General practitioner - patient communication in palliative care

- Availability
- Current issues
- Anticipation

Willemjan Slort

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Availability, current issues and anticipation

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The studies presented in this thesis were conducted within the Department of General Practice & Elderly Care Medicine of the EMGO+ Institute for Health and Care Research, VU University Medical Center Amsterdam. The EMGO+ Institute participates in the Netherlands School of Primary Care Research (CaRe).

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A cairn is a gathering of stones,
often used to mark trails across landscapes
where the path might easily be lost.

Each and every day we encounter cairns
as we journey through life;
they are the people and the moments
that orient us to our truest selves and the fullest life.

From: http://cairnwalking.blogspot.nl/2010/02/love-poem.html

Voor:
de patiënten in onze praktijk
die ik mocht begeleiden tijdens de laatste fase van hun leven;
zij gaven de inspiratie voor dit onderwerp.

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CHAPTER 1

Introduction

Questions from general practice

The choice to start a research project on GP-patient communication in palliative care stemmed from my personal experiences with providing palliative care as a GP. In the Netherlands, GPs play a central role in providing palliative care.[1,2] Although palliative care constitutes only a limited portion of the GP's job, most GPs consider it an important and challenging task. As a GP in the Netherlands, I have witnessed many patients during the period of transition from curative to palliative care because of advanced life-limiting illnesses. I often was impressed by the intense emotional reactions of patients and their relatives to the bad news that their disease is no longer responsive to curative treatment. After such a transition I felt responsible to provide optimal palliative care to my patients who were facing the end of their life, to help allay patients' fears and minimize their pain and suffering. Many times I experienced this as a difficult task, due to the seriousness and complexity of the situation, involving a mix of medical, psychological, social and spiritual/existential issues. If I could not communicate effectively with the patients, I might fail to identify some, if not many, of the problems that they were facing. Consequently, I would not be able to take the appropriate actions, and the patients' quality of life would be unnecessarily impaired. Additionally, realizing that I have only one opportunity to deliver optimal palliative care to patients (because at the end of the palliative phase the patients will be dead) made me feel even more responsible.

During periods of providing palliative care to patients, I often wondered whether I was using appropriate communication skills and attitudes, and whether I had discussed all essential issues with them. From these practice experiences the questions arose how the GP should communicate with patients receiving palliative care, and which issues he should discuss with them. Additionally, the quality of communication by GPs with their palliative care patients appeared not yet to have been sufficiently investigated. In discussions, several colleagues, including palliative care consultants, told me about troublesome cases in palliative care, because of problems with GP-patient communication. On the other hand, we could not find any evidence in the literature that the quality of GPs' communication with their patients in palliative care is unsatisfactory.

Previous research

In the Netherlands, van den Muijsenbergh (2001) performed a combined quantitative (questionnaires) and qualitative (interviews with patients and GPs) study on palliative care by the GP. She interviewed 19 GPs and 26 of their patients. She concluded that patients were satisfied with the palliative care provided by their GPs, and that the GPs were able to meet the needs of their patients.[3,4] Furthermore, she found that patients wished that their GPs were available for them, provided information and support, and showed personal commitment. She reported that patients appreciated their GP being honest and straightforward, but did not want their GP to discuss the bad prognosis too often. Although her study added much knowledge on palliative care provided by (Dutch) GPs, the generalizability of her positive conclusions was limited, because she did not investigate a representative sample of GPs, the participating GPs included the patients (possible selection bias), and she did not use validated questionnaires. Borgsteede (2006) studied epidemiological issues related to the quality of end-of-life care, but did not measure whether the care provided by GPs was sufficient, or how end-of-life care by GPs might be improved.[5] He mentioned the following methodological problems in research on end-of-life care: there is a lack of measurable elements of practice performance, and it is difficult to determine what is 'good' end-of-life care. In his paper on communication about euthanasia in general practice, he suggests, given that GPs experience talking about death as difficult, more attention should be paid to training them in communication about death and dying, with the aim of gaining better insight in patients' end-of-life preferences.[6] Osse (2006) developed and evaluated the use of 'Problems and Needs in Palliative Care' questionnaires as instruments to identify problems and needs for care, and to stimulate communication and increase patient-centredness of care.[7] He reported that palliative care patients encounter a wide variety of problems, and that problems and unmet needs were found in all of the various dimensions assessed, including physical symptoms, social, psychological and spiritual issues, autonomy, and informational needs.

In Australia, Burgess et al. (2004) developed a booklet to provide practical and useful guidelines for GPs in their communication with palliative care patients.[8] They were particularly interested in 'Advance Health Care Directives'. Although they undertook a literature search, focus groups and interviews to develop their guidelines, they did not report any information about the methods of the literature review, nor about the reliability and validity of their data. Therefore, we consider the value of their guidelines to be restricted by methodological limitations.

In Belgium, Deschepper et al. (2003) developed a comprehensive guideline that aims to put difficult end-of-life issues into the broader context of integrated terminal care, suitable to be used as a practical guide for GPs and as a teaching aid in palliative and terminal care.[9]

Research on doctor-patient communication, in general, has provided evidence that good communication between health care professionals and patients is essential for the delivery of high quality care. Patients consider communication, especially 'willingness to listen and explain' an essential attribute of a health care professional.[10] Effective communication has been shown to be beneficial to patient recovery, effective pain control, adherence to treatment regimens, and psychological functioning.[11] Conversely, ineffective communication has been linked to adverse effects on patient compliance with recommended treatment regimes[12] and to increased stress and emotional burn-out among health care professionals.[13,14] Furthermore, poor communication can leave patients anxious, uncertain and dissatisfied with their care.[15] Communicating with patients who are facing death has been acknowledged to be more difficult than communicating with patients with less serious conditions.[16]

Although there is a good deal of evidence that doctor-patient communication in general is important, we could not find much evidence specifically on GP-patient communication in palliative care.[10-16] We identified some systematic reviews on communication between health care professionals and patients suffering from advanced life-limiting illnesses, but very few of the studies included in these reviews were focused on GPs.[17-19] Most of the experimental studies focused on oncologists and oncology nurses and reported that training programmes on communication skills for these health care professionals were effective.[20-27] For GPs this has not yet been studied in a controlled study. Moreover, only a limited amount of research has focused on how GP-patient communication actually takes place in palliative care.[3-9]

In summary, we could not identify evidence-based practical guidelines or training programmes on how the GP should communicate with palliative care patients and which issues he should discuss with them. Moreover, we could not find conclusive studies on the quality of GP-patient communication in palliative care. Thus it was unclear if the quality of such communication is satisfactory, or whether there is still need for improvement.

Aim and outline of this thesis

Considering the knowledge derived from previous research, probably optimal doctor-patient communication is also important for GPs in palliative care, and even more importantly for the patients and their relatives. As GP-patient communication in palliative care can be rather difficult and there are no evidence-based guidelines or training programmes on these skills, we assume that GPs sometimes may fail to communicate effectively. The only knowledge on GP-patient communication in palliative care is based on explorative studies; there are not yet any studies based on direct assessment of GPs' behaviour in their communication with patients receiving palliative care. Furthermore, instruments to measure quality of communication or palliative care by GPs are not well developed. Studies among oncologists and nurses showed that communication training programmes were effective; for GPs this has not yet been investigated.

Our study focused exclusively on communication between GPs and adult patients in palliative care; GP-family member communication, GP-nurse communication or GP-specialist communication were excluded.

Aim

The aim of our research project was to develop and test an evidence-based communication training programme for GPs and GP trainees providing care to patients in palliative care, in order to improve health-related patient outcomes.

Outline

The project comprised three parts: 1. explorative studies; 2. development of the ACA training programme; and 3. experimental studies.

1. Explorative studies

In order to identify barriers and facilitators for GP-patient communication in palliative care as a first step in developing a guideline for effective GP-patient communication in palliative care, we performed a literature review and a qualitative study. The overarching research question posed in both explorative studies was: which facilitators and barriers for GP-patient communication in palliative care do GPs, palliative care patients and their relatives, and end-of-life consultants report? Knowledge about factors that hinder or facilitate GPs in their communication with patients in palliative care would enable us to develop a communication training programme to equip GPs and GP trainees to be more effective communicators, and ultimately to improve the quality of the palliative care they provide and the quality of life of their patients.

In **chapter 2** we report on a systematic review of the literature aimed at identifying barriers and facilitators of GP-patient communication in palliative care based on a search in seven computerized databases. For the critical appraisal of the identified qualitative and quantitative questionnaire studies, we adapted existing sets of criteria for use in an assessment instrument suitable for these types of studies.

In **chapter 3** we present the results of a qualitative study on facilitators and barriers of GP-patient communication in palliative care to identify possible facilitators and barriers, in addition to those identified in our systematic review. For this part of the study, we interviewed palliative care patients, asked GPs to discuss this issue in focus groups, and asked end-of-life consultants to complete a questionnaire. We included the latter group especially, as we expected the consultants to have quite a detailed impression of the occurrence of problems in GP-patient communication in palliative care, because they are consulted by GPs in particular in cases of troublesome palliative care.

2. Development of a new communication training programme

In **chapter 4** we describe the development of a new palliative care specific communication training programme for GPs and we present an evaluation of the applicability of this new training programme in a group of GPs and a group of GP trainees, in order to formulate recommendations for its future use. To support the new communication training programme, we incorporated the GP-related facilitators identified in the explorative studies into the 19-items ACA checklist, divided into three categories: [1] the *availability* of the GP for the patient, [2] *current issues* that should be raised by the GP, and [3] the GP *anticipating* various scenarios (ACA).

3. The experimental studies

In the third part of this thesis we report on studies that evaluated the effectiveness of the palliative care ACA communication training programme for GPs and GP trainees. We hypothesized that GPs and GP trainees exposed to the ACA training programme would be more available for the patient and would discuss more current and anticipated issues with the patient compared to control GPs and GP trainees. The research questions of the experimental studies were: which effect has the new palliative care communication training programme [1] at the GP / GP trainee level in terms of the availability of the GP or GP trainee for the patient and on the number of current and anticipated issues he discusses with the patient; and [2] at the patient level on patient reported palliative care outcomes, patient satisfaction and perceived GP's availability and current and anticipated issues discussed?

In chapters 5 and 6 we report the results of a controlled trial among GPs who attend a two-year Palliative Care Peer Group Training Course in the Netherlands. The intervention GPs received the ACA training programme as an addition to the existing course.

In chapter 5 we present the outcomes of this trial at the GP level. For each GP, we videotaped a 15-minute consultation with a simulated palliative care patient at baseline and at 12 months follow-up. Outcomes were the availability of the GP for the patient and the number of current and anticipated issues he discussed with the patient. To measure these outcomes, we performed a quantitative content analysis of the videotaped consultations.

In **chapter 6** we present the results of this trial at the patient level. We asked palliative care patients of the participating GPs to complete a questionnaire at baseline and at 12 months follow-up. Outcomes were palliative care outcomes, satisfaction of the patient with the communication with his GP, and the patient's perception of the GP's availability and the extent to which current and anticipated issues were discussed.

The GPs who attended the aforementioned two-year course in palliative care were already experienced to a certain extent and probably had a specific interest in palliative care. We also wanted to evaluate the effectiveness of the ACA training in a group less experienced doctors, therefore we performed a second trial among GP trainees.

In **chapter 7** we report on a controlled trial among GP trainees during the first six months of their third year of the GP vocational training programme at two Dutch GP vocational institutes. For each GP trainee, we videotaped a 20-minute consultation with a simulated palliative care patient at baseline and at six months follow-up. Outcomes were the availability of the GP trainee for the patient and the number of current and anticipated issues he discussed with the patient. To measure these outcomes we performed a quantitative content analysis of the videotaped consultations.

Finally, in **chapter 8** we summarize the main findings of our studies and discuss methodological issues and the implications of our results for general practice, GP vocational training, and future research.

References

1 **Janssens RJ, ten Have HA.** The concept of palliative care in the Netherlands. *Palliat Med* 2001; 15: 481-486.

2 **Francke AL, Willems DL.** Palliatieve zorg vandaag en morgen. *Maarssen: Elsevier gezondheidszorg,* 2000.

3 **Van den Muijsenbergh METC.** Palliatieve zorg door de huisarts. [Palliative care by the GP.] *Thesis. University of Leiden,* 2001.

4 **Van den Muijsenbergh METC.** Palliatieve zorg: De persoonlijke specialiteit van elke huisarts. *Huisarts Wet* 2003; 46: 80-85.

5 **Borgsteede SD.** End-of-life care in general practice in the Netherlands. *Thesis. Amsterdam, VUmc,* 2006.

6 **Borgsteede SD, Deliens L, Graafland-Riedstra C, Francke AL, Van der Wal G, Willems DL.** Communication about euthanasia in general practice: Opinions and experiences of patients and their general practitioners. *Patient Educ and Couns* 2007; 66: 156-161.

7 **Osse BHP.** Needs-assessment in palliative care. Development of instruments for clinical practice. *Thesis. University of Nijmegen,* 2006.

8 **Burgess TA, Brooksbank M, Beilby JJ.** Talking to patients about death and dying. *Aust Fam Physician* 2004; 33: 85-86.

9 **Deschepper R, Vanderstichele R, Mortier F, Deliens L.** Zorgzaam thuis sterven. Een zorgleidraad voor huisartsen. *Gent, Academia Press,* 2003 (in Dutch).

10 **Department of Health.** The NHS cancer plan. *London,* 2000.

11 **Razavi D, Delvaux N, Marchal S, De Cock M, Farvacques C, Slachmuylder JL.** Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators. *Psychooncology* 2000; 9: 293-302.

12 **Turnberg L.** Improving communication between doctors and patients. *Royal College of Physicians.* 1997.

13 **Fallowfield L.** Communication skills for oncologists. *Clinical Medicine* 1995; 5: 99-103.

14 **Ramirez AJ, Graham J, Richards MA, Cull A, Gregory WM, Leaning MS, Snashall DC, Timothy AR.** Burnout and psychiatric disorder among cancer clinicians. *Br J Cancer* 1995;71:1263-1269.

15 **Audit Commission.** What seems to be the matter: communication between hospitals and patients. *NHS Report. London* 1993. Report No 12.

16 **Korsch B, Putnam SM, Frankel R, Roter D.** An overview of research on medical interviewing. *The Medical Interview, Frontiers of Primary care. New York, NY, USA: Springer-Verlag,* 1995: 475-481.

17 **Fellowes D, Wilkinson S, Moore P.** Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004; Art. No.: CD003751. DOI: 10.1002/14651858.CD003751.pub2.

18 **Gysels M, Richardson A, Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Support Care Cancer* 2004; 12: 692-700.

19 **Gysels M, Richardson A, Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer* 2005; 13: 356-366.

20 **Baile WF, Lenzi R, Kudelka AP, Maguire P, Novack D, Goldstein M, Myers EG, Bast RC Jr.** Improving physician-patient communication in cancer care: outcome of a workshop for oncologists. *J Cancer Educ* 1997; 12: 166-173.

21 **Baile WF, Kudelka AP, Beale EA, Glober GA, Myers EG, Greisinger AJ, Bast RC Jr, Goldstein MG, Novack D, Lenzi R.** Communication skills training in oncology. Description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer* 1999; 86: 887-897.

22 **Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R.** Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet* 2002; 359: 650-656.

23 **Razavi D, Delvaux N, Marchal S, Bredart A, Farvacques C, Paesmans M.** The effects of a 24-h psychological training program on attitudes, communication skills and occupational stress in oncology: a randomised study. *Eur J Cancer* 1993; 29A: 1858-1863.

24 **Razavi D, Delvaux N, Marchal S, Durieux JF, Farvacques C, Dubus L, Hogenraad R.** Does training increase the use of more emotionally laden words by nurses when talking with cancer patients? A randomized study. *Br J Cancer* 2002; 87: 1-7.

25 **Razavi D, Merckaert I, Marchal S, Libert Y, Conradt S, Boniver J, Etienne AM, Fontaine O, Janne P, Klastersky J, Reynaert C, Scalliet P, Slachmuylder JL, Delvaux N.** How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of post training consolidation workshops. *J Clin Oncol* 2003; 21: 3141-3149.

26 **Finset A, Ekeberg O, Eide H, Aspegren K.** Long term benefits of communication skills training for cancer doctors. *Psychooncology* 2003; 12: 686-693.

27 **Wilkinson SM, Leliopoulou C, Gambles M, Roberts A.** Can intensive three-day programmes improve nurses' communication skills in cancer care? *Psychooncology* 2003; 12: 747-759.

PART 1

Explorative studies

CHAPTER 2

Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review

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Abstract

While effective general practitioner (GP)-patient communication is required for the provision of good palliative care, barriers and facilitators for this communication are largely unknown. We aimed to identify barriers and facilitators for GP-patient communication in palliative care. In a systematic review seven computerized databases were searched to find empirical studies on GP-patient communication in palliative care. Fifteen qualitative studies and seven quantitative questionnaire studies were included. The main perceived barriers were GPs' lack of availability, and patients' and GPs' ambivalence to discuss 'bad prognosis'. Main perceived facilitators were GPs being available, initiating discussion about several end-of-life issues and anticipating various scenarios. Lack of availability and failure to discuss former mistakes appear to be blind spots of GPs. GPs should be more forthcoming to initiate discussions with palliative care patients about prognosis and end-of-life issues. Empirical studies are needed to investigate the effectiveness of the perceived barriers and facilitators.

Introduction

Although there are cross-national differences, general practitioners (GPs) play a central role in providing palliative care in many countries. In order to provide high-quality care, effective communication between health care professionals and patients is considered to be an essential requirement.[1–6] Communication is deemed effective if it relates to positive outcomes for one or more of the participants (i.e. patients, family members, or health care professionals).[7] When they are receiving palliative care, patients sometimes have to adapt to a rapid deterioration in their condition and they are facing the end of their life. Due to the severity and complexity of this situation, involving a mix of medical, psychological, social and spiritual issues, GP-patient communication in palliative care will often be difficult. If the communication is not effective, some, if not many, of the problems that patients are facing might not be identified by GPs.[8,9] Consequently, it is likely that GPs will not be able to take the appropriate actions, and the patient's quality of life may be unnecessarily impaired. Knowledge about factors that hinder or facilitate GPs in their communication with patients in palliative care is needed for the development of effective training programs to equip GPs to be effective communicators, and ultimately to improve the quality of the palliative care they provide and the quality of life of their patients. Identifying barriers and facilitators for GP-patient communication in palliative care can also be a first step in developing guidelines and indicators for effective GP-patient communication in palliative care.

