group dynamics to obtain information that may not be available through individual interviews or quantitative methods. The first group was a convenience sample of GPs who met to discuss scientific topics during monthly meetings. The second group was recruited by purposeful sampling to ensure heterogeneity of the members (sex, age, experience, and urban or rural practice). The GPs in the focus groups discussed which facilitators and barriers for GP–patient communication in palliative care they considered to be most important. The discussions were facilitated by a moderator, audiotaped, transcribed verbatim, and anonymised. Fragments from the transcriptions concerning facilitators and barriers for GP–patient communication were identified and classified. This content analysis of the transcriptions was performed by two of the authors. During the analysis the validity was ensured by critical discussion, and after the analysis by sending all participants a summary of the findings and asking them for their consent and comments (member check).

Patient interviews regarding facilitators

The perceptions of palliative care patients with regard to the communication skills and attitudes of their GPs were studied in 2005 by means of semi-structured, in-depth interviews. GPs who participated in the focus groups invited patients from their practice who were over 18 years of age and had an advanced illness with a life expectancy of less than 6 months (estimated by the GP) to participate in the study. After obtaining informed consent, the GP completed a registration form and sent it to the research team, who contacted the patient. Because the condition of these patients could deteriorate rapidly, they were visited at home as soon as possible, by the first author, for a 60-minute interview. Patients were sampled until content saturation was reached (no additional themes emerged during the final phase of analysis). The patients were interviewed about their experiences with their own GP, and asked which communication skills and attitudes they considered essential in a GP. The interviews were audiotaped, transcribed verbatim, and anonymised. Fragments from the transcriptions concerning facilitators for GP–patient communication in palliative care were identified and classified. The content analysis of the transcription was performed by two of the authors. A member

check some months after the interview was impossible, because of the deteriorating condition of the patients.

End-of-life consultant questionnaires concerning barriers

The perspectives of end-of-life consultants with regard to barriers for GP–patient communication in palliative care were studied in 2003 by means of questionnaires that were sent by email to a convenience sample of 55 end-of-life consultants: 45 Support and Consultation on Euthanasia in the Netherlands (SCEN) consultants,[19,20] and 10 palliative care consultants, in three regions of the Netherlands. No reminders were sent. In the Netherlands, end-of-life consultants are GPs or nursing home physicians who have completed a training programme to be able to elicit and clarify the problems underlying a consultation request and to advise colleagues concerning palliative care problems or euthanasia requests. The consultants were expected to have quite a detailed impression of the occurrence of barriers for GP–patient communication in palliative care, because they are consulted by GPs in particular in cases of troublesome palliative care. The consultants were asked to describe the barriers for GP–patient communication that they had observed in the previous year. Fragments from their written answers concerning barriers were identified and classified. The content analysis was performed by two of the authors.

RESULTS

Participating GPs

The 10 GPs participating in the first group were members of the scientific committee (CWO) of the Dutch College of General Practitioners (NHG). In the second group of 10 GPs, more GPs who were female or who worked in a (semi-)rural setting were purposely sampled. The characteristics of the participating GPs are presented in Table 1.

Participating palliative care patients

Nine patients were invited by six GPs to participate (three of the GPs asked two patients each); they all agreed. The condition of three patients deteriorated too rapidly (in a few days) to allow participation, so six patients from five GPs were interviewed. Because no additional themes emerged from the analyses of the last two interviews, it was decided that after six interviews content saturation was reached, and there was therefore no need to recruit additional patients. All patients had cancer: malignant melanoma, non-Hodgkin's lymphoma, pancreatic, prostate, liver, or breast cancer. Other patient characteristics are presented in Table 1.

Table 1. Characteristics of GPs and palliative care patients.

Characteristics of participants	Results
GPs (n = 20)	
Sex, *n*	
Male	13
Female	7
Mean age (range), years	49.5 (36–59)
Mean cinical work experience (range), years	17.7 (5–31)
Practice location area, *n*	
Urban	14
Semi-rural	6
Group or single-handed practice, *n*	
Group practice	17
Single-handed practice	3
Working part-time or full-time, *n*	
Part-time	13
Full-time	7
GP vocational trainers, *n*	
Yes	10
No	10
Very experienced in palliative care, *n*	
Yes	6
No	14
Palliative care patients (*n* = 6)	
Sex, *n*	
Male	5
Female	1
Mean age (range), years	62 (48–77)
Living alone/with partner	
Alone	3
With partner	3
Diagnosis: cancer	6
Condition: moderate	6
ADL independent	
Yes	5
No	1
Satisfied with care from their GP	
Satisifed	3
Mixed feelings	2
Unsatisfied	1

ADL = activities of daily life.