Recently, several systematic reviews on communication between health care professionals and patients suffering from advanced life-limiting illnesses have been published. Hancock et al.[10] showed that, although the majority of health care professionals are of the opinion that patients should be told the prognosis as far as physicians can predict this, in practice many avoid discussing this topic or withhold information. Clayton et al.[11] found that balancing hope with honesty is an important skill for health care professionals, and that patients mostly prefer honest and accurate information, provided with empathy and understanding. Rodin et al.[12] have noted the problem of variability in patient preferences, but still aim to develop general approaches with regard to communication. Very few of the studies included in these reviews have focused on GPs. Most studies focused on oncologists and nurses, and not all focused on the palliative phase. Moreover, only a limited amount of research has focused on how GP-patient communication actually takes place in daily palliative care practice.

The objective of this review was to identify barriers and facilitators for GP-patient communication in palliative care.

Methods

This review was conducted in accordance with the standard procedure of a systematic review: establishing the questions to be addressed; developing a review protocol; searching for studies across a range of bibliographic sources; applying inclusion and exclusion criteria; extracting data; assessing the methodological quality; and synthesizing the findings.[13-15]

Search strategy for the identification of studies

We developed a search strategy in collaboration with a medical information specialist (IR). Relevant computerized databases were searched for eligible studies: Embase (through Elsevier's Embase.com), PubMed, PsycINFO (through CSA Illumina), CINAHL (through EBSCOhost), and CDSR, DARE and CENTRAL in the Cochrane Library (through Wiley Interscience). A search was set up for each database separately, with no language or date restrictions, and no methodological filter.

The searches were updated until January 2010. Word groups representing the key elements 'general practitioner', 'communication' and 'palliative care' were combined in several ways, using controlled vocabulary (MeSH, Emtree, Thesaurus of Psychological Index Terms) and free text. Detailed search histories are available from the first author on request. The reference lists of the identified articles were screened for additional relevant studies.

Inclusion and exclusion criteria

An article was included in the review if it reported empirical data (1) on GP (2)-patient communication (3) in palliative care (4), and was written in English, German, French or Dutch (5). The inclusion criteria were further defined as follows.

(1) Empirical data: articles reporting on original studies that contained an explicitly formulated research question, and collected either qualitative or quantitative data. Editorials, narrative reviews and case reports were excluded. Systematic reviews were only included in our review if the separate studies included in such reviews met our inclusion criteria.

(2) GP: a GP, family physician or primary care physician providing care for patients living at home or in a nursing home. This could also be a GP vocational trainee. Studies focusing on medical students were excluded. If a study included various types of health care professionals, separate analyses and results for GPs had to be reported.

(3) Communication: restricted to communication between GPs and adult patients. Studies that focused exclusively on GP-family member communication, GP-nurse communica-

tion or GP-specialist communication were excluded. The Results section of the article had to include more detailed information on communication than simply the term ‘communication’. For example, the mere statement that ‘patients considered good communication with their GP to be very important’ was not considered to be a sufficient reason for inclusion.

(4) Palliative care: refers to the total medical care that is provided for a patient and his/her family when the patient has a life-threatening disease that no longer responds to curative treatment (excluding non-palliative ‘cancer care’ studies focusing on ‘breaking bad news’).

Inclusion procedure

A two-stage selection procedure was applied. Firstly, two reviewers (WS and EA) independently applied the inclusion criteria to each article that was identified (title and abstract). Disagreements were resolved by discussion. The full text of an article was retrieved if the review criteria were met, or the abstract contained insufficient information to make it possible to assess eligibility. Two reviewers (WS and BS) independently examined the full texts to select the articles that met the inclusion criteria. Where necessary, a third reviewer (AB) was involved in the discussions and selection process.

Assessment of the quality of the studies

There is no universally accepted set of criteria with which to assess the quality of qualitative and quantitative questionnaire studies. The criteria that we used to assess the methodological quality of the studies were based on those suggested in various methodological publications on qualitative research.[16-24] In the most recent study, Harden et al.[24] applied 12 criteria. For our review, we combined the three criteria for assessing the extent to which the study findings reflected the perspectives and experiences of the population studied into one criterion. To Harden et al.’s remaining 10 criteria we added six criteria derived from the other studies focusing on qualitative research.

In this way, we assessed each qualitative study according to 16 criteria, sub-divided into two dimensions. The first dimension was *clarity of reporting*: a clear description of the context, study aims, research question, choice of specific study design, sampling, data collection and analysis, and findings. The second dimension was the *robustness of the study methods*: a comprehensive sampling strategy, reliability and validity of the data collection and analysis, rooting of the findings in the perspectives and experiences of the respondents, logically proceeding from data to interpretation, and reflexivity.

For the critical appraisal of the quantitative questionnaire studies we used the same set of criteria, but omitted the following four criteria that were not applicable to quantitative studies: ‘Were the findings really rooted in the perspectives and experiences of the population studied?'; 'Was evidence of reflexivity in the process reported?'; 'Did the research move logically from a description of the data to analysis and interpretation?'; 'Were various methods used to establish the validity of the data analysis?'. We added 'a sufficient response rate' as a criterion for the second dimension, resulting in a 13-item list. For the assessment instruments used in this review, see Table 1.

Each criterion was rated 'yes' or 'no'. If there was insufficient information the score was 'no'. Equal weights were applied, resulting in a total quality score, ranging from zero to 16 for qualitative studies, and from zero to 13 for quantitative questionnaire studies. The quality of the studies we reviewed was assessed independently by two reviewers (WS and BS). Disagreements were resolved by discussion and, where necessary, a third reviewer's opinion was sought (AB).

Data extraction and analysis

We recorded the study characteristics and the results of the studies included in the review on a standardized data-extraction form. Two investigators (WS and BS) independently extracted all factors related to GP-patient communication in palliative care from the results of the studies, and discussed the extracted data until a final classification of the factors was obtained. The factors were classified as barriers or facilitators for communication, according to the description of the separate factors in the article, and as related to structure, process or outcome.[25] In our study, structure refers to the prerequisites for GP-patient communication that are present before the actual consultation takes place (e.g. the availability of the GP and the patient's life expectancy). The process refers to factors influencing the communication during the actual consultation. These factors assess the topics that the GPs and patients address in palliative care consultations, and how well this is done. Outcome factors describe the effects (of the structural and process factors) of GP-patient communication on palliative care patient outcomes, such as quality of life, symptoms and satisfaction with the communication. In cases of disagreement or doubt, an issue was discussed with a third reviewer (AB). Two tables were generated from the data extraction sheet, one describing the characteristics of the studies included in the review (Table 2) and the other dealing with the data obtained from these studies (Table 3).

For all studies in our review, both qualitative and quantitative, we examined the possible relationship between the quality of the study (as measured by our quality assessment instruments) and the study characteristics and results. Specifically, we compared the differences in designs (quantitative or qualitative), participants (patients, GPs or both) and results (distribution of results across barriers or facilitators and across structural factors, 'how' factors or topics) of the studies of medium quality (meeting between 10 and 12 criteria for qualitative studies, and meeting 10 criteria for quantitative studies) with those of high quality (meeting 13 or more criteria for qualitative studies and 11 or more criteria for quantitative studies).

Table 1. Quality assessment instruments for qualitative and quantitative questionnaire studies

		Qualitative studies	Quantitative questionnaire studies
Clarity of reporting			
1.	*Was the context of the study clearly described?* [a]	X	X
2.	*Were the goals of the study clearly described?*	X	X
3.	Was the research question clearly defined?	X	X
4.	Was the design adequate for the study goal/question?	X	X
5.a.	*Was the identification and the recruitment of the sample clearly described and justified?*	X	
5.b.	Was there an adequate description of the study population (setting, selection criteria, age/gender)?		X
6.	*Were the data collection methods clearly described?*	X	X
7.	*Were the data analysis methods clearly described?*	X	X
8.	Were the findings clearly described?	X	X
Robustness of the study methods			
9.a.	Was the sampling strategy comprehensive to ensure the generalizability of the results?	X	
9.b.	Was the size of the study population sufficient to ensure the generalizability of the results?		X
9.c.	Was the response rate sufficient to ensure the generalizability of the results?		X
10.a.	*Were methods used to establish the reliability of the data collection methods?*	X	
10.b.	Were reliable measurement instruments used?		X
11.a.	*Were methods used to establish the validity of data collection?*	X	
11.b.	Were valid measurement instruments used?		X
12.a.	*Were methods used to establish the reliability of the data analysis?*	X	
13.a.	*Were methods used to establish the validity of the data analysis?*	X	
12.b.	and 13.b. Were adequate analysis techniques used?		X
14.	Did the research move logically from a description of the data, through quotations or examples, to an analysis and interpretation of the meanings and their significance?	X	
15.	Was evidence of reflexivity in the process reported (interim data analyses guides further data collection and analyses)?	X	
16.	*Were the findings really rooted in the perspectives of the population studied?*	X	
Number of positive criteria		**0-16**	**0-13**

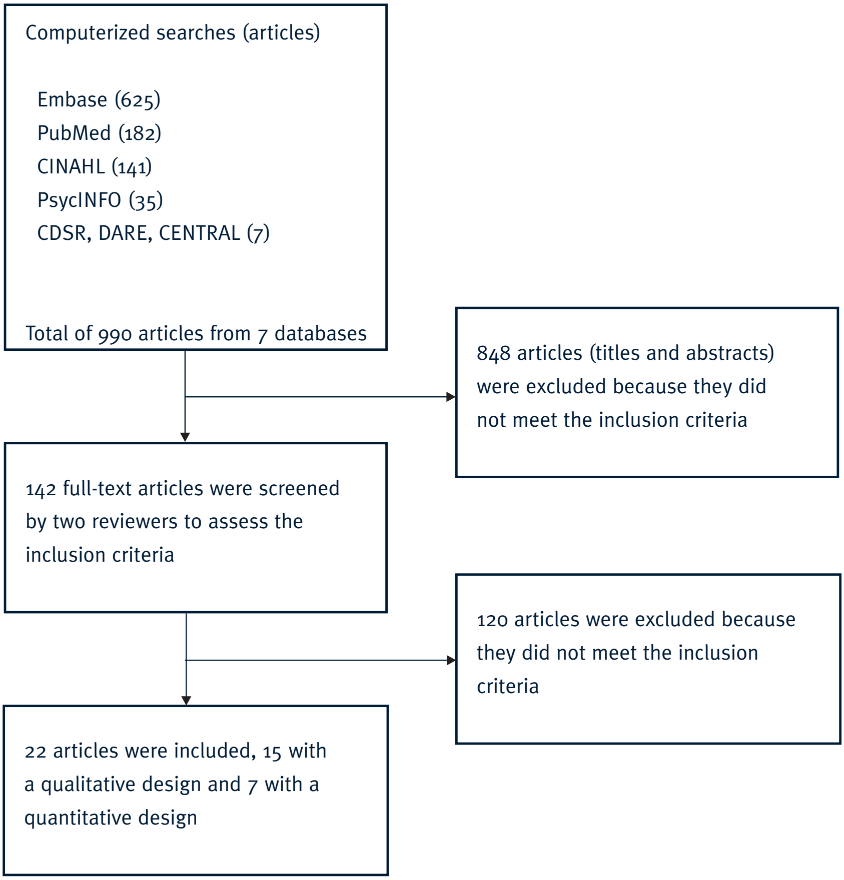
[a] Ten criteria derived from Harden et al.[24] are printed in *italics*.

Results

Identification of relevant studies

Our searches yielded 990 citations. After screening the titles and abstracts, 142 citations initially appeared to meet the inclusion criteria. All 142 full-text articles were retrieved and reviewed in more detail. Of these, 22 met our inclusion criteria and formed the basis of the full review for methodological quality assessment and data extraction. Articles were mainly excluded because they did not contain detailed information about communication. Some other articles were excluded because they did not focus on GPs or palliative care. Four studies that seemed to satisfy our inclusion criteria at first were excluded later because we could not identify any research question in the article;[26-29] among these were the Australian and Belgian articles about guidelines for GP-patient communication at the end of life·[26,27] Eventually, we included 15 qualitative studies and seven quantitative questionnaire studies (see Figure 1).

Figure 1. Literature search and selection of articles



Methodological quality of the identified studies

We applied our quality criteria to the 22 included studies, but because there is currently no consensus about the minimum required quality assessment scores for inclusion in a review, we did not exclude articles on these grounds. Of the 15 qualitative articles, we categorized nine as high quality (meeting 13 or more criteria) and six as medium quality (meeting between 10 and 12 criteria). Of the seven quantitative articles, we categorized five as high quality (meeting 11 or more criteria) and two as medium quality (both met 10 criteria). The characteristics of the 22 studies included in the review and their assessment scores are summarized in Table 2.

Barriers and facilitators for effective GP-patient communication at the end of life

Table 3 summarizes the factors reported in the articles as barriers, facilitators or both. This table also summarizes the classification of these barriers and facilitators as a *structural* factor or a *process* factor. We did not identify any factors related to *outcome*. Factors related to process were further sub-divided into factors related to *how* the communication should take place and which *topics* should be addressed in palliative care consultations.

The largest percentage of all the factors we identified were classified into the 'how' category. The majority of the factors were facilitators with regard to how the communication should take place, at GP level.

The first part of Table 3 presents the barriers and facilitators related to structure. At patient level, factors classified as *barriers related to structure* were certain patient characteristics (e.g. the medical condition of the patient, and language and cultural factors), the characteristics of palliative care (e.g. unpredictability of the clinical course of the disease) and the role of the patient's spouse and relatives. At patient level, factors classified as *facilitators related to structure* were certain patient characteristics (older age and a longer life expectancy) and certain patient opinions (e.g. patients want their GP to be honest).

At GP level, factors classified as *barriers related to structure* were the GP's lack of availability and knowledge and the characteristics of palliative care (e.g. the complexity of the medical information and the uncertainty of the prognosis). At GP level, factors classified as *facilitators related to structure* were the availability of the GP (particularly making home visits and taking the necessary time), certain GP characteristics (e.g. long-standing GP-patient relationship, and experience and training in palliative care) and certain GP opinions (e.g. that patients have the right to know the prognosis).

The second and third parts of Table 3 present the barriers and facilitators related to process. The 'how' factors are listed first, followed by the 'topics'. At patient level, factors classified as *barriers related to how the communication should take place* were the

Table 2. Characteristics and assessments of the quality of the qualitative and quantitative articles (N=22)

Study	Country	Research question	Design	Participants	Clarity of reporting	Robustness of the study methods	Quality assessment sum-score
Qualitative articles					(0–8)	(0–8)	(0–16)
1. Borgsteede et al. (2007)[56]	Netherlands	Do terminally ill patients and their GPs talk about euthanasia and, if so, how do they communicate about it?	Semi-structured, in-depth interviews	20 GPs and 30 of their patients	8	5	13
2. Deschepper et al. (2008)[40]	Belgium	To describe the attitudes towards truth-telling of both terminal patients and professional care-givers, and to determine their perceived barriers to full information exchange.	In-depth interviews and focus groups	17 patients, 8 relatives, 14 GPs, 4 specialists, 10 nurses, 1 psychologist	6	4	10
3. Exley et al. (2005)[57]	UK	To identify and meet the needs of people who are dying in the community of both malignant and non-malignant disease.	Semi-structured interviews (patients, carers) and focus groups (professionals)	29 patients (number of participating professionals was not reported)	7	6	13
4. Farber et al. (1999)[58]	USA	To explore important issues in delivering end-of-life care to patients and families.	Semi-structured interviews and focus groups	42 members of staff of the Department of Family Medicine	7	6	13
5. Farber et al. (2002)[59]	USA	To determine the perceptions of practicing clinicians regarding quality end-of-life care.	Semi-structured interviews and focus groups	38 members of staff of the Department of Family Medicine	7	7	14
6. Farber et al. (2003)[60]	USA	To study the perceptions of patients, care-givers, and physicians who are already connected with one another in an end-of-life care experience.	In-depth, open-ended, face-to-face interviews	42 patients, 39 care-givers, 39 members of staff of the Department of Family Medicine	8	6	14
7. Field (1998)[61]	UK	To study GPs' experiences of caring for dying people.	Open interviews	25 GPs	7	5	12
8. Kelly et al. (2008)[62]	Australia	To investigate psychosocial issues faced by GPs in the management of patients receiving palliative care and to investigate the themes relevant to the psychosocial care for dying patients.	Semi-structured interviews	15 GPs	7	3	10
9. Meijler et al. (2005)[63]	Netherlands	To identify the GPs' perception of educational needs in palliative care.	Focus groups	39 GPs	7	3	10

(continued)

Table 2. Continued

Study	Country	Research question	Design	Participants	Clarity of reporting	Robustness of the study methods	Quality assessment sum-score
10. Michiels et al. (2007)[64]	Belgium	To explore terminal patients' perceptions of the role of their GP in providing continuity of care, and to identify barriers to the delivery of continuous primary end-of-life care.	Semi-structured interviews	17 terminally ill patients	8	5	13
11. Van den Muijsenbergh (2003)[42]	Netherlands	To study palliative care provided by GPs, and its shortcomings, and to study the needs of dying people and their care-givers.	Semi-structured interviews	19 GPs, 26 patients and 13 care-givers	6	4	10
12. Norman et al. (2001)[33]	Canada	To explore factors that affect the integrity of palliative cancer patients' relationships with family physicians (FPs) and to explore how cancer patients perceive FPs' roles in their care.	Semi-structured interviews	25 patients (palliative care inpatients in a very advanced stage of their disease)	8	8	16
13. Osse et al. (2002)[34]	Netherlands	To construct a comprehensive overview of the problems cancer patients experience in palliative care.	Interviews (a two-step method)	First step: 9 patients and 7 relatives Second step: 31 patients and 15 relatives	8	8	16
14. Pfeiffer et al. (1994)[65]	USA	To identify primary care patients' and physicians' beliefs, attitudes, preferences and expectations regarding discussions of end-of-life medical care, and to identify factors limiting the quality and frequency of these discussions.	Face-to-face, structured, and open-ended interviews	47 patients and 43 physicians	7	6	13
15. Steinmetz et al. (1993)[66]	USA	To determine family physicians' perceptions of the difficulty in caring for dying patients and how prepared they are to provide such care.	Interviews	35 family physicians (doctors of medicine and doctors of osteopathy)	7	5	12

(continued)

Table 2. Continued

Study	Country	Research question	Design	Participants	Clarity of reporting	Robustness of the study methods	Quality assessment sum-score
Quantitative articles					**(0–8)**	**(0–5)**	**(0–13)**
16. Burge et al. (2000)[67]	Canada	How well are residency programs preparing Canadian family physicians for their role in providing palliative care in the future?	50-item survey on end-of-life care	31 entering and 26 exiting residents	7	4	11
17. Eggerman and Dusting (1985)[68]	USA	To study the physician's attitude towards death and how these attitudes relate to the physician's openness in communicating with patients about terminal illness.	Terminal Illness Questionnaire and a Threat Index	15 family physicians (plus 103 medical students and 8 physician's assistants)	7	4	11
18. Elkington et al. (2001)[35]	UK	How do GPs themselves see their role in discussing the prognosis with patients with severe COPD?	Questionnaire	214 GP principals	8	5	13
19. Groot et al. (2007)[36]	Netherlands	To identify the obstacles that hinder the delivery of primary palliative care.	Questionnaire	320 GPs	8	5	13
20. Higginson et al. (1990)[69]	UK	To investigate the current problems and needs of terminally ill cancer patients and their family members, and to discover their views of hospital, community and support team services.	Questionnaire interviews in the patients' homes	65 patients, each with a member of their family or a care-giver	7	3	10
21. Holmes et al. (2006)[70]	USA	To explore the spiritual concerns of seriously ill patients, and the spiritual-care practices of primary care physicians.	Questionnaire	65 (seriously ill) patients and 67 primary care physicians	8	4	12
22. Michiels et al. (2009)[41]	Belgium	To examine physicians' practices regarding information disclosure to terminally ill patients and to their relatives, without informing the patient.	Questionnaire	1716 (1459 clinical specialists and 257 GPs)	7	3	10

Table 3. Barriers and facilitators related to structure, ‘how’ or ‘topics’, at patient or GP level, reported by patients and/or GPs

	Barriers	Facilitators
1. Factors related to *structure*		
Patient level	*Patient characteristics:* – medical condition (throat cancer, aphasia, delirium) [13.PT][a] – language [9.GP] and cultural factors [16.GP] *Characteristics of palliative care:* – cardio-respiratory disease (compared to cancer) [1.GP; 3.PT] – unpredictability of clinical course [6.GP] *Role of the spouse and family:* – patient and relative do not admit their grief to each other [13.PT; 19.GP] – presence of spouse [8.GP] or several other persons [9.GP] – disagreement between relatives [19.GP]	*Patient characteristics:* – older age [17.GP] – longer life-expectancy [17.GP] *Patients’ opinions:* – patient wants their GP to be honest [2.PT; 11.PT] – patients value communication with their GP [3.PT] – patients value end-of-life discussions with their GP [14.PT]
GP level	*GPs’ lack of availability:* – lack of time [2.B; 10.PT; 11.PT] – absence (e.g. holiday) [10.PT] – not making home visits [20.PT] *GP characteristics:* – lack of knowledge (about palliative care) [10.PT] *Characteristics of palliative care:* – complexity of medical information [2.GP; 14.PT] – uncertainty of (exact) prognosis [4.GP] – limits of medical knowledge [2.GP]	*GPs’ availability:* – making home visits [1.B; 3.PT; 11.PT 13.PT; 15.GP; 20.PT] – taking the necessary time [3.PT; 7.GP; 13.PT; 15.GP] – telephone access to the practice [3.PT; 12.PT] – continuity of care [10.PT; 11.GP] – quick appointment with GP of choice [3.PT] *GP characteristics:* – longstanding GP-patient relationship [1.B; 8.GP; 11.GP; 15.GP] – more experience in palliative care [19.GP; 21.GP] – specific training in palliative care [19.GP; 21.GP] – good interpersonal skills [3.PT] – female GPs pay more attention to patients’ spiritual concerns [21.GP] *GPs’ opinions:* – GP values communication with the patient [15.GP] – GP values discussions about prognosis with the patient [18.GP] – GP thinks that patients have the right to know [17.GP] – GP thinks that (s)he should inform the patient [17.GP]
2. Process factors related to *how* the communication should take place		
Patient level	*Patients not talking honestly and clearly:* – ambivalence about or unwillingness to hear the prognosis [2.PT; 4.GP; 15.GP] – not talking about their problems and needs [15.GP; 19.GP] – patients’ dependence on the GP [9.PT; 13.PT] – ashamed because they do not understand the GP’s info [13.PT] – not clear in formulating their expectations [1.B] – patients’ ideas and preferences may change over time as the disease progresses [4.GP]	

(continued)

Table 3. Continued

	Barriers	Facilitators
GP level	*GPs not talking honestly, unwilling to listen actively:* – being concerned about the effect of openness on the patient's hope [2.PT; 7.GP; 14.GP; 8.GP; 18.GP] – finding it difficult to judge the right moment (to start discussing end-of-life issues) [1.GP; 15.GP; 18.GP] – using difficult medical terms [2.PT; 13.PT] – finding it difficult because GP's job is to try to cure people [14.GP] – withholding or deferring information [2.PT] – not knowing which patients want to discuss this subject [18.GP] – preferring to provide information (instead of addressing emotional issues) [8.GP] – using euphemisms [8.GP] – not listening carefully [11.PT] – leaving it to the patient to raise (emotional or spiritual) issues [8.GP] *GP's personal obstacles:* – difficult to deal with the patient's denial [9.GP] – feeling helpless [9.GP] – stressful to make decisions concerning palliative care [6.GP] – providing information in a harsh way [3.PT] – lacking the initiative (to visit or phone patients spontaneously) [8.GP; 10.PT] – discussing bad prognosis too often [11.PT]	*GPs showing commitment and being open and honest:* – showing commitment, sharing, connecting [4.GP; 6.PT; 7.GP; 11.PT; 12.PT; 13.PT; 15.GP] – being open [4.GP; 9.GP; 13.PT], allowing any topic to be discussed [4.GP; 11.PT; 20.PT] – being honest, straightforward [2.PT; 4.GP; 7.GP; 14.PT]; lying is not acceptable [2.B] – being friendly, sympathetic, respectful [3.PT; 20.PT], treating the patient as a person [3.PT; 6.PT] – just being there [11.PT; 13.PT] – providing support (warmth, encouragement, emotional support) [12.PT] – giving the patient hope [2.PT] – being humorous [13.PT] *GP listening actively:* – listening and taking seriously [6.PT; 11.PT; 13.PT; 14.GP] – being sensitive to signals [1.GP] – helping the patient to articulate his/her concerns [4.GP] – anticipating what the patient is thinking [4.GP] – leaving the silence [4.GP] – exploring the patient's agenda [15.GP] – giving the patient the opportunity to express emotions [13.PT] – monitoring changes in the patient's opinion [1.GP] *GPs' way of providing information:* – taking the initiative to talk about things [3.PT; 11.PT; 13.PT; 14.GP] – providing all the information [2.PT; 13.PT], and not withholding any information at the family's request [16.GP] – reaching consensus (on the meaning of the diagnosis) [4.GP; 6.GP] – keeping the pace slow, gradual and tailored to the patient [2.B] – discussing things into detail [1.GP] – checking whether the patient has understood the information [16.GP] – re-labelling the problem [9.GP] *GPs' shared decision making:* – discussing the meaning of a medical condition (in order to choose the appropriate treatment) [5.GP] – making recommendations based on personal and professional understanding [5.GP] – negotiating palliative care options [4.GP; 5.GP; 10.PT] – deciding on treatment together with the patient [5.GP] – being proactive [9.GP]

(continued)

Table 3. Continued

	Barriers	Facilitators
3. Process factors related to which *topics* should be addressed		
Patient level	*Topics that some patients do not want to discuss:* - spiritual issues [21.PT] - euthanasia (e.g. for religious reasons) [1.PT]	- patients' belief in an afterlife [15.GP]
GP level	*Topics that some GPs do not discuss:* - their mistakes, e.g. (former) delay in diagnosis or referral [13.PT; 20.PT] - the patient's spiritual concerns or religious beliefs [8.GP; 21.GP] - euthanasia [1.B; 11.PT] - the final stage of the patient's disease [3.PT]	*Topics that GPs should address:* - diagnosis and prognosis [4.GP; 5.GP; 10.PT; 16.GP; 18.GP; 22.GP] - preparation for death [8.GP; 9.GP; 11.PT; 16.GP] - the patient's psychological/emotional issues, e.g. fears and anger [9.GP; 10.PT; 16.GP; 22.GP] - the patient's social issues [9.GP; 10.PT; 22.GP] - the patient's spiritual concerns [21.GP; 22.GP] - the patient's end-of-life preferences [1.B; 14.PT] - the aim of the (palliative) treatment [22.GP] - possible complications [22.GP] - medical futility can focus the patients on expected outcome [14.PT] - options to withhold/withdraw life-prolonging treatment [22.GP] - situations that could give rise to euthanasia requests, or end-of-life decisions [1.B; 22.GP] - living wills help to open up a discussion on end-of-life issues [14.GP] - holistic care [10.PT]

[a] Numbers refer to the number of the article in Table 2; GP/PT/B refers to factors reported by GPs, by patients, or by both.

patients' ambivalent attitude towards the prognosis, not talking (spontaneously) about their problems and needs and a possible change in their ideas and preferences over time as the disease progresses. At patient level, we did not identify any *'how'* facilitators.

At GP level, factors classified as *barriers related to how the communication should take place* were not talking honestly about end-of-life issues (e.g. because the GP is concerned about the unfavourable effect that openness can have on the patient's hope or because the GP finds it difficult to choose the right moment to initiate a discussion on this issue), certain personal obstacles that GPs have (e.g. difficulty in dealing with the patient's denial) and not taking the initiative to contact patients spontaneously. At GP level, factors classified as *facilitators related to how the communication should take place* were showing commitment, being open and honest, listening actively, the way in which information was given (particularly taking the initiative to talk about end-of-life issues) and shared decision making.

The third part of Table 3 presents the process barriers and facilitators related to various topics. At patient level, factors classified as *barriers related to topics* were unwillingness to talk about spiritual issues or about euthanasia. At patient level, the only *facilitator related to topics* was a patient's belief in the afterlife.

At GP level, factors classified as *barriers related to topics* were that some GPs did not discuss their own mistakes (e.g. delay in diagnosis or referral), the spiritual concerns of their patients and euthanasia. At GP level, factors classified as *facilitators related to topics* were willingness to talk about diagnosis and prognosis, preparation for death, the patient's emotional, social and spiritual issues and the patient's end-of-life preferences.

We examined the possible relationship between the quality of the studies in our review and the characteristics and results of these studies. We compared differences in the designs, participants and results of the studies of medium with those of high quality. We could not identify any consistent differences between the studies on these factors as a function of study quality.

Discussion

We included 22 empirical studies focusing on GP-patient communication in palliative care, 15 of which were based on qualitative research methods and seven on quantitative research methods. In these studies, a number of factors influencing GP-patient communication in palliative care were identified, and classified as barriers or facilitators, and as related to structure, 'how' (the communication should take place) or topics (that should be addressed in palliative care consultations).

However, some factors that were reported as barriers might also be facilitators (e.g.

the presence of the patient's spouse during the discussions) and vice versa.

Across the studies, the most frequently reported barriers for GP-patient communication (reported in three or more of the included articles) were: the GP's lack of time, the patient's ambivalence or unwillingness to know about the prognosis and the GP not talking honestly about the diagnosis or prognosis. The most frequently reported facilitators (reported in three or more of the included articles) were: the availability of the GP, longstanding GP-patient relationships, GPs showing commitment, being open and allowing any topic to be discussed, being honest and friendly, listening actively and taking patients seriously, taking the initiative to talk about end-of-life issues, not withholding information, negotiating palliative care options, being willing to talk about the diagnosis and prognosis, preparation for death, the patient's psychological, social and spiritual issues and the patient's end-of-life preferences.

Almost all structural factors, apart from a few patients' opinions and some factors on GPs' availability, were identified in studies based on GP perspective. Probably patients are not really aware of such abstract factors that describe the prerequisites for GP-patient communication that are already present before the actual consultation takes place. In addition, it is remarkable that patients report facilitating as well as inhibiting aspects of GPs' availability, while GPs only report facilitating factors regarding this; GPs' unawareness of the possibility that patients might be unsatisfied with their availability may reflect a blind spot of GPs.

Considering the 'how' factors, several items show the ambivalence of patients, as well as GPs, about discussing the prognosis. Most patients report that they want full information but sometimes they seem reluctant to know about a 'bad prognosis'. Patients also report that they want their GP to take the initiative to talk about such issues. On the other hand, GPs report being concerned about the effect of openness on the patient's hope and finding it difficult to judge the right moment to start discussing such issues. The skill to deal effectively with their own and the patient's ambivalence regarding discussing sensitive end-of-life issues appears to be a major challenge for GPs providing palliative care. Most findings indicate that GPs may be more forthcoming to initiate discussions with palliative care patients about prognosis and end-of-life issues.

Considering the 'topics', GPs' mistakes, such as (former) delay in diagnosis or referral, is reported in two studies based on patient perspective, while it is not reported in studies based on GP perspective; this may reflect another blind spot of GPs.

The results of our review suggest that, to be effective communicators in the palliative care setting, GPs should be available for their patients, and take the initiative to talk honestly about the many relevant end-of-life issues. Although the life expectancy of palliative care patients may be rather short, we identified several factors concerning the future of the patient, which emphasize the importance of anticipating various scenarios when GPs are providing palliative care.

We aimed to identify quality indicators (structural, process or outcome) of GP-patient communication in palliative care. However, none of the studies reported on the development of such quality indicators. Furthermore, none of the studies included in our review reported factors related to the outcome of GP-patient communication in palliative care, and none of these studies evaluated the possible effects of structural and process factors on existing palliative care outcome measures, for example, the Palliative Care Outcome Scale (POS)[30] and the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C15-PAL.[31] Because we did not identify any studies that evaluated relations between barriers or facilitators of communication and outcomes of palliative care, this review appeared to be rather a synthesis of the perspectives of patients and GPs on barriers and facilitators for GP-patient communication in palliative care than a review on the effectiveness of communication.

When examining the possible relationship between the quality of the studies in our review and the characteristics and results of these studies, we could not identify any consistent differences between the studies on these factors as a function of study quality. Nevertheless, considering triangulation as a criterion for robustness and validity of the findings,[32] it is remarkable that the four studies in our review with the maximal quality assessment scores [33-36] are based on one perspective only.

Comparison with existing literature

To find out which perceived barriers and facilitators are specific for palliative care we compared our findings on GP-patient communication in palliative care with the findings of a few studies on GP-patient communication in general.[37-39] The majority of our findings were also found in the literature on GP-patient communication in general (e.g. giving the patient room to tell his story, expressing empathy, exploring emotions, discussing diagnosis and prognosis, shared decision making and discussing alternatives). Therefore, we conclude that GP-patient communication in palliative care is not completely different from this communication in general. A few of our findings could not be found in these articles on GP-patient communication in general and are maybe specific for GP-patient communication in palliative care. A barrier related to structure at the patient level that seems typical for GP-patient communication in palliative care is the unpredictability of the clinical course. Because of this unpredictability, GPs have to deal more with uncertainty of the prognosis and need more to anticipate various scenarios before and as they unfold in palliative care than in general practice. From the ‘how’ factors, the ambivalence of the patients and the GPs in dealing with the bad prognosis seems to play a major role in communication in the final phase of life. Although this ambivalence plays a role in almost all doctor-patient communication, in palliative care this may be even more important because the relevant issues - somatic, psychological, social and spiritual - come into play in the context of impending death. Another ‘how’ factor that seems typical for palliative care is that patients’ ideas and preferences may change over time as the disease progresses. Therefore, GPs need to continually re-appraise the needs of patients and their families with regard to the disclosure of information, and to tailor the information and care accordingly.[40,41] In addition, GPs should distinguish between the problems of their patients and their perceived needs; patients may not wish to discuss or to be helped with all of their problems.[9,34,42] Among the factors related to topics, specific palliative care issues are the explanation of the final stage of the patient’s disease, strong patient emotions, end-of-life preferences, spiritual concerns, medical futility, life-prolonging treatment options, end-of-life decisions (e.g. living wills) and the patient’s belief in afterlife.

To find out which perceived barriers and facilitators for communication in palliative care are specific for GPs we compared our findings with those of the extensive monograph on patient-centred communication in cancer care by Epstein and Street.[43] The few differences that we found between our findings and those of the monograph on communication in cancer care were the possibility for GPs to make home visits, the prognosis of life-threatening diseases other than cancer (such as heart failure and chronic obstructive pulmonary disease) being even more unpredictable than that of cancer and a stronger emphasis on anticipating various scenarios in our findings.

In a systematic review, Hancock et al.[10] showed that many professionals avoid discussing the actual prognosis. These results are in line with our findings, that is, that the ambivalence of patients and GPs in dealing with the prognosis appears to be an important barrier to open and honest communication about end-of-life issues. In another review, Clayton et al.[11] found that the majority of patients prefer honest information, and that they seem to be able to maintain a sense of hope despite acknowledging the terminal nature of their illness. These conclusions are in line with our findings, that is, that patients appreciate their GP being honest and straightforward, taking the initiative to talk about end-of-life issues and providing all the necessary information in a paced, gradual and tailored way. Moreover, the results of our review indicate that in order to be able to maintain hope, patients prefer that their GPs do not discuss the (poor) prognosis too often, that they are also willing to talk in everyday language about any day-to-day topic that the patient wishes to discuss, that they give encouragement and hope and are humorous. The findings of these two reviews and our review emphasize that dealing with ambivalence seems to be one of the most serious challenges GPs and other health care professionals face in palliative care.

From the reference lists of the studies included in our review, we identified many intervention studies on communication between health care professionals and cancer care or palliative care patients. These studies were primarily concerned with teaching basic communication skills (e.g. breaking bad news) to oncologists and oncology nurses.[44-55] None of these intervention studies focused on GPs.