Participating end-of-life consultants

Twenty-two questionnaires were returned. The response was 60% from the palliative care consultants (6/10) and 36% from the SCEN consultants (16/45). Data on characteristics of the consultants were not collected. From the 22 responding end-of-life consultants, 20 had observed barriers for GP–patient communication in the past year, so they were able to answer the questions.

Facilitators reported by GPs and palliative care patients

Facilitators reported by GPs and patients were: GP is accessible; taking the necessary time; listening carefully; showing empathy; straightforward; paying

attention to the patient's symptoms; and giving the patient a feeling of trust. Facilitators reported by GPs, but not by patients were: GP making regular home visits; respecting the patient's dignity, autonomy, wishes, and expectations; ensuring continuity of care; and anticipating various scenarios. Facilitators reported by patients, but not by GPs, were: GP taking the initiative to call in or phone the patient spontaneously; encouraging the patient (for example, putting his/her hand on the patient's arm); being open and willing to talk in everyday language and about any subject that is relevant for the patient; adapting to the pace of the patient; explaining clearly (for example, about the diagnosis and prognosis); helping the patient to deal with unfinished business; taking the initiative to talk about end-of-life issues; making appointments for follow-up visits; the longstanding GP–patient relationship; and the GP's practice being located near the patient's home.

All facilitators reported by GPs and/or patients are presented in Box 1. There were more facilitators reported by the patients only than by the GPs only.

Barriers reported by GPs and end-of-life consultants

Barriers reported by GPs and end-of-life consultants were: GP having difficulty in dealing with former doctor's delay in diagnosis of the disease; having difficulty in dealing with strong demands of patient's relatives; not being able to take enough time to provide palliative care and to ensure continuity of care. Barriers reported by GPs, but not by end-of-life consultants were: GP having difficulty in dealing with patient's fears and other strong emotions; not being able to handle a troublesome relationship with the patient or to deal with patient and relatives together; not knowing the patient's wishes and expectations (for example, specific wishes and expectations of immigrant patients); and not being able to control the patient's symptoms adequately.

The main problem reported by the consultants was a lack of clarity in many issues, because the GP–patient communication was inhibited by various barriers. Barriers reported by the end-of-life consultants only were: GP clarifying the patient's problems and concerns insufficiently; making promises that cannot be kept (for example, about pain management); becoming too much involved; feeling helpless; being irritated; not being able to handle pressure exerted by patient or relatives; not being clear about his/her own opinion with regard to euthanasia; lacking certain knowledge; having pre-existing emotional problems; not being able to make proper arrangements for out-of-hours care; and not anticipating various scenarios.

All barriers reported by GPs and/or end-of-life consultants are presented in Box 2. There were more barriers reported by end-of-life consultants only than by GPs only.

DISCUSSION

Summary of main findings

It was found that patients as well as GPs value accessibility, taking time, showing commitment, and listening carefully as essential facilitators. Moreover, the GPs emphasised a respectful attitude towards

Box 1. Facilitators for GP–patient communication in palliative care reported by GPs (*n* = 20) and palliative care patients (*n* = 6).

GPs only

- GP makes regular home visits
- GP respects the patient's dignity
- GP respects the patient's autonomy
- GP respects the patient's wishes and expectations
- GP ensures continuity of care
- GP anticipates various scenarios

GPs and patients

- GP is accessible and available
- GP takes the necessary time for the patient
- GP listens carefully
- GP shows empathy and commitment
- GP is honest and straightforward
- GP pays attention to the patient's symptoms
- GP gives the patient a feeling of trust

Patients only

- GP takes the initiative to visit or phone patients spontaneously
- GP encourages and reassures the patient
- GP puts his/her hand on the patient's arm
- GP has an open attitude
- GP allows any topic to be discussed
- GP talks in everyday language, not using difficult medical terms
- GP adapts to the pace of the patient
- GP explains clearly (for example, diagnosis)
- GP talks about the unfavourable prognosis
- GP helps the patient to deal with unfinished business
- GP takes the initiative to talk about relevant issues (for example, diagnosis and prognosis)
- GP should take the initiative to talk about euthanasia (*n* = 1) or GP should not do so (*n* = 2)
- GP makes appointments for follow-up visits
- GP–patient relationship is longstanding
- GP's practice is near the patient's home

Box 2. Barriers for GP–patient communication in palliative care reported by GPs (*n* = 20) and end-of-life consultants (*n* = 22).