Study strengths and limitations

To our knowledge, this is the first systematic review that specifically addresses factors relating to GP-patient communication in palliative care. We applied a very sensitive search strategy for our review, including articles reporting the point of view of patients as well as GPs. All steps in the review process were performed by two reviewers. However, we did not identify any relevant intervention studies, which might have proven that the identified factors really influence the communication, thus the level of evidence is limited.

Recommendations for further research

In our review we summarized and categorized the barriers and facilitators for GP-patient communication at the end of life, based on the available results of qualitative and quantitative studies. Empirical studies are needed to investigate the effects of these perceived barriers and facilitators on the outcomes of palliative care. Acknowledging the wide variety of patient and GP characteristics, we still aim to develop a general approach to communication between ‘all’ GPs and ‘all’ (adult) palliative care patients. Based on general guidelines, GPs can tailor their communication to the needs and wishes of individual patients. Specific guidelines and training programmes should be developed, and the effects should be evaluated in order to provide GPs with evidence-based guidelines and appropriate training programmes.

Implications for general practice

Our results suggest that, to be effective communicators in the palliative care setting, GPs should be available for their patients, they should have an open approach and full commitment, listen actively, take the initiative to talk about several end-of-life issues and anticipate various scenarios before and as they unfold. GPs may need to pay more attention to their patient’s perception of the GP’s availability and their wish to discuss the GP’s (former) mistakes. GPs should recognize their own and their patient’s ambivalence towards discussing end-of-life issues, and nevertheless should initiate discussion about these issues. GPs need to continually re-appraise their patient’s needs and preferences, and their patient’s willingness to undergo or wish to discontinue certain treatment or procedures. In order to discuss the emotional, spiritual and end-of-life issues of their patients, GPs need a high level of communication skills.

References

1 **Audit Commission.** What seems to be the matter? Communication between hospitals and patients. *Report No 12. London: NHS,* 1993.

2 **Ford S, Fallowfield L and Lewis S.** Doctor-patient interactions in oncology. *Soc Sci Med* 1996; 42: 1511-1519.

3 **Lerman C, Daly M, Walsh WP, et al**. Communication between patients with breast cancer and health care providers. Determinants and implications. *Cancer* 1993; 72: 2612-2620.

4 **Razavi D, Delvaux N, Marchal S, et al.** Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators. *Psychooncology* 2000; 9: 293-302.

5 **Stewart MA.** Effective physician-patient communication and health outcomes: a review. *Can Med Assoc J* 1995; 152: 1423-1433.

6 **Turnberg L.** Improving communication between doctors and patients. *Improving Communication between Doctors and Patients: a report of a working party*. *London: Royal College of Physicians,* 1997.

7 **Eggly SS, Albrecht TL, Kelly K, et al.** The role of the clinician in cancer clinical communication. *J Health Commun* 2009; 14: 66-75.

8 **Grande GE, Barclay SIG and Todd CJ.** Difficulty of symptom control and general practitioners' knowledge of patients' symptoms. *Palliat Med* 1997; 11: 399-406.

9 **Osse BH, Vernooij-Dassen MJ, Schade E and Grol RP**. The problems experienced by patients with cancer and their needs for palliative care. *Support Care Cancer* 2005; 13: 722-732.

10 **Hancock K, Clayton JM, Parker SM, et al.** Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007; 21: 507-517.

11 **Clayton JM, Hancock K, Parker S, et al.** Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psychooncology 2008;* 17: 641-659.

12 **Rodin G, Zimmermann C, Mayer C, et al.** Clinician-patient communication: evidence-based recommendations to guide practice in cancer. *Curr Oncol* 2009; 16: 42-49.

13 **Cooper H and Hedges L.** The handbook of research synthesis. *New York: Russell Sage Foundation*, 1994.

14 **Egger M, Davey Smith G and Altman D.** Systematic reviews in health care: meta-analysis in context. *London: BMJ Books,* 2001.

15 **Peersman G, Oliver S and Oakley A.** Systematic reviews of effectiveness. *In: Oliver S and Peersman G (eds). Using research for effective health promotion. Buckingham: Open University Press,* 2001, pp.96-108.

16 **Popay J, Rogers A and Williams G.** Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998; 8: 341-351.

17 **Hawker S, Payne S, Kerr C, Hardey M and Powell J.** Appraising the evidence: reviewing disparate data systematically. *Qual Health Res* 2002; 12: 1284-1299.

18 **Vermeire E, Van Royen P, Griffiths F, et al.** The critical appraisal of focus group research articles. *Eur J Gen Pract* 2002; 8: 104-108.

19 **Dixon-Woods M, Fitzpatrick R and Roberts K.** Including qualitative research in systematic reviews: opportunities and problems. *J Eval Clin Pract* 2001; 7: 125-133.

20 **Dixon-Woods M, Sutton A, Shaw R, et al.** Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *J Health Serv Res Policy* 2007; 12: 42-47.

21 **Oliver S, Harden A, Rees R, et al.** Young people and mental health: novel methods for systematic review of research on barriers and facilitators. *Health Educ Res* 2008; 23: 770-790.

22 **Noyes J, Popay J, Pearson A, et al.** Qualitative research and Cochrane reviews. *In: Higgins JPT and Green S (eds). Cochrane handbook for systematic reviews of interventions. 5.0.2 [updated September 2009], http://www.cochranehandbook.org. The Cochrane Collaboration,* 2009.

23 **Harden A, Garcia J, Oliver S, et al.** Applying systematic review methods to studies of people's views: an example from public health research. *J Epidemiol Community Health* 2004; 58: 794-800.

24 **Harden A, Brunton G, Fletcher A and Oakley A.** Teenage pregnancy and social disadvantage: systematic review integrating controlled trials and qualitative studies. *Br Med J* 2009; 339: b4254.

25 **Grunfeld E, Lethbridge L, Dewar R, et al.** Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. *Palliat Med* 2006; 20: 769-777.

26 **Burgess TA, Brooksbank M and Beilby JJ.** Talking to patients about death and dying. *Aust Fam Physician* 2004; 33: 85-86.

27 **Deschepper R, Vander Stichele R, Bernheim JL, et al.** Communication on end-of-life decisions with patients wishing to die at home: the making of a guideline for GPs in Flanders, Belgium. *Br J Gen Pract* 2006; 56: 14-19.

28 **Freeman WL, Altice P, Betton HB, Lincoln JA and Robbins CM.** Care of the dying patient. *J Fam Pract* 1976; 3: 547-555.

29 **Todd C and Still A. General** practitioners' strategies and tactics of communication with the terminally ill. *Fam Pract* 1993; 10: 268-276.

30. **Hearn J and Higginson IJ.** Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. *Qual Health Care* 1999; 8: 219-227.

31 **Groenvold M, Petersen MA, Aaronson NK, et al.** The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. *Eur J Cancer* 2006; 42: 55-64.

32 **Mays N and Pope C.** Qualitative research in health care. Assessing quality in qualitative research. *BMJ* 2000; 320: 50-52

33 **Norman A, Sisler J, Hack T and Harlos M.** Family physicians and cancer care. Palliative care patients' perspective. *Can Fam Physician* 2001; 47: 2009-2016.

34 **Osse BHP, Vernooij-Dassen MJFJ, Schade E, et al.** Problems to discuss with cancer patients in palliative care: A comprehensive approach. *Patient Educ Couns* 2002; 47: 195-204.

35 **Elkington H, White P, Higgs R and Pettinari CJ.** GPs' views of discussions of prognosis in severe COPD. *Fam Pract* 2001; 18: 440-444.

36 **Groot MM, Vernooij-Dassen MJFJ, Verhagen SCA, Crul BJP and Grol RPTM.** Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliat Med* 2007; 21: 697-703.

37 **Van den Brink-Muinen A, Verhaak PF, Bensing JM, Bahrs O, Deveugele M, Gask L, Mead N, Leiva-Fernandez F, Perez A, Messerli V, Oppizzi L and Peltenburg M.** Communication in general practice: differences between European countries. *Fam Pract* 2003; 20: 478-485.

38 **Hobma SO, Ram PM, Muijtjens AM, Grol RP and van der Vleuten CP.** Setting a standard for performance assessment of doctor patient communication in general practice. *Med Educ* 2004; 38: 1244-1252.

39. **Deveugele M, Derese A, de Bacquer D, van den Brink- Muinen A, Bensing J and de Maeseneer J.** Consultation in general practice: a standard operating procedure? *Patient Educ Couns* 2004; 54: 227-233.

40 **Deschepper R, Bernheim JL, Stichele RV, et al.** Truth- telling at the end of life: A pilot study on the perspective of patients and professional caregivers. *Patient Educ Couns* 2008; 71: 52-56.

41 **Michiels E, Deschepper R, Bilsen J, Mortier F and Deliens L.** Information disclosure to terminally ill patients and their relatives: self-reported practice of Belgian clinical specialists and general practitioners. *Palliat Med* 2009; 23: 345-353.

42 **Van den Muijsenbergh M.** Palliatieve zorg: De persoonlijke specialiteit van elke huisarts. *Huisarts Wet* 2003; 46: 80-85.

43 **Epstein RM, Street RL, Jr.** Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. *Bethesda: National Cancer Institute, 2007, NIH Publication No. 07-6225.*

44 **Baile WF, Lenzi R, Kudelka AP, et al.** Improving physician-patient communication in cancer care: outcome of a workshop for oncologists. J *Cancer Educ* 1997; 12: 166-173.

45 **Baile WF, Kudelka AP, Beale EA, et al.** Communication skills training in oncology. Description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer* 1999; 86: 887-897.

46 **Fallowfield L, Jenkins V, Farewell V, et al.** Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet* 2002; 359: 650-656.

47 **Razavi D, Delvaux N, Marchal S, et al.** The effects of a 24-h psychological training program on attitudes, communication skills and occupational stress in oncology: a randomised study. *Eur J Cancer* 1993; 29A: 1858-1863.

48 **Razavi D, Delvaux N, Marchal S, et al.** Does training increase the use of more emotionally laden words by nurses when talking with cancer patients? A randomised study. *Br J Cancer* 2002; 87: 1-7.

49 **Razavi D, Merckaert I, Marchal S, et al.** How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of post training consolidation workshops. *J Clin Oncol* 2003; 21: 3141-3149.

50 **Fellowes D, Wilkinson S, Moore P.** Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004; Art. No.: CD003751. DOI: 10.1002/14651858.CD003751.pub2.

51 **Finset A, Ekeberg O, Eide H and Aspegren K.** Long term benefits of communication skills training for cancer doctors. *Psychooncology* 2003; 12: 686-693.

52 **Gysels M, Richardson A and Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Support Care Cancer* 2004; 12: 692-700.

53 **Gysels M, Richardson A and Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer* 2005; 13: 356-366.

54 **Wilkinson SM, Leliopoulou C, Gambles M and Roberts A.** Can intensive three-day programmes improve nurses' communication skills in cancer care? *Psychooncology* 2003; 12: 747-759.

55 **Wilkinson S, Perry R, Blanchard K and Linsell L.** Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: a randomised controlled trial. *Palliat Med* 2008; 22: 365-375.

56 **Borgsteede SD, Deliens L, Graafland-Riedstra C, et al.** Communication about euthanasia in general practice: Opinions and experiences of patients and their general practitioners. *Patient Educ Couns* 2007; 66: 156-161.

57 **Exley C, Field D, Jones L and Stokes T.** Palliative care in the community for cancer and end-stage cardiorespiratory disease: The views of patients, lay-carers and health care professionals. *Palliat Med* 2005; 19: 76-83.

58 **Farber SJ, Egnew TR and Herman-Bertsch JL.** Issues in end-of-life care: family practice faculty perceptions. *J Fam Pract* 1999; 48: 525-530.

59 **Farber SJ, Egnew TR and Herman-Bertsch JL.** Defining effective clinician roles in end-of-life care. *J Fam Pract* 2002; 51: 153-158.

60 **Farber SJ, Egnew TR, Herman-Bertsch JL, Taylor TR and Guldin GE.** Issues in end-of-life care: Patient, caregiver, and clinician perceptions. *J Palliat Med* 2003; 6: 19-31.

61 **Field D.** Special not different: General practitioners' accounts of their care of dying people. *Soc Sci Med* 1998; 46: 1111-1120.

62 **Kelly B, Varghese FT, Burnett P, et al.** General practitioners' experiences of the psychological aspects in the care of a dying patient. *Palliative Supportive Care* 2008; 6: 125-131.

63 **Meijler WJ, Van Heest F, Otter R and Sleijfer DT.** Educational needs of general practitioners in palliative care: Outcome of a focus group study. *J Cancer Educ* 2005; 20: 28-33.

64 **Michiels E, Deschepper R, Van Der Kelen G, et al.** The role of general practitioners in continuity of care at the end of life: A qualitative study of terminally ill patients and their next of kin. *Palliat Med* 2007; 21: 409-415.

65 **Pfeifer MP, Sidorov JE, Smith AC, et al.** The discussion of end-of-life medical care by primary care patients and physicians: A multicenter study using structured qualitative interviews. *J Gen Intern Med* 1994; 9: 82-88.

66 **Steinmetz D, Walsh M, Gabel LL and Williams PT.** Family physicians' involvement with dying patients and their families. Attitudes, difficulties, and strategies. *Arch Fam Med* 1993; 2: 753-760.

67 **Burge F, McIntyre P, Kaufman D, et al.** Family Medicine residents' knowledge and attitudes about end-of-life care. *J Palliat Care* 2000; 16: 5-12.

68 **Eggerman S and Dustin D.** Death orientation and communication with the terminally ill. *Omega (Westport)* 1985; 16: 255-265.

69 **Higginson I, Wade A and McCarthy M.** Palliative care: views of patients and their families. *BMJ* 1990; 301: 277-281.

70 **Holmes SM, Rabow MW and Dibble SL.** Screening the soul: Communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life. *Am J Hosp Palliat Care* 2006; 23: 25-33.

CHAPTER 3

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.

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 health care 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 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?

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 clinical 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 (activities of daily life) independent	
Yes	5
No	1
Satisfied with care from their GP	
Satisfied	3
Mixed feelings	2
Unsatisfied	1

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)

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 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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References

1 **Razavi D, Delvaux N, Marchal S, et al.** Testing health care professionals' communication skills: the usefulness of highly emotional standardized roleplaying sessions with simulators. *Psychooncology* 2000; 9(4): 293-302.

2 **Stewart MA.** Effective physician-patient communication and health outcomes: a review. *CMAJ* 1995; 152(9): 1423-1433.

3 **Ford S, Fallowfield L, Lewis S.** Doctor-patient interactions in oncology. *Soc Sci Med* 1996; 42(11): 1511-1519.

4 **Lerman C, Daly M, Walsh WP, et al.** Communication between patients with breast cancer and health care providers. Determinants and implications. *Cancer* 1993; 72(9): 2612-2620.

5 **Turnberg L.** Improving communication between doctors and patients: a report of a working party. *London: Royal College of Physicians,* 1997.

6 **Audit Commission.** What seems to be the matter? Communication between hospitals and patients. *Report No 12.* London: NHS, 1993.

7 **Korsch B, Putman SM, Frankel R, Roter D.** The medical interview: clinical care, education and research. Frontiers of primary care. New York: *SpringerVerlag,* 1995.

8 **Higginson I, Wade A, McCarthy M.** Palliative care: views of patients and their families. *BMJ* 1990; 301(6746): 277-281.

9 **Mitchell GK.** How well do general practitioners deliver palliative care? A systematic review. *Palliat Med* 2002; 16(6): 457-464.

10 **Barclay S, Wyatt P, Shore S, et al.** Caring for the dying: how well prepared are general practitioners? A questionnaire study in Wales. *Palliat Med* 2003; 17(1): 27-39.

11 **Lloyd-Williams M, Lloyd-Williams F.** Palliative care teaching and today's general practitioners — is it adequate? *Eur J Cancer Care (Engl)* 1996; 5(4): 242-245.

12 **Burgess TA, Brooksbank M, Beilby JJ.** Talking to patients about death and dying. *Aust Fam Physician* 2004; 33(1-2): 85-86.

13 **Elkington H, White P, Higgs R, Pettinari CJ.** GPs' views of discussions of prognosis in severe COPD. *Fam Pract* 2001; 18(4): 440-444.

14 **Farber SJ, Egnew TR, Herman-Bertsch JL.** Issues in end-of-life care: family practice faculty perceptions. *J Fam Pract* 1999; 48(7): 525-530.

15 **Farber SJ, Egnew TR, Herman-Bertsch JL.** Defining effective clinician roles in end-of-life care. *J Fam Pract* 2002; 51(2): 153-158.

16 **Field D.** Special not different: general practitioners' accounts of their care of dying people. *Soc Sci Med* 1998; 46(9): 1111-1120.

17 **Osse BHP, Vernooij-Dassen MJFJ, Schade E, et al.** Problems to discuss with cancer patients in palliative care: a comprehensive approach. *Patient Educ Couns* 2002; 47(3): 195-204.

18 **Steinhauser KE, Christakis NA, Clipp EC, et al.** Factors considered important at the end of life by patients, family, physicians, and other care providers. *J Am Med Assoc* 2000; 284(19): 2476-2482.

19 **Van Wesemael Y, Cohen J, Onwuteaka-Philipsen BD, et al.** Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium. *BMC Health Serv Res* 2009; 9: 220.

20 **Van Wesemael Y, Cohen J, Bilsen J, et al.** Consulting a trained physician when considering a request for euthanasia: an evaluation of the process in Flanders and The Netherlands. *Eval Health Prof* 2010; 18 May epub ahead of print.

21 **Murphy E, Dingwall R, Greatbatch D, et al.** Qualitative research methods in health technology assessment: a review of the literature. *Health Technol Assess* 1998; 2(16): 1-13.

22 **Clayton JM, Hancock K, Parker S, et al.** Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psychooncology* 2008; 17(7): 641-659.

23 **Singer PA, Robertson G, Roy DJ.** Bioethics for clinicians: 6. Advance care planning. *CMAJ* 1996; 155(12): 1689-1692.

24 **Detering KM, Hancock AD, Reade MC, Silvester W.** The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.

PART 2

Development of the ACA training programme

CHAPTER 4

The ACA training programme to improve communication between general practitioners and their palliative care patients: development and applicability

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Abstract

We describe the development of a new training programme on GP-patient communication in palliative care, and the applicability to GPs and GP Trainees. This 'ACA training programme' focuses on *Availability* of the GP for the patient, *Current issues* that should be raised by the GP, and *Anticipating* various scenarios. Evaluation results indicate the ACA training programme to be applicable to GPs and GP Trainees. The ACA checklist was appreciated by GPs as useful both in practice and as a learning tool, whereas GP Trainees mainly appreciated the list for use in practice.

Training programme on GP-patient communication in palliative care

Although there are differences between countries, general practitioners (GPs) often play a central role in providing palliative care. Palliative care refers to the total care that is provided for a patient and his/her family when the patient has a life-threatening disease that no longer responds to curative treatment. GPs involved in palliative care need to be skilful in communicating with patients, their families, and care-givers. Communicating with palliative care patients has been acknowledged to be more difficult than communicating with patients with less serious conditions,[1] because communication in palliative care involves a complex mix of medical, psychosocial and spiritual issues within the context of impending death. Physicians, including GPs, often fail to communicate effectively with patients about palliative care issues,[2,3] and most GPs have never received any training in communication skills with a specific focus on palliative care at all throughout their career. [4,5]

Moreover, there is still no evidence-based training programme available to improve the skills of GPs and GP Trainees (GPTs) in their communication with palliative care patients.

In the Palliative Care Centre of Expertise at the VU University Medical Center we designed a new training programme for GP-patient communication in palliative care. The results of our recent studies yielded three categories of factors reported to be relevant for GP-patient communication in palliative care: the *availability* of the GP for the patient, *current issues* that should be raised by the GP, and the GP *anticipating* various scenarios.[6,7] We used the first letters of the three categories (ACA) as an acronym for the training programme. The first objective of this paper is to describe the development of this 'ACA training programme' to improve GP-patient communication in palliative care. The second objective is to evaluate the first experiences of a group of GPs and a group of GPTs with this new training programme, in order to formulate recommendations for its future use.

Development of the ACA training programme

We designed a new training programme for GP-patient communication in palliative care, including the following educational components deduced from two recent reviews: the programme is learner-centred, using several methods, carried out over a longer period of time, mostly in small groups to encourage more intensive participation, combining theoretical information with practical rehearsal and constructive feedback from peers and skilled facilitators.[8,9] To support this new training programme we developed a checklist, based on the results of a systematic review [6] and qualitative study [7] which we have conducted previously to identify factors reported by palliative care patients, their relatives, GPs or end-of-life consultants as relevant for GP-patient communication in palliative care.

Table 1 shows the original article(s) from which it was derived for each item of the ACA checklist. In our qualitative study most of the factors identified in the review were confirmed, but as indicated in Table 1 the items 'paying attention to physical symptoms', 'wishes for the present and the coming days', 'unfinished business', and 'offering follow-up appointments' were additional to the results of the review. From all identified factors we selected the facilitating aspects of the communicative behaviour of a GP providing palliative care and the issues that should be raised by the GP, and we summarized these factors into the 19 items of the ACA checklist. We divided these items into three categories: [1] the *availability* of the GP for the patient, [2] *current issues* that should be raised by the GP, and [3] the GP *anticipating* various scenarios (ACA).

The GP should apply all six items concerning availability during each visit, because these items can be considered as necessary conditions for effective communication. The eight items for 'current issues' and the five items for 'anticipating' should be explicitly addressed by the GP, but not necessarily all during one visit. It seems even preferable to spread discussion about these 13 issues over several visits, allowing GP and patient to take the necessary time for each issue. During every visit the GP and the patient can identify and discuss those issues on the ACA checklist which are most relevant for the patient at that moment. GPs can use the ACA checklist in practice in the following ways: [1] using the checklist before and during a palliative care consultation gives an overview of the issues that can be addressed; [2] after a series of consultations the checklist can be used to check if all essential issues are discussed with the patient; [3] GPs or consultants can use the checklist to detect possible causes of problems in communication.

The ACA training programme was established to enable GPs and GPTs to:

- Obtain knowledge about ACA communication skills
- Achieve better insight into (individual shortcomings in) their communication skills
- Improve their ACA communication skills
- Develop self-education skills, using the ACA checklist as a tool for self-assessment of their communication skills.

For the eight steps of the ACA training programme, see Table 2.

Table 1. The ACA checklist *(Availability-Current issues-Anticipating)*, factors derived from our recent systematic review [6] and/or qualitative study [7]

ACA checklist	**From review [6] [source]**	**From qualitative study [7]**
Availability *(of the GP for the patient):*		
1. taking time	X [10-16]	X
2. allowing any subject to be discussed	X [2,14,15,17,18]	X
3. active listening	X [14-17,19-21]	X
4. facilitating behaviour (e.g. empathic, respectful, attentive, occasionally als phoning or visiting the patient spontaneously)	X [2,10-17,19-23]	X
5. shared decision-making with regard to diagnosis and treatment plan	X [13,17,20,24,25]	X
6. accessibility (e.g. phone numbers)	X [11,13,14,23]	X
Current issues *(that should be raised by the GP):*		
7. diagnosis	X [10,13,15,17,20,24-28]	X
8. prognosis	X [10,13,15-17,20,24-28]	X
9. patient's complaints and worries:- physical	-	X
10. - psychosocial	X [13,18,25,28]	X
11. - spiritual	X [22,28,29]	X
12. wishes for the present and the coming days	-	X
13. unfinished business, bringing life to a close	-	X
14. discussing treatment and care options (concerning 7-13)	X [13,17,19,24,25,28]	X
Anticipating *(various scenarios):*		
15. offering follow-up appointments	-	X
16. possible complications	X [28]	-
17. wishes for the coming weeks/months (personal wishes as well as preferences with regard to medical decisions)	X [17,19,21,28]	X
18. the actual process of dying (final hours/days)	X [11,14,18,21,22,25]	-
19. end-of-life decisions	X [14,19,21,28]	X

Table 2 The consecutive steps of the ACA training programme (and the estimated time spent by participants on each step)

At the start of the ACA training programme; at the residential course:

Step 1

Each participating GP or GP Trainee (GPT) had a *videotaped physician-patient interview* with a trained actor simulating a patient in an advanced stage of lung or colon cancer, according to a detailed script; immediately after the interview the participant received general feedback on communication style from the actor (30 minutes).

Step 2

Instructions on the ACA checklist, using oral presentations and written information (ACA booklet) in order to enhance the understanding of the participants of effective GP-patient communication in palliative care; each participant also received a plastic chart of the ACA checklist for use in daily practice (30 minutes).

Within two months after the start of the programme, outside the residential course:

Step 3

All participants received *feedback according to the ACA checklist* on their performance during the videotaped physician-patient interview in step 1. The GPs received individual written feedback from an experienced facilitator, the GPTs received oral feedback from their peers and facilitators in small groups (60 minutes).

Between the start of the programme and halfway through the programme, outside the residential course:

Step 4

The participants were asked to enhance their understanding of the ACA checklist and their insight into their own communication skills by *studying* the written information, *discussing* this material with their peers in small groups, *and trying out* newly acquired skills in their own general practice to identify problem areas from their own experience (60 minutes).

Before the residential course at halfway through the programme; outside the residential course:

Step 5

The participants were asked to *formulate learning goals* based on the individual shortcomings in their ACA communication skills identified at all previous steps (30 minutes).

Halfway through the programme; at the residential course:

Step 6

All participants were offered *role-play exercises* tailored to their individual learning goals. Hence, they could practise the desired behaviour in the safe environment of small groups and with the help of feedback on their performance from their peers and facilitators. GPs performed role-play with actors simulating a patient, GPTs performed role-play with other participants in the course, which had the additional advantage of enabling them to experience the position and emotions of the patient (60 minutes).

At the end of the ACA training programme; at the residential course:

Step 7

Each participant had a *second videotaped interview* with an actor simulating a patient; immediately after the interview the participant again received general feedback on communication style from the actor (30 minutes).

Step 8

All participants could use the second videotaped interview and the ACA checklist as tools for *self-assessment* of their communication skills, and they could then (off course) formulate new learning goals and start a new learning cycle (60 minutes).

The estimated total duration of all steps in the ACA training programme is six hours.

Applicability of the ACA training programme

Two settings

We evaluated the applicability of the ACA training programme in two groups with different characteristics: practising GPs who attended a 2-year Palliative Care Peer Group Training Course, and inexperienced GPTs from two vocational training institutes.

The training programme for the GPs took place during the first year of a two-year Palliative Care Peer Group Training Course. This course consisted of four two-day residential courses, followed by two-hour peer group sessions with five GPs in each group, facilitated by a palliative care consultant, every six to eight weeks. The GPs who enrolled for this study were participants in two such courses affiliated with the Comprehensive Cancer Centres of Eindhoven and Rotterdam, which started in 2006 and 2007, respectively. Most of the steps in the ACA training programme were conducted by the regular facilitators of the course, supervised by one of the authors (BW); steps 2 and 3 of the programme were conducted by the first author (WS).

The training programme for the GPTs took place during the first six months of the third year of their vocational training. In this final year the trainees worked for 3-4 days a week in the practice of their vocational GP trainer, and on one day a week they attended training programmes at their vocational training institute. Each group consists of approximately 10 trainees, facilitated by a GP and a behavioural scientist. The GPTs who enrolled for this study were participants in five such groups that started between October 2007 and March 2008 (two groups at the VU University Medical Center in Amsterdam and three groups at the University Medical Centre in Utrecht). The ACA training programme was, as recommended by Reinders et al.,[30] conducted by the regular teachers in the vocational GP training institutes, who had received detailed instructions about the training programme from the first author (WS).

Time schedule of the ACA training programme

Steps 1 and 2 (see Table 2) were planned on the first day of the training programme. Within two months after the first day all participants received individual feedback on their videotaped simulation interview (= step 3). During the following months they had to complete step 4 in order to formulate their personal learning goals (= step 5). Six months after the start of the programme, the GPs participated in role-play exercises which were tailored to their learning goals (= step 6); the GPTs performed their role-play exercises 3-4 months after the start of their programme. Finally, a second interview with an actor simulating a patient was videotaped, so that the participants could subsequently use this to assess their communication skills against the ACA checklist.

Characteristics of the participants

The following data on the participating GPs were recorded at baseline: gender, age, years of experience in general practice, group, duo, or single-handed practice, urban or rural practice, working part-time or full-time, vocational GP trainership, courses on palliative care attended during the previous two years, and number of palliative care patients in the GP practice who had died during the previous year at any location.

The following data on the participating GPTs were recorded at baseline: gender, age, group, duo or singlehanded vocational practice, urban or rural vocational practice, part-time or full-time vocational training, specific experience in palliative care, and number of palliative care patients for whom the GPT had provided palliative care during the first year of vocational training.

Attendance and appreciation of the ACA training programme

At the end of the ACA training programme all participating GPs and GPTs were asked to complete an evaluation form. To assess the applicability of the programme we evaluated the rate of attendance of GPs and GPTs and their appreciation of the different steps of the programme. Steps 7 and 8 were not included in this evaluation, because the forms were completed directly before step 7. At first, we developed an evaluation form for the GPs to score their appreciation on a 10-point Likert scale ranging from one (= no appreciation at all) to 10 (= maximal appreciation). Afterwards, this form was adapted for the GPTs to the format of evaluation forms that were customary at the vocational training; therefore, GPTs scored on a 5-point Likert scale ranging from one to five. For presenting the results in the outcome table, the scores of the GPs were divided by two to equalize these scores to those of the GPTs. For each step of the programme the scores were reported as mean scores (and standard deviations) for GPs and GPTs separately. We also asked the participants to indicate their learning goals and the aspects of the programme which facilitated or inhibited the learning process to their experience.

Findings

Characteristics of the participants

Of the 62 participating GPs, 45% were female, their mean age was 48, they had an average of 17 years of experience as a GP, and 64% were working in a (semi-)rural area. Of the 50 GPTs who completed the questionnaire at baseline, 72% were female, their mean age was 31, and 48% were working in a (semi-)rural area. Other characteristics are presented in Table 3.

Response to the evaluation form

The GP response to the evaluation form was 85% (= 53/62). Nine participants in the course did not respond for the following reasons: one had become ill, one form was filled in but got lost, two GPs did not complete the form because they considered that certain components of the ACA training programme had disrupted other parts of the Palliative Care Peer Group Course, and five did not respond for unknown reasons, despite several requests. The GPT response to the evaluation form was 67% (= 36/54). Reasons for non-response were absence at the final session (pregnancy leave 5x, illness 3x, holiday 2x, other course on the same day 2x, and unknown reason 2x), and 4 GPTs (from one group) did not complete the form because they had missed several steps of the programme.

Attendance and appreciation of the ACA training programme

Steps 1-3a and 6 were attended by 87-100% of the GPs. Although 94% of the GPs studied the written feedback according to the ACA checklist, only 57% watched the video-recording of their interview. A smaller percentage of GPs (55-79%) completed the various parts of step 4, which they were asked to do ‘at home’, outside the residential courses. The various steps of the training programme were attended by 78-94% of the GPTs.

We estimated that each participant required six hours to complete all steps of the programme (see Table 2).

GPs appreciated all steps with mean scores ranging from 3.5 to 3.9 on a 1-5 scale. The mean GPT scores ranged from 2.9 to 4.0. For all steps the GP scores were higher than the GPT scores. The responding GPs and GPTs appreciated most the videotaped interview with feedback (steps 1 and 3), the role-play to practise individual learning goals (step 6), and the use of the ACA checklist in practice (step 4c). Among GPTs we found rather low appreciation scores for the use of the ACA checklist as a learning tool (studying the ACA booklet, formulation of individual learning goals, and applying the ACA checklist in discussions with vocational GP trainer or peers). For attendance and appreciation of all steps of the ACA training programme, see Table 4.

The five most frequently spontaneously reported GP learning goals (8x or more) were: active listening, allowing any subject to be discussed, anticipating, wishes for the coming weeks/months, and using the ACA checklist as a guide. The GPTs most frequently reported using the ACA checklist as a guide (12x) and active listening (6x).

The two facilitating factors of the programme that GPs most frequently reported spontaneously were the peer group sessions (13x) and the ACA checklist (12x). The interview with an actor, the feedback, and seeing many palliative care patients in practice during the course were mentioned four times. The facilitating factor most frequently reported by the GPTs was the interactive feedback (according to the ACA checklist) on

Table 3. Socio-demographic and professional characteristics of participating general practitioners (GPs) and general practice trainees (GPTs)

Characteristics of participants	**GPs, N = 62**	**GPTs, N = 50[1]**
Gender, female N (%)	28 (45%)	36 (72%)
Age, mean (range)	48 (33-60)	31 (26-47)
Years of experience as a GP, mean (range)	17 (1-34)	n.a.[2]
Group or single-handed (vocational) practice		
- group practice, N (%)	24 (39%)	16 (32%)
- duo practice, N (%)	23 (37%)	20 (40%)
- single-handed practice, (%)	15 (24%)	14 (28%)
(Vocational) practice location area urban or rural		
- urban, N (%)	22 (36%)	26 (52%)
Working or attending vocational training part-time or full-time[3]		
- part-time, N (%)	32 (52%)	11 (22%)
Vocational GP trainers, N (%)	17 (27%)	n.a.
Courses in palliative care attended by GP during the previous two years, N (%)	31 (50%)	n.a.
Specific experience of GPT in palliative care at baseline, N (%)	n.a.	16 (32%)
GP estimate of number of palliative care patients in the practice who died during the previous year, mean (range)[4]	8 (1-40)	n.a.
GPT estimate of number of palliative care patients for whom GPT provided palliative care during the first year of vocational training, mean (range)	n.a.	2 (0-5)

[1] four GPTs did not complete their form (holiday 2x and unknown reason 2x);
[2] n.a. = not applicable; [3] full-time = 90-100%; [4] one GP answered 'don't know'.

Table 4. Attendance and appreciation of the ACA training programme by responding general practitioners (GPs, N= 53) and general practice trainees (GPTs, N= 36)[1]

	GPs, attendance	GPs, appreciation scores 1-5[2], mean (SD)	GPTs, attendance	GPTs, appreciation scores 1-5[2], mean (SD)
Step 1a: Videotaped interview	100%	3.8 (0.5)	92%	3.7 (0.6)
Step 1b: Oral feedback from actor	100%	3.9 (0.5)	92%	3.5 (0.8)
Step 2a: Oral presentation on ACA checklist *(GPs only)*	98%	3.5 (0.6)	n.a.[3]	n.a.
Step 2b: Usefulness of content of ACA booklet *(GPTs only)*	n.a.	n.a.	94%	3.9 (0.7)
Step 3a: Written feedback on videotaped interview *(GPs only)*	94%	3.6 (0.5)	n.a.	n.a.
Step 3b: DVD of the videotaped interview *(GPs only)*	57%	3.7 (0.4)	n.a.	n.a.
Step 3c: Interactive feedback on videotaped interview *(GPTs only)*	n.a.	n.a.	81%	4.0 (0.4)
Step 4a: Studying the ACA booklet	79%	3.8 (0.4)	83%	2.9 (0.9)
Step 4b: Applying the ACA checklist in peer group discussions	55%	3.6 (0.4)	92%	3.0 (0.9)
Step 4c: Using the ACA checklist in palliative practice	68%	3.7 (0.4)	89%	3.6 (0.9)
Step 4d: Applying the ACA checklist in discussions with vocational GP trainer *(GPTs only)*	n.a.	n.a.	89%	3.2 (1.0)
Step 5: Formulation of individual learning goals *(GPTs only)*	n.a.	n.a.	83%	2.9 (1.2)
Step 6: Role-play to practise individual learning goals	87%	3.9 (0.5)	78%	3.6 (0.9)
Overall satisfaction with ACA training programme *(GPTs only)*	n.a.	n.a.	94%	3.5 (0.8)

[1] Response was 85% for GPs and 67% for GPTs; [2] Scores from one (= no appreciation at all) to 5 (= maximal appreciation); [3] n.a. = not applicable.

the video-taped interview (5x).