GPs only

- GP has difficulty in dealing with the patient's fears and other strong emotions
- GP cannot handle a troublesome relationship with the patient
- GP cannot deal with the patient and the patient's relatives together
- GP does not know the patient's wishes and expectations
- GP cannot control the patient's symptoms adequately
- GP is not familiar with the specific wishes and expectations of immigrant patients

GPs and consultants

- GP cannot deal with former doctor's delay in diagnosis
- GP has difficulty in dealing with strong demands from the patient's relatives
- GP cannot take enough time for palliative care
- GP is not able to ensure continuity in palliative care

Consultants only

- GP clarifies the patient's problems and concerns insufficiently
- GP makes promises that cannot be kept (for example, about pain management or euthanasia)
- GP is impeded by becoming too closely involved
- GP is impeded by irritation, or by feelings of helplessness
- GP is not able to handle pressure exerted by the patient or relatives
- GP's position remains unclear (for example, position on euthanasia)
- GP's lack of knowledge about medical palliative treatments
- GP's pre-existing emotional problems
- GP fails to make proper arrangements for out-of-hours care (GP not accessible)
- GP does not anticipate various scenarios
- GP's extreme opinion causes problems in communication (for example, general rejection of euthanasia as well as a premature introduction of this subject can hamper communication)

the patient and anticipating various scenarios, while the patients especially appreciated a GP who behaves in a friendly way (visiting patients spontaneously, encouraging the patient, and talking in everyday language about any topic the patient wants to discuss), and who takes the initiative to talk about end-of-life issues such as unfavourable prognosis and unfinished business.

Major barriers reported by GPs as well as end-of-life consultants were difficulty in dealing with a former doctor's delay and with strong demands from a patient's relatives. The GPs reported difficulty in dealing with strong emotions and with troublesome doctor–patient relationships, while the consultants reported insufficient clarification of the patient's problems and concerns, promises that could not be kept, helplessness, too close involvement on the part of the GP, and insufficient anticipation.

The results of all three parts of the study suggest that the quality of the GP–patient communication in palliative care needs to be improved. Almost all participating end-of-life consultants had observed problems in GP–patient communication in the past year. Moreover, GPs in the focus groups reported successful as well as less successful examples of providing palliative care. Furthermore, some of the participating patients had mixed feelings or were dissatisfied with the quality of communication with their GP.

Strengths and limitations of the study

Previous qualitative studies of caregiver–patient communication in palliative care either focused on caregivers and patients separately,[8,12,17] or did not focus on GPs.[18] The present study focused on GP–patient communication within the context of palliative care, from different perspectives: to complement the information from the GPs additional information was gathered from some of their patients and from end-of-life consultants (data triangulation).[21]

The results of this study are based only on the experiences and opinions of small samples of GPs, patients, and end-of-life consultants. Furthermore, 50% of GPs interviewed were members of a scientific committee, which might have affected the prevalence of the issues mentioned. Moreover, out of the six included patients, only one was female and there were no patients with a non-cancer diagnosis; the results should therefore be interpreted as exploratory. From this qualitative study, no conclusions can be drawn about the incidence of problems in GP–patient communication in daily palliative care.

Comparison with existing literature

From interviews with 25 GPs, Field reported that virtually all responders stressed the importance of honesty in communication, although openness about the terminal prognosis might sometimes need to be gradual and tempered to the needs and wishes of the patient.[16] More recently, Clayton *et al* conducted a systematic review on sustaining hope when communicating with terminally-ill patients.[22] Their findings suggest that balancing hope with honesty is an important skill for health professionals. The patients mainly preferred honest and accurate information, provided with empathy and understanding. The patients in the present study also wanted GPs to be honest and open, and to initiate discussions about relevant end-of-life issues. This latter finding may stimulate GPs to be more forthcoming to initiate

discussions with palliative care patients about end-of-life issues, and to explore whether the patient is ready for such discussions. This finding may also stimulate GPs to apply recommended end-of-life strategies like 'advance care planning'.[23,24] Osse *et al* interviewed 40 patients and 22 relatives, and reported that patients also want their GP to take the initiative to talk about sensitive topics. Furthermore, they reported that patients want their GP to find solutions in practical matters and to just to be there for emotional issues. GPs should take the necessary time, avoid difficult medical terms, use humour, and show interest in their patients' wellbeing.[17] These results are in line with the present findings, suggesting that patients appreciate a friendly GP.

Implications for future research and clinical practice

The results of this study suggest that to communicate effectively, GPs should pay attention to how they communicate with their palliative care patients (for example, taking time, listening carefully, being willing to talk about any subject, reflecting on their own personal barriers), but they should also take the initiative to discuss various end-of-life issues (for example, the patient's symptoms, fears, wishes and expectations, unfinished business, and end-of-life preferences). Now these factors have been identified, larger quantitative studies are needed to increase the generalisability of the findings in order to contribute further to the development of training programmes that will enable GPs to be effective communicators, and to ultimately improve the quality of palliative care and the quality of life of their palliative care patients.

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Ethical approval

The Medical Ethics Committee of the VU University Medical Center exempted this study from approval.

Competing interests

The funding sources had no involvement in or influence on the study. The authors have stated that there are none.

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