The inhibiting factors most frequently spontaneously reported by the GPs were only very few palliative care patients in their practice during the course (11x) and not enough time available for the training programme (10x). Inhibiting factors reported by the GPTs were that medical elements were lacking in the programme (5x) and that not all steps in the programme had been addressed (3x). During the 6 months duration of the programme the GPTs provided palliative care for an average of two patients (range 0-5).

Discussion

Main findings

We developed the ACA training programme to improve communication between GPs and their palliative care patients, consisting of eight consecutive steps, and based on three key areas of attention in communication: *availability* of the GP for the patient, *current issues* that should be raised by the GP, and *anticipating* various scenarios. The results of this study show that the programme appears to be applicable to practising GPs who attended a 2-year Palliative Care Peer Group Training Course and to (inexperienced) GPTs from five vocational training groups. The ACA checklist was appreciated by GPs as useful both in practice and as a learning tool, whereas GPTs mainly appreciated the list for use in practice. A quarter of the GPs and a third of the GPTs spontaneously reported the ACA checklist to be a useful guide for communication with palliative care patients.

Strengths and limitations of this study

Both content and educational approach of the ACA training programme are evidence-based. The content of the ACA training programme is based on the results of recent studies among palliative care patients, their relatives, GPs, and end-of-life consultants. The educational approach was derived from two systematic reviews of methods in training programmes for communication in palliative and cancer care.

Attendance and appreciation of the training programme were evaluated for each step of the programme.

The newly developed training programme was assessed among practising GPs and inexperienced GPTs. The GPs participated in a two-year Palliative Care Peer Group Training Course, and probably had a more than average commitment to palliative care, unlike the GPTs, who participated as part of their vocational training, with no special commitment. This might explain the moderate GPT response rate (67%) and their lower scores for appreciation. The appreciation scores of the two groups can only be compared with caution, because the GPs scored their appreciation on a 10-point scale and the GPTs on a 5-point scale. Non-responding GP(T)s might have had lower attendance rates and lower appreciation scores.

Although we evaluated the applicability of the ACA training programme in two different settings, our results can only be generalised with caution to use of the programme in other settings.

This study was a merely quantitative evaluation of the training programme; a qualitative study might have given additional insight in factors that would facilitate or inhibit effectiveness of this training programme.

The applicability was assessed with evaluation forms that were completed at the end of the training programme; registration of attendance and appreciation during the course might have yielded more accurate data.

Comparison with existing literature

In their review of educational interventions in palliative care for primary care physicians, Alvarez *et al.* state that key elements of GP-patient communication in palliative care should be designed more specifically to obtain favourable results, and that effective training methods in key communication skills for doctors should be addressed in three phases: cognitive input, modelling, and practising key skills with feedback about performance.[8] These statements are in line with our findings that the GPs and GPTs appreciated the checklist with the 19 items and also the diverse methods in the ACA training programme.

Acquiring new consultation skills requires time. Blankenstein *et al.* found that GPs needed 20 hours of training and feedback sessions to learn how to apply new consultation skills aimed at somatising patients.[31] In our study, 10 GPs reported that they did not have enough time available for the ACA training programme. The estimated total duration of six hours for the programme might be too short.

Recommendations for trainers

This study revealed possibilities to improve the applicability of the ACA training programme. Because the GPTs appreciated using the ACA checklist in practice more than using it as a learning tool, we recommend that first they try out the checklist in practice or role-play and afterwards reflect on their experiences with peers or their GP trainer. Therefore, the GP trainers should receive detailed instructions about the training programme like the regular teachers in the vocational GP training institutes. Because the attendance of the GPs to discussions about the ACA communication skills in their peer group was low, the facilitators of the peer groups should receive more training. As suggested by several GPTs, we recommend that the ACA training programme should be combined with training programmes for other medical and palliative care issues such as the Palliative Care Peer Group Training Course for GPs. Providing care for many palliative care patients in daily practice during the training period probably enhances the learning process for GP(T)s.

We were surprised that even a well-known communication skill such as 'active listening' was chosen by several experienced GPs as their main individual learning goal. We consider the opportunities for GP(T)s to assess their individual shortcomings in communication skills and to participate in role-play exercises tailored to their own learning goals as strong characteristics of the ACA training programme. The use of a checklist to clarify individual learning goals to facilitate the learning process might be extended to other topics and educational areas.

Conclusions

The ACA training programme appears to be applicable to GPs and GPTs. Future research should assess the effectiveness of the ACA training programme with regard to GP(T) behaviour as well as patient outcomes.

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References

1 **Korsch B, Putman SM, Frankel R, Roter D:** The medical interview: clinical care, education and research. *Frontiers of Primary Care. New York, NY, USA: Springer;* 1995:475-481.

2 **Higginson I, Wade A, McCarthy M:** Palliative care: views of patients and their families. *BMJ* 1990, 301:277-281.

3 **Mitchell GK:** How well do general practitioners deliver palliative care? A systematic review. *Palliat Med* 2002, 16:457-464.

4 **Barclay S, Wyatt P, Shore S, Finlay I, Grande G, Todd C:** Caring for the dying: how well prepared are general practitioners? A questionnaire study in Wales. *Palliat Med* 2003, 17:27-39.

5 **Lloyd-Williams M, Lloyd-Williams F:** Palliative care teaching and today's general practitioners - is it adequate? *Eur J Cancer Care* 1996, 5:242-245.

6 **Slort W, Schweitzer BPM, Blankenstein AH, Abarshi EA, Riphagen II, Echteld MA, Aaronson NK, Van der Horst HE, Deliens L:** Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliat Med* 2011, 25:613-629.

7 **Slort W, Blankenstein AH, Deliens L, Van der Horst HE:** Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011, 61:167-172.

8 **Alvarez MP, Agra Y:** Systematic review of educational interventions in palliative care for primary care physicians. *Palliat Med* 2006, 20:673-683.

9 **Gysels M, Richardson A, Higginson IJ:** Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer* 2005, 13:356-366.

10 **Deschepper R, Bernheim JL, Van der Stichele R, Van den Block L, Michiels E, Van der Kelen G, Mortier F, Deliens L:** Truth-telling at the end of life: A pilot study on the perspective of patients and professional caregivers. *Patient Educ Couns* 2008, 71:52-56.

11 **Exley C, Field D, Jones L, Stokes T:** Palliative care in the community for cancer and end-stage cardiorespiratory disease: The views of patients, lay-carers and health care professionals. *Palliat Med* 2005, 19:76-83.

12 **Field D: Special not different:** General practitioners' accounts of their care of dying people. *Soc Sci Med* 1998, 46:1111-1120.

13 **Michiels E, Deschepper R, Van Der Kelen G, Bernheim JL, Mortier F, Van der Stichele R, Deliens L:** The role of general practitioners in continuity of care at the end of life: A qualitative study of terminally ill patients and their next of kin. *Palliat Med* 2007, 21:409-415.

14 **Van den Muijsenbergh M:** Palliatieve zorg: De persoonlijke specialiteit van elke huisarts. *Huisarts Wet.* 2003, 46:80-85.

15 **Osse BHP, Vernooij-Dassen MJFJ, Schadé E, De Vree B, Van den Muijsenbergh ME, Grol RP:** Problems to discuss with cancer patients in palliative care: A comprehensive approach. *Patient Educ Couns* 2002, 47:195-204.

16 **Steinmetz D, Walsh M, Gabel LL, Williams PT:** Family physicians' involvement with dying patients and their families. Attitudes, difficulties, and strategies. *Arch Fam Med* 1993, 2:753-760.

17 **Farber SJ, Egnew TR, Herman-Bertsch JL:** Issues in end-of-life care: family practice faculty perceptions. *J Fam Pract* 1999, 48:525-530.

18 **Meijler WJ, Van Heest F, Otter R, Sleijfer DT:** Educational needs of general practitioners in palliative care: Outcome of a focus group study. *J Cancer Educ* 2005, 20:28-33.

19 **Borgsteede SD, Deliens L, Graafland-Riedstra C, Francke AL, Van der Wal G, Willems DL:** Communication about euthanasia in general practice: Opinions and experiences of patients and their general practitioners. *Patient Educ Couns* 2007, 66:156-161.

20 **Farber SJ, Egnew TR, Herman-Bertsch JL, Taylor TR, Guldin GE:** Issues in end-of-life care: Patient, caregiver, and clinician perceptions. *J Palliat Med* 2003, 6:19-31.

21 **Pfeifer MP, Sidorov JE, Smith AC, Boero JF, Evans AT, Settle MB:** The discussion of end-of-life medical care by primary care patients and physicians: A multicenter study using structured qualitative interviews. *J Gen Intern Med* 1994, 9:82-88.

22 **Kelly B, Varghese FT, Burnett P, Turner J, Robertson M, Kelly P, Mitchell G, Treston P:** General practitioners' experiences of the psychological aspects in the care of a dying patient. *Palliat Support Care* 2008, 6:125-131.

23 **Norman A, Sisler J, Hack T, Harlos M:** Family physicians and cancer care. Palliative care patients' perspective. *Can Fam Physician* 2001, 47:2009-2016.

24 **Farber SJ, Egnew TR, Herman-Bertsch JL:** Defining effective clinician roles in end-of-life care. *J Fam Pract* 2002, 51:153-158.

25 **Burge F, McIntyre P, Kaufman D, Cummings I, Frager G, Pollet A:** Family Medicine residents' knowledge and attitudes about end-of-life care. *J Palliat Care 2000, 16:5-12.*

26 **Eggerman S, Dustin D:** Death orientation and communication with the terminally ill. *Omega (Westport)* 1985, 16:255-265.

27 **Elkington H, White P, Higgs R, Pettinari CJ:** GPs' views of discussions of prognosis in severe COPD. *Fam Pract* 2001, 18:440-444.

28 **Michiels E, Deschepper R, Bilsen J, Mortier F, Deliens L:** Information disclosure to terminally ill patients and their relatives: self-reported practice of Belgian clinical specialists and general practitioners. *Palliat Med* 2009, 23:345-353.

29 **Holmes SM, Rabow MW, Dibble SL:** Screening the soul: Communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life. *Am J Hosp Palliat Care* 2006, 23:25-33.

30 **Reinders ME, Blankenstein AH, Van Marwijk HWJ, Schleypen H, Schoonheim PL, Stalman WAB:** Development and feasibility of a patient feedback programme to improve consultation skills in general practice training. *Patient Educ Couns* 2008, 72:12-19.

31 **Blankenstein AH, Van der Horst HE, Schilte AF, De Vries D, Zaat JOM, Knottnerus JA, Van Eijk JTM, De Haan M:** Development and feasibility of a modified reattribution model for somatising patients, applied by their own general practitioners. *Patient Educ Couns* 2002, 47:229-235.

PART 3

Experimental studies

CHAPTER 5

Effectiveness of the ACA (Availability, Current issues and Anticipation) training programme on GP-patient communication in palliative care; a controlled trial

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Abstract

Background

Communicating effectively with palliative care patients has been acknowledged to be somewhat difficult, but little is known about the effect that training general practitioners (GPs) in specific elements of communication in palliative care might have. We hypothesized that GPs exposed to a new training programme in GP-patient communication in palliative care focusing on *availability* of the GP for the patient, *current issues* the GP should discuss with the patient and *anticipation* by the GP of various scenarios (ACA), would discuss more issues and become more skilled in their communication with palliative care patients.

Methods

In this controlled trial among GPs who attended a two-year Palliative Care Peer Group Training Course in the Netherlands only intervention GPs received the ACA training programme. To evaluate the effect of the programme a content analysis (Roter Interaction Analysis System) was performed of one videotaped 15-minute consultation of each GP with a simulated palliative care patient conducted at baseline, and one at 12 months follow-up. Both how the GP communicated with the patient ('availability') and the number of current and anticipated issues the GP discussed with the patient were measured quantitatively. We used linear mixed models and logistic regression models to evaluate between-group differences over time.

Results

Sixty-two GPs were assigned to the intervention and 64 to the control group. We found no effect of the ACA training programme on how the GPs communicated with the patient or on the number of issues discussed by GPs with the patient. The total number of issues discussed by the GPs was eight out of 13 before and after the training in both groups.

Conclusion

The ACA training programme did not influence how the GPs communicated with the simulated palliative care patient or the number of issues discussed by the GPs in this trial. Further research should evaluate whether this training programme is effective for GPs who do not have a special interest in palliative care and whether studies using outcomes at patient level can provide more insight into the effectiveness of the ACA training programme.

Trial registration: ISRCTN56722368

Background

While effective communication between health care professionals and patients is considered to be an essential requirement in order to provide high-quality care,[1-6] communicating with palliative care patients has been acknowledged as being more difficult than communicating with patients with less serious conditions.[7] Communication in palliative care involves addressing a complex mix of physical, psychosocial and spiritual/existential issues within the context of impending death. If a health care professional does not communicate as well as he could, some, if not many, of the problems that patients are facing might not be identified. Consequently, it is likely that the health care professional will not be able to take the appropriate actions, and the patient's quality of life may be unnecessarily impaired.

Several studies have demonstrated the effectiveness of basic communication skills training programmes in improving oncologists' or oncology nurses' communication with oncology patients, including those receiving palliative care.[8,9]

General practitioners (GPs) are trained in doctor-patient communication as part of their pre- and postgraduate education. However, this does not always cover specific training in communication with palliative care patients.[10] Little is known about the effectiveness of training GPs in specific elements of communication in palliative care.

To fill this gap, we designed a new training programme for GP-patient communication in palliative care, based on recent studies.[8,11-13] This programme, focusing on *availability* of the GP for the patient, *current issues* the GP should discuss with the patient, and *anticipation* by the GP of various scenarios (ACA), appeared to be applicable to GPs and GP trainees (see Tables 1 and 2).[14] In this paper we report on a controlled clinical trial which evaluated the effectiveness of this ACA training programme on GP-patient communication in palliative care. We hypothesized that GPs exposed to the training programme would discuss more current and anticipated issues and would become more skilled in their communication with palliative care patients.

Methods

Setting and participants

This controlled trial was conducted in the context of an existing postgraduate two-year Palliative Care Peer Group Training Course (PCPT), consisting of four two-day residential courses, followed by two-hour peer group sessions with five GPs in each group, facilitated by a palliative care consultant, every six to eight weeks. All GPs enrolled in the four PCPT courses in 2006 and 2007 were invited to take part in the study. As our intervention was added to an existing training course, we had to assign whole training groups to either the intervention or the control condition. Because we wanted to start with an intervention group in 2006, and to prevent contamination between groups, GPs enrolled in the PCPT courses conducted in Eindhoven (2006) and Rotterdam (2007) were assigned to the intervention condition in which the ACA training programme was integrated into the PCPT course. GPs who enrolled in the PCPT courses in Amsterdam (both 2007) were assigned to the control condition in which the ACA training programme component was not included.

Table 1. The eight steps of the ACA (availability, current issues, anticipation) training programme

Step 1
Videotaped GP-patient interview with a trained actor simulating a patient in an advanced stage of lung (role A) or colon (role B) cancer, according to detailed scripts; immediately after the interview the participant receives general feedback on communication style from the actor.

Step 2
Instructions on the ACA checklist, using oral presentations and written information (ACA booklet).

Step 3
Feedback according to the ACA checklist on GP performance during the videotaped GP-patient interview in step 1.

Step 4
Studying the ACA checklist, *discussing* this material with peers in small groups, and *trying out* newly acquired skills in their own general practice to identify problem areas from their own experience.

Step 5
Formulating learning goals based on the previous steps.

Step 6
Role-play exercises tailored to the GP's individual learning goals.

Step 7
A second videotaped interview with an actor simulating a patient.

Step 8
Using the second videotaped interview and the ACA checklist as tools for *self-assessment* of their communication skills.

Table 2. The ACA *(availability, current issues, anticipation)* checklist

Availability *(of the GP for the patient):*

1. Taking time
2. Allowing any subject to be discussed
3. Active listening
4. Facilitating behaviour (e.g. empathic, respectful, attentive, occasionally also phoning or visiting the patient spontaneously)
5. Shared decision-making with regard to diagnosis and treatment plan
6. Accessibility (e.g. phone numbers)

Current issues *(that should be raised by the GP):*

1. Diagnosis
2. Prognosis
3. Patient's complaints and worries: - physical
4. - Psychosocial
5. - Spiritual/existential
6. Wishes for the present and the coming days
7. Unfinished business, bringing life to a close
8. Discussing treatment and care options (concerning 1-7)

Anticipating *(various scenarios):*

1. Offering follow-up appointments
2. Possible complications
3. Wishes for the coming weeks/months (personal wishes as well as preferences with regard to medical decisions)
4. The actual process of dying (final hours/days)
5. End-of-life decisions

Intervention

The development of the ACA training programme has been reported elsewhere.[14] The programme consists of eight steps (see Table 1) and is supported by the ACA checklist (see Table 2). Steps 1 and 2 took place on the first day of the training programme. Within two months all participants received individual feedback on their videotaped simulated consultation (step 3). During the following months they had to complete step 4 in order to formulate their personal learning goals (step 5). Six months after the start of the programme, the GPs participated in role-play exercises that were tailored to their learning goals (step 6).

Finally, a second consultation with an actor simulating a patient was videotaped (step 7) to allow participants to assess their communication skills against the ACA checklist (step 8).

Sample size

For calculating sample size, we used the outcome measure 'number of issues discussed by the GP' and considered a difference of 0.5 standard deviation (which corresponded with one extra issue discussed by the GP) between intervention and control conditions as a clinically relevant difference. Such a difference can be detected with 64 GPs in each group (power 0.80, two-sided alpha 0.05).

Outcome measures

Outcome measures of this study were determined in discussion with a panel of experts in palliative care research. We decided to measure both how the GP communicated with the patient and what he discussed with him. These outcomes fit in well with the content of the ACA training programme on how to communicate with the patient (availability items) and what to discuss (the current and anticipated issues). Both 'how' and 'what' were measured quantitatively.

The number of issues discussed ('what') was defined as the summed number of 13 current and anticipated issues about which the GP made at least one utterance concerning that issue, during the simulated consultation. Additionally, we calculated for each issue the percentage of consultations in which the GPs discussed that issue.

The quality of a GP's communicative behaviour ('how') was defined as their scores on the six availability items. Because this complex outcome consisted of several numbers and percentages its sub-scores could not be summed up and were reported separately. Additionally, verbal dominance was calculated to evaluate whether the training influenced the GP's dominance during the consultation.

Measurement instrument

To measure both outcomes ('how' and 'what') from the videotaped consultations we used the Roter Interaction Analysis System (RIAS).[15,16] The RIAS, which was developed in the United States, has been used successfully in previous studies in Dutch general practice settings.[17] It distinguishes mutually exclusive and exhaustive categories into which verbal utterances that convey a complete thought can be classified. A distinction is made between instrumental or task-oriented categories, and affective or socio-emotional categories. Task-oriented categories refer to utterances that address a patient's physical or psychosocial problems. Affective categories carry explicit emotional content and refer to aspects of communication that are needed to establish a therapeutically effective relationship. The RIAS also rates 'global affects' on 6-point scales (e.g. friendliness/warmth).

For the outcome 'number of issues discussed' we added the current and anticipated issues to the task-oriented categories of the original RIAS. For the outcome quality of GP's communicative behaviour we added several study-specific 6-point scales to the RIAS (e.g. the extent to which the GP took time with the simulated patient). Four of the six availability items could be scored positively (e.g. 'taking time') as well as negatively (e.g. 'not taking time'). As we were especially interested in the communication by the GPs, we only calculated scores for the GPs (and not for the simulated patient).

Measurement procedure

For each GP participating in the study, we videotaped a 15-minute consultation with a simulated palliative care patient at baseline and at follow-up. The baseline assessment took place on the first day of the course; the follow-up assessment 12 months later, halfway through the two-year PCPT course. At baseline, half of the GPs from each of the four PCPT courses had a consultation with a trained actor who role-played a patient with advanced stage lung cancer. The other 50% had a consultation with an actor playing the role of a patient with advanced colon cancer. At the follow-up assessment, the simulated patient to whom the GPs were assigned was reversed from the baseline assessment. The setting in which the consultation took place was standardized to avoid any environmental variability.

The participating GPs were aware of their group allocation, but the actors involved in role-playing a palliative care patient and those who rated the videotaped GP-simulated patient encounters were not.

Coding procedure

Coding was carried out directly from videotape by four trained raters using The Observer® software (http://www.noldus.com/). Average coding time was three to four times the duration of the consultation. Throughout the coding period, a random sample of 11.5% of the tapes was rated by all coders to assess interrater reliability. Interrater reliability averaged for the ACA issues 0.85 (range 0.68-0.99) and for the percentages of utterances with a mean occurrence greater than 2% 0.71 (range 0.56-0.89), respectively.[15,16] These reliability estimates are comparable to those achieved in other studies.[18-21]

Statistical analysis

We assessed the comparability of the GPs in the intervention and the control condition with regard to socio-demographic and professional characteristics using the Chi-square statistic for categorical variables and the Mann-Whitney test for continuous variables. Variables on which the two groups were not comparable at baseline were entered as covariates in subsequent multivariable analyses.

We summed the number of 13 current and anticipated issues that were discussed by the GP during the simulated consultation. Consequently, the scale ranged from 0 to 13. For each issue we calculated the percentage of consultations in which that issue was discussed. For the outcome quality of communicative behaviour we calculated mean numbers and percentages of the several sub-scores. Verbal dominance was calculated by dividing the sum of all GP utterances by the sum of all patient utterances.

We used linear mixed models and accompanying effect sizes to evaluate between-group differences over time for interval level outcome variables (e.g. mean numbers and percentages). For dichotomous outcome variables (e.g. whether a given issue was discussed) we used the logistic regression method of generalized estimating equations (GEE) to account for dependence of data due to repeated measures, yielding odds ratios. In all analyses we used the GP's sex, years of experience as GP, urban versus rural or semi-rural practice location, the actor, and duration of the consultation longer than 15 minutes as covariates. In order to adjust for multiple testing, the level of significance was set at 0.01. All data were entered and analysed in SPSS 20.0 (SPSS, Inc., Chicago, IL).

Results

GP characteristics

All 126 GPs eligible for this study agreed to participate. Sixty-two were assigned to the intervention and 64 to the control group (see Figure 1). GPs in the intervention group were less likely to practise in an urban location and had a few more years of experience than those in the control group. No further significant between-group differences were observed (Table 3).

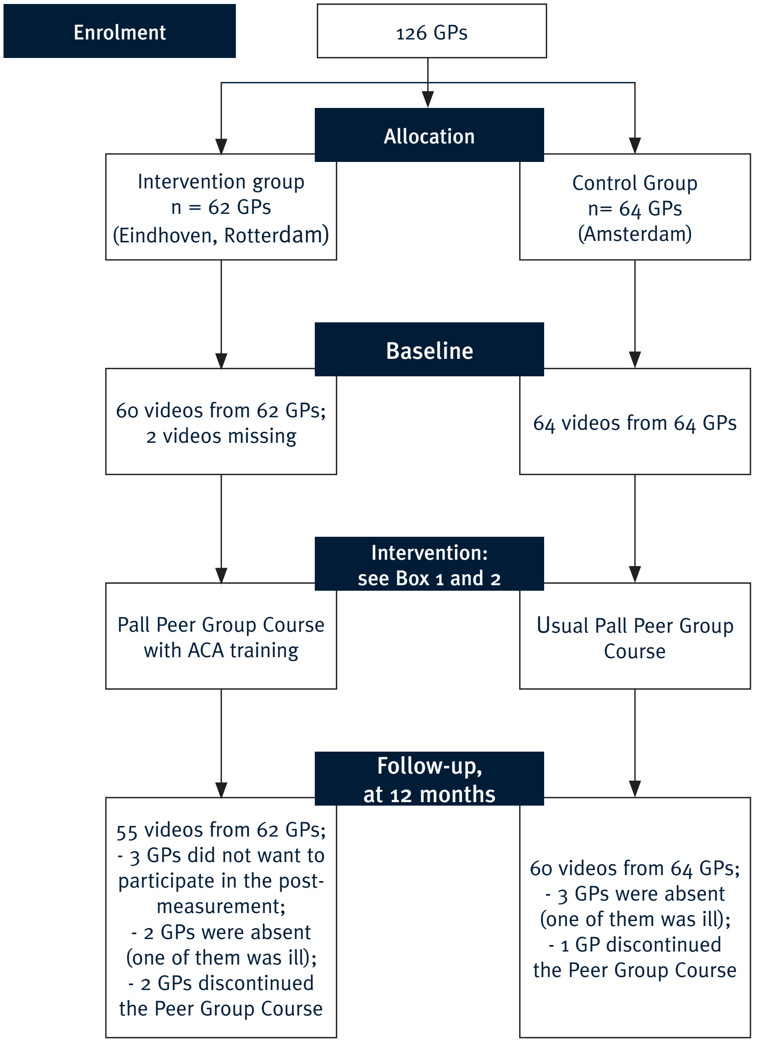
Number of issues discussed ('what')

We found no statistically significant differences over time between the intervention and control group in the mean total number of ACA issues, the mean number of current issues or the mean number of anticipated issues discussed (Table 4). In the total study sample, GPs raised on average eight of the 13 ACA issues during the consultation with the simulated palliative care patient (4.5 current and 3.5 anticipated issues).

Different issues discussed

A significant between-group difference over time was found only in the percentage of consultations in which the anticipated issue 'end-of-life decisions' was discussed: the percentage of consultations in which this issue was discussed decreased from 50% at baseline to 27% at follow-up in the intervention group, while an increase from 31% to

Figure 1. ACA trial Consort flow diagram



41% was seen in the control group (Table 4).

The four ACA issues physical complaints, psychosocial complaints, discussing treatment and care options and offering follow-up appointments were addressed in 90-100% of the consultations in both groups at baseline and follow-up measurements. Spiritual/existential issues and 'unfinished business' were infrequently addressed by the GPs.

Quality of communicative behaviour (‘how’)

No statistically significant between-group differences over time were observed in any of the outcomes related to availability, with the exception of the task-focused utterance ‘check’ (Table 5).

Verbal dominance showed no significant between-group difference over time (P=0.6), with or without inclusion of the rather frequently scored back channels (=utterances indicating attentive listening, such as ‘mmm-huh’). In both groups the verbal dominance was about 1 and decreased slightly from baseline to follow-up (i.e. GPs became slightly less dominant in terms of proportion of given utterances).

Table 3. Socio-demographic and professional characteristics of participating general practitioners (GPs)

Characteristics of participating GPs	**Intervention group; n=62 GPs**	**Control group; n=64 GPs**	**P**
Gender female, n (%)	28 (45%)	38 (59%)	.15
Age (years)*	49 (33–60)	48 (33–61)	.23
Years of experience as a GP*	16 (1–34)	14 (1–32)	**.034**
Group or single-handed practice			.98
- Group practice, n (%)	24 (39%)	24 (39%)	
- Duo practice, n (%)	23 (37%)	24 (36%)	
- Single-handed practice, n (%)	15 (24%)	16 (25%)	
Practice location urban (versus rural/semi-rural), n (%)	22 (35%)	44 (69%)	< **.001**
Working percentage of FTE*	.80 (.50-1.00)	.75 (.40-1.00)	.06
Vocational GP trainers, n (%)	17 (27%)	19 (30%)	.84
Courses in palliative care attended by GP during the previous two years, n (%)	31 (50%)	37 (58%)	.47

Data are presented as number (percentage) or * median (range); P= p-value using chi square test or Mann Whitney tests as appropriate.

Table 4. Number and type of current and anticipated issues that the GPs addressed during the simulated 15-minute consultations in intervention group (n=62) and control group (n=64)

ACA issues	Baseline		Follow-up		Effect (difference[3] or odds ratio[4]) (95% confidence interval)	P-value
	Intervention n=60	Control n=64	Intervention n=55	Control n=60		
All current and anticipated issues (0-13)[1]	8.00 (1.46)	7.80 (1.84)	8.05 (1.69)	7.78 (1.63)	-.07 (-.82; .69)[3]	.86
Current issues (0-8)[1]	4.48 (.87)	4.58 (1.05)	4.73 (1.10)	4.52 (1.11)	.29 (-.20; .78)[3]	.24
1. Diagnosis[2]	43	50	42	57	.76 (.25; 2.26)[4]	.63
2. Prognosis[2]	60	55	65	53	1.23 (.45; 3.36)[4]	.69
3. Complaints, -physical[2]	100	100	100	100	-[5]	-
4. -Psychosocial[2]	100	98	100	98	-[5]	-
5. -Spiritual/existential[2]	7	2	2	7	.06 (.001; 3.03)[4]	.16
6. Wishes, at present[2]	33	39	35	32	1.53 (.52; 4.53)[4]	.44
7. Unfinished business[2]	10	17	29	13	5.81 (1.32; 25.61)[4]	.020
8. Treatment and care options[2]	95	97	100	92	-[5]	-
Anticipated issues (0-5)[1]	3.52 (1.20)	3.22 (1.24)	3.33 (1.17)	3.27 (1.31)	-.39 (-.98; .20)[3]	.19
1. Follow-up appointments[2]	93	92	100	90	-[5]	-
2. Possible complications[2]	73	72	60	70	.47 (.14; 1.63)[4]	.23
3. Wishes, for the coming months[2]	85	78	93	77	2.12 (.41; 10.94)[4]	.37
4. The actual process of dying[2]	50	48	53	50	.82 (.27; 2.45)[4]	.72
5. End-of-life decisions[2]	50	31	27	40	**.13 (.03; .50)**[4]	**.003**

1 Observed mean (and standard deviation) of the number of issues the GP addressed during the consultation by at least one utterance concerning an issue; interrater reliability for the ACA issues averaged 0.85 (range 0.68-0.99). 2 Observed percentage of consultations in which a GP made at least one utterance concerning this issue. 3 Effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (years of experience as GP and urban versus rural/semi-rural practice location) and for possible influences of the GP's sex, several actors simulating palliative care patients, and duration of the coansultations longer than 15 minutes. 4 Odds ratio (95% confidence interval) using a logistic regression (generalized estimating equations=GEE) model, adjusted for baseline differences (years of experience as GP and urban versus rural/semi-rural practice location) and for possible influences of the GP's sex, several actors simulating palliative care patients, and duration of the consultations longer than 15 minutes. 5 The logistic regression (GEE) model is not fit for results of binomial data close to 0 or 100% respectively.

Table 5. Scores on the availability items ('communicative behaviour') during the simulated 15-minute consultations of GPs in intervention group (n=62) and control group (n=64)

Availability items	**Baseline**		**Follow-up**		**Effect (difference[7] or odds ratio[8]) (95% confidence interval)**	**P-value**
POSITIVE	**Intervention n=60**	**Control n=64**	**Intervention n=55**	**Control n=60**		
1. ***Taking time*** (3 GARs, 3-18) [1]	13.23 (2.35)	13.05 (2.15)	12.95 (2.63)	12.40 (2.42)	.21 (-1.03; 1.46) [7]	.73
2. ***Allowing any subject to be discussed*** (2 GARs, 2-12) [1]	8.45 (1.60)	8.55 (1.67)	8.38 (1.63)	8.12 (1.69)	.31 (-.55; 1.17) [7]	.47
3. ***Active listening***						
A. Open/Closed Questions Ratio[2]	.65 (1.00)	.73 (1.12)	.57 (.44)	.58 (.74)	.07 (-.37; .52) [7]	.74
B. Affective utterances (RIAS):						
1. Back-channel responses[3]	29.5 (11.4)	30.8 (11.5)	31.9 (8.7)	32.8 (12.6)	.31 (-3.10; 3.71) [7]	.86
2. Shows approval (=approval +compliment)[4]	.49 (.79)	.33 (.53)	.52 (.91)	.58 (.89)	-.22 (-.64; .19) [7]	.29
3. Verbal attention (= empathy + legitimizes + partnership)[4]	4.33 (2.87)	4.96 (3.53)	4.46 (3.35)	4.36 (2.79)	.81 (-.66; 2.27) [7]	.28
4. Shows concern or worry[4]	.04 (.23)	.11 (.53)	.00 (.00)	.08 (.40)	-.004 (-.20; .19) [7]	.96
5. Reassurance (e.g. reassures, encourages, shows optimism)[4]	1.24 (2.26)	.84 (1.32)	1.17 (1.69)	1.23 (1.53)	-.66 (-1.49; .17) [7]	.12
6. Agreement (shows agreement or understanding)[4]	1.51 (1.61)	1.45 (2.09)	1.56 (1.49)	2.03 (2.44)	-.56 (-1.30; .17) [7]	.13
7. Personal remarks, laughs[4]	4.25 (2.60)	5.50 (2.86)	4.03 (1.91)	5.17 (2.25)	.19 (-.97; 1.35) [7]	.75
8. Silence[5]	12	17	34	33	1.55 (.43; 5.62) [8]	.51
C. Task-focused utterances (RIAS):[4]						
1. Check (paraphrase/checks for understanding)	4.68 (2.91)	6.84 (4.33)	5.53 (3.74)	5.24 (3.36)	**2.60** (**.92**; **4.29**) [7]	**.003**
2. Gives orientation, instructions, introduction	2.72 (3.02)	3.25 (3.07)	3.13 (2.26)	3.08 (2.82)	.60 (-.80; 2.01) [7]	.40
3. Bids for repetition	.30 (0.84)	.27 (1.13)	.16 (.37)	.18 (.51)	-.05 (-.44; .35) [7]	.82
4. Asks for understanding	.06 (.23)	.06 (.23)	.04 (.22)	.01 (.10)	.02 (-.09; .12) [7]	.72
5. Asks for opinion	1.43 (1.14)	1.49 (1.23)	1.37 (1.21)	1.31 (1.14)	.17 (-.40; .75) [7]	.55
4. ***Facilitating behaviour***						
A. Facilitating behaviour (5 GARs, 5-30) [1]	22.15 (3.28)	21.92 (3.70)	22.29 (3.50)	21.17 (3.62)	.65 (-.99; 2.30) [7]	.43
B. Meta-communication[5]	22	16	22	15	.98 (.29; 3.33) [8]	.97
5. ***Shared decision making with regard to diagnosis and treatment plan***						
A. Shared Decision Making (3 GARs, 3-18) [1]	11.77 (2.22)	12.13 (2.58)	11.80 (2.36)	11.22 (2.31)	.88 (-.37; 2.14) [7]	.17
B. Extent of shared decision making (Range per topic 1-4) [6]	2.14 (.54)	2.22 (.57)	2.23 (.56)	2.16 (.57)	.14 (-.16; .45) [7]	.35
6. ***Accessibility***[5]	10	12	11	12	1.03 (.20; 5.34) [8]	.97

Continued

Table 5. Continued

Availability items	Baseline		Follow-up		Effect (difference[7] or odds ratio[8]) (95% confidence interval)	P-value
NEGATIVE	Intervention n=60	Control n=64	Intervention n=55	Control n=60		
1. ***Not taking time*** Hurried/Rushed (1 GAR, 1–6)[1]	2.60 (1.37)	2.80 (1.16)	2.53 (1.34)	2.62 (1.33)	.14 (–.52; .79) [7]	.68
2. ***Not allowing any subject to be discussed*** Disregard[5]	15	3	7	5	.24 (.02; 3.24) [8]	.28
3. ***Not listening actively*** Disagreement (=shows disapproval, criticism)[5]	0	0	2	2	- [9]	–[9]
4 ***Not facilitating behaviour*** (2 GARs, 2–12)[1]	2.37 (.74)	2.30 (.61)	2.24 (.58)	2.35 (.71)	-.19 (–.51; .14) [7]	.26

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[1] Observed mean rating (and standard deviation) of a (or of the sum of some) Global Affect Rating(s) (GARs) for the GP; the scale of each Global Affect Rating ranges from 1 to 6; interrater reliability of the GARs averaged 0.19 (range 0-0.39; these ICCs were rather low due to low variances in the GARs between consultations); 3 GARs ‘taking time’: calmness, speaking quietly, and showing involvement; 2 GARs ‘allowing any subject to be discussed’: GP’s open attitude and allowing any subject to be discussed; 5 GARs ‘facilitating behaviour’: interest/attentiveness, friendliness/warmth, responsiveness/engagement, sympathetic/empathetic, and respectfulness; 3 GARs ‘shared decision making’: with regard to treatment and care options taking patient’s quality of life and meaningfulness into consideration, informing patient adequately, and involving patient in decisions about treatment and care options; 1 GAR ‘not taking time’: (hurried/rushed); and 2 GARs ‘not facilitating behaviour’: anger/irritation and anxiety/nervousness.

[2] Observed mean ratio (and standard deviation) of the total number of GP’s open questions divided by the total number of GP’s closed questions during a consultation; because at baseline in the intervention group two GPs scored respectively 27 and 33 while the range of the other scores was from 0 to 5.67, we replaced these two outlying scores by the third to highest score (namely 5.67) to prevent a disproportional influence of these two scores on the mean ratio.

[3] Observed mean percentage (and standard deviation) of the total number of back channels by the GP divided by the total number of all utterances (including the back-channels) by the GP during a consultation; interrater reliability of the scores on the RIAS utterance back channel was 0.89.

[4] Observed mean percentage (and standard deviation) of the total number of this type of utterance by the GP divided by the total number of all utterances (with the exception of the back-channels) by the GP during a consultation (the back-channels were excepted to prevent dominance of all results by the rather high en variable number of back-channels that were scored during the consultations when compared to the numbers of all other utterances); interrater reliability of the scores on the four RIAS utterances with a mean occurrence greater than 2% (verbal attention, personal remarks, check, and giving orientation) averaged 0.66 (range 0.56-0.75).

[5] Observed percentage of consultations of the intervention and control group at baseline and post-measurement in which the GP made at least one utterance concerning this issue.

[6] Observed mean ratio (and standard deviation) of the sum of the ratings for the extent to which the GP had discussed the treatment or care options concerning the addressed problems with the patient (= shared decision making, rating 1 to 4) divided by the number of problems that were addressed during the consultation.

[7] Effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (years of experience as GP and urban versus rural/semi-rural practice location) and for possible influences of the GP’s sex, several actors simulating palliative care patients, and duration of the consultations longer than 15 minutes.

[8] Odds ratio (95% confidence interval) using a logistic regression (GEE) model, adjusted for baseline differences (years of experience as GP and urban versus rural/semi-rural practice location) and for possible influences of the GP’s sex, several actors simulating palliative care patients, and duration of the consultations longer than 15 minutes.

[9] The logistic regression (GEE) model is not fit for results of binomial data close to 0 or 100% respectively.

Discussion

In this controlled trial we found no significant effect of the ACA training programme on the total number of current and anticipated issues that GPs discussed in consultations with simulated palliative care patients, or on the quality of their communicative behaviour.

The total number of issues discussed by the GPs was eight out of 13 before and after the training in both groups. We consider this a rather high number during a 15-minute consultation. It may be that the high scores at baseline allowed little room for improvement on this outcome. This possible ceiling effect could be related to the fact that all GPs in this study were participating in a two-year Palliative Care Peer Group Training Course (PCPT), and probably had a more than average commitment to palliative care.

The results indicate that the frequency with which GPs exposed to the training programme discussed 'end-of-life decisions' actually declined over time, while it increased in the control group. For this finding and for the significant difference in the task-focused utterance 'check' we have no explanation other than that these are coincidental. The current issue 'patient's spiritual/existential complaints and worries' was seldom discussed by the GPs, and did not change over time. This reflects findings from previous studies that GPs do not always consider discussing spiritual issues as part of their professional competence or responsibility. [22]

Although we developed an evidence based intervention and used sound methods to evaluate its effectiveness, we found no effect on how and what the GP discussed with the simulated palliative care patient. Besides a possible ceiling effect in this group of GPs with more than average interest in palliative care, we considered also other possible explanations for these 'negative' results. The intervention might not have been effective or the outcome measures might not have been sensitive to change over time. Although the ACA checklist provides a concise summary of the essential factors for GP-patient communication in palliative care, all separate items ('how') and issues ('what') are not new, especially not for experienced GPs. Our quantitative content analysis (RIAS) of the consultations might not be sensitive enough in assessing overall quality of the GP's communication with the patient. Although we discussed extensively the best outcomes for this intervention, in retrospect we doubt whether the number of issues discussed by the GP is an appropriate indicator of quality of communication. It might be that the GP discussed the same number of issues at baseline and at follow-up, but discussed these issues in a better way at follow-up. However, we also failed to detect a significant effect on the 'how' of GP-patient communication. Although we included the several actors who role-played a patient with advanced stage cancer in our analyses as a covariate, this factor might have influenced our results more than we could identify.

Strengths and limitations of this study

To our knowledge, this is the first study on effectiveness of a communication training programme specifically targeted at GP-patient communication in palliative care.[12] Our intervention largely meets the recommendations for communication skills training in oncology as formulated at a recent consensus meeting by Stiefel et al.[23] Both educational approach and content of the intervention are evidence-based.[14] The outcomes of our trial were based on behavioural observations of simulated GP-patient consultations assessed by a validated quantitative instrument (RIAS).

As we had to assign participating GPs to either the intervention or the control condition without randomization, we carefully compared both groups and included significant between-group differences on background characteristics as covariates in the subsequent analyses. The GPs were not blind to their training condition. As a trial with videotaped consultations of GPs with real palliative care patients was not deemed to be feasible, we used trained actors to simulate patients with advanced stage cancer. Our study was based on the four levels of competence according to the pyramid model of Miller; 1. knows (knowledge), i.e. recall of basic facts, principles, and theories; 2. knows how (applied knowledge), i.e. ability to solve problems, make decisions, and describe procedures; 3. shows how (performance), i.e. demonstration of skills in a controlled setting; and 4. does (action), i.e. behaviour in real practice.[24] We focused our effectiveness evaluation on the third level. Moreover, we measured one 15-minute consultation, while in daily practice, Dutch GPs visit their palliative care patients frequently at home and thus discussion of the 13 issues will be spread over several visits.

Comparison with existing literature

We found no effectiveness studies that specifically address GP-patient communication in palliative care.[12] Two systematic reviews on effectiveness of communication training programmes for health professionals in cancer care reported positive effects (e.g. more open questions, expressions of empathy) from such training programmes.[8,9] These health professionals (not GPs) had probably received less extensive training in doctor-patient communication as part of their educational curriculum, and therefore the baseline level of their communication skills might have allowed more room for improvement compared with the GPs in our trial. Furthermore, these studies focused primarily on ‘breaking bad news’ and ‘dealing with patients’ feelings’ surrounding diagnosis, prognosis, and treatment options, while the ACA programme is targeted at issues in palliative care and anticipating the patient’s end-of-life concerns. In previous studies the primary outcomes were typically basic communication skills such as the availability aspects of the ACA checklist, while our primary outcome included the number of current and anticipated issues discussed by GPs. In their monograph on patient-centred communication in cancer care, Epstein and Street emphasize communication skills (i.e., how to provide information) more than specific issues to be addressed.[25] In their systematic review, Parker et al. discuss in detail the specific content as well as the style of end-of-life communication; the content areas they cover are similar to those of the ACA checklist.[26] However, the ACA checklist lays more emphasis on the patient's personal wishes, unfinished business and bringing life to a close.

Conclusion

In this trial with a specific group of GPs, the ACA training programme did not influence how the GPs communicated with the simulated palliative care patient or the number of issues discussed by the GPs. Further research should evaluate whether this training programme is effective for GPs who do not have a special interest in palliative care. Moreover, a study using outcomes at patient level might provide more insight into the effectiveness of the ACA training programme.

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References

1 **Audit Commission:** What seems to be the matter? Communication between hospitals and patients. *Report No 12. London: HS;* 1993.

2 **Ford S, Fallowfield L, Lewis S:** Doctor-patient interactions in oncology. *Soc Sci Med* 1996, 42:1511-1519.

3 **Lerman C, Daly M, Walsh WP, Resh N, Seay J, Barsevick A, Birenbaum L, Heggan T, Martin G:** Communication between patients with breast cancer and health care providers. Determinants and implications. *Cancer* 1993, 72:2612-2620.

4 **Razavi D, Delvaux N, Marchal S, De Cock M, Farvacques C, Slachmuylder JL:** Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators. *Psychooncology* 2000, 9:293-302.

5 **Stewart MA:** Effective physician-patient communication and health outcomes: a review. *Can Med Assoc J* 1995, 152:1423-1433.

6 **Turnberg L:** Improving communication between doctors and patients. Improving Communication between Doctors and Patients: a report of a working party. London: *Royal College of Physicians;* 1997.

7 **Korsch B, Putman SM, Frankel R, Roter D:** The medical interview: clinical care, education and research. *New York, NY, USA: Springer-Verlag: Frontiers of Primary Care;* 1995:475-481.

8 **Gysels M, Richardson A, Higginson IJ:** Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer* 2005, 13:356-366.

9 **Fellowes D, Wilkinson S, Moore P:** Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004. doi:10.1002/14651858.CD003751.pub2.

10 **Low J, Cloherty M, Wilkinson S, Barclay S, Hibble A:** A UK-wide postal survey to evaluate palliative care education amongst General Practice Registrars. *Palliat Med* 2006, 20:463-469.

11 **Alvarez MP, Agra Y:** Systematic review of educational interventions in palliative care for primary care physicians. *Palliat Med* 2006, 20:673-683.

12 **Slort W, Schweitzer BPM, Blankenstein AH, Abarshi EA, Riphagen II, Echteld MA, Aaronson NK, Van der Horst HE, Deliens L:** Perceived barriers and facilitators for general practitioner-patient communication in palliative care: a systematic review. *Palliat Med* 2011, 25:613-629.

13 **Slort W, Blankenstein AH, Deliens L, Van der Horst HE:** Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011, 61:167-672.

14 **Slort W, Blankenstein AH, Wanrooij BS, Van der Horst HE, Deliens L:** The ACA training programme to improve communication between general practitioners and their palliative care patients: development and applicability. *BMC Palliative Care* 2012, 11:9. doi:10.1186/1472-684X-11-9.

15 **Roter DL:** The Roter Method of Interaction Process Analysis: RIAS Manual. *Baltimore: Johns Hopkins University;* 1993.

16 **Roter D, Larson S:** The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Educ Couns* 2002, 46:243-251.

17 **Bensing JM:** Doctor-Patient Communication and the Quality of Care. An observational study into affective and instrumental behavior in general practice. *Doctoral Dissertation. NIVEL: Utrecht;* 1991.

18 **Roter D, Lipkin M Jr, Korsgaard A:** Sex differences in patients' and physicians' communication during primary care medical visits. *Med Care* 1991, 29:1083-1093.

19 **Timmermans LM, Van der Maazen RWM, Verhaak CM, Van Roosmalen MS, Van Daal WAJ, Kraaimaat FW:** Patient participation in discussing palliative radiotherapy. *Patient Educ Couns* 2005, 57:53-61.

20 **Verhaak CM, Kraaimaat FW, Staps ACJ, Van Daal WAJ:** Informed consent in palliative radiotherapy: participation of patients and proxies in treatment decisions. *Patient Educ Couns* 2000, 41:63-71.

21 **Ong LM, Visser MR, Kruyver IP, Bensing JM, Van den Brink-Muinen A, Stouthard JM, Lammes FB, De Haes JC:** The Roter Interaction Analysis System (RIAS) in oncological consultations: psychometric properties. *Psychooncology* 1998, 7:387-401.

22 **Holmes SM, Rabow MW, Dibble SL:** Screening the soul: communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life. *Am J Hosp Palliat Care* 2006, 23:25-33.

23 **Stiefel F, Barth J, Bensing J, Fallowfield L, Jost L, Razavi D, Kiss A:** Communication skills training in oncology: a position paper based on a consensus meeting among European experts in 2009. *Annals of Oncology* 2010, 21:204-207. doi: 10.1093/annonc/mdp564.

24 **Miller GE:** The assessment of clinical skills/competence/performance. *Acad Med* 1990, 65(9 Suppl):S63-S67.

25 **Epstein RM, Street RL Jr:** Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. *NIH Publication No. 07-6225. Bethesda: National Cancer Institute;* 2007.

26 **Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MHN:** A Systematic Review of Prognostic/End-of-Life Communication with Adults in the Advanced Stages of a Life-Limiting Illness: Patient/Caregiver Preferences for the Content, Style, and Timing of Information. *J Pain Symptom Manage* 2007, 34:81-93.

CHAPTER 6

Effectiveness of the palliative care 'Availability, Current issues and Anticipation' (ACA) communication training programme for general practitioners on patient outcomes: A controlled trial

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Abstract

Background

Although communicating effectively with patients receiving palliative care can be difficult, it may contribute to maintaining or enhancing patients' quality of life. Little is known about the effect of training general practitioners (GPs) in palliative care-specific communication. We hypothesized that palliative care patients of GPs exposed to the 'Availability, Current issues and Anticipation' (ACA) communication training programme would report better outcomes than patients of control GPs.

Aim

To evaluate the effectiveness of the ACA training programme for GPs on patient-reported outcomes.

Design

In a controlled trial, GPs followed the ACA programme or were part of the control group. Patients receiving palliative care of participating GPs completed the Palliative Care Outcome Scale, the EORTC QLQ-C15-PAL, the Rest & Peace Scale, the PSQ-III and the ACA Scale, at baseline and 12 months follow-up. We analysed differences between groups using linear mixed models.

Setting/participants

GPs who attended a two-year Palliative Care Training Course in the Netherlands.

Results

Questionnaire data were available for 145 patients (89 in intervention and 56 in control group). We found no significant differences over time between the intervention and control group in any of the five outcome measures. Ceiling effects were observed for the Rest & Peace Scale, PSQ-III and ACA Scale.

Conclusion

GP participation in the ACA training programme did not have a measurable effect on any of the outcomes investigated. Patients reported high levels of satisfaction with GP-care, regardless of group assignment. Future research might focus on GPs without special interest in palliative care.

Trial registration: ISRCTN56722368.

Introduction

While effective communication between health care professionals and patients is considered to be an essential requirement for providing high-quality care,[1-6] communicating with patients receiving palliative care has been acknowledged to be more difficult than communicating with patients with less serious conditions.[7] Communication in palliative care involves addressing a complex mix of physical, psychosocial and spiritual/existential issues within the context of impending death. If a health care professional does not communicate skilfully, some, if not many, of the problems that patients are facing may not be identified and addressed, and the patient's quality of life may be unnecessarily impaired. The results of our previous qualitative study suggest that the quality of general practitioner (GP)-patient communication in palliative care could be improved.[8]

Earlier studies on communication skills training in cancer care among medical specialists and oncology nurses demonstrated moderate effects of training on communication behaviour, but little if any effects on patient-reported outcomes.[9-20] To our knowledge, no such studies among GPs has been published.[21] To fill this gap, we designed a palliative care communication training programme for GPs, based on the results of recent studies on educational interventions in palliative care and on essential elements of GP-patient communication in palliative care.[8,17,21-23] This training programme focuses on *availability* of the GP to the patient, *current issues* the GP should discuss with the patient, and *anticipation* of various scenarios by the GP (Availability, Current issues and Anticipation (ACA)). In an earlier paper we reported on the effects of this programme on GPs' competence.[24] The quantitative analysis of videotaped consultations of GPs with simulated patients did not show an effect of the ACA training programme on the number of issues discussed or the quality of GPs' communicative behaviour. Using simulated patients to establish an effect is not optimal because it focuses on a single consultation, while in daily practice communication between doctors and patients evolves during several serial consultations. Also, as communication skills training is ultimately geared toward enhancing health outcomes, it is important to assess patient-reported outcomes as well.

In this article, we report on outcomes reported by patients who received palliative care of GPs who participated in the ACA trial. We hypothesized that palliative care patients of GPs who had participated in the ACA training programme would score better on (1) palliative care outcome measures, (2) satisfaction with the communication with their GP, and (3) ratings of their GP's availability, and discussion of current and anticipated issues.

Methods

Setting and participating GPs

This controlled trial was conducted during the first year of an existing post-graduate, two-year Palliative Care Peer Group Training Course (PCPTC) for GPs in the Netherlands, where care to most patients in the palliative phase is provided in the patient's home by generalists such as GPs and primary care nurses, with advice from end-of-life consultants when needed. The PCPTC consists of four two-day residential courses, followed by two-hour peer group sessions with five GPs in each group, facilitated by a palliative care consultant, every six to eight weeks. The residential courses focus on symptom control, ethical and spiritual/existential issues, management of care and communication skills. The peer group sessions provide inter-GP consultation. In an evaluation of the PCPTC, GPs reported an increase in their end-of-life care knowledge and skills.[25]

All GPs enrolled in the four PCPTCs which started in 2006 and 2007 were invited to take part in the study. Without randomization, we assigned two PCPTCs (Eindhoven, 2006, and Rotterdam, 2007) to the intervention condition in which the ACA training programme was integrated into the existing course, and two PCPTCs (both in Amsterdam, 2007) to the control condition. For the latter group, all communication skills training was moved to the second year of the programme, that is, after the follow-up assessment.

Patients

After enrolment in the study, we asked the GPs (by a letter, with one or two phone calls as reminders) to select all patients who met the following criteria during the three months preceding the first (baseline) and third (12-month follow-up) residential course: (1) advanced illness with a life expectancy of less than six months (estimated by the GP), (2) at least 18 years of age, (3) adequate command of the Dutch language, (4) no serious psychopathology or cognitive disorder and (5) receiving care primarily from the participating GP. Given the short life expectancy of this population of patients, the patients included at 12-month follow-up were other patients than those at baseline.

The GP briefly described the study to eligible patients and asked them to participate. Patients interested in participating were sent an information sheet about the study, an informed consent form, a questionnaire, and a postage-paid return envelope. If we did not receive a completed informed consent form and questionnaire within two weeks, the patient was phoned once or twice as a reminder.

Intervention

The ACA training programme consisted of eight steps (see Box 1), supported by the ACA checklist (see Box 2).[23] Steps 1 and 2 took place on the first day. Within two months, GPs received individual feedback on their videotaped consultation (step 3). During the following months they completed step 4 in order to formulate their personal learning goals (step 5). Six months after the start of the programme, the GPs participated in role-play exercises (step 6). Finally, a second simulated consultation was videotaped (step 7) to allow participants to assess their communication skills against the ACA checklist (step 8).

Box 1. The eight steps of the Availability, Current issues, Anticipation (ACA) training programme

Step 1

Videotaped general practitioner (GP)-patient interview with a trained actor simulating a patient in an advanced stage of lung (role A) or colon (role B) cancer, according to detailed scripts; immediately after the interview the participant receives general feedback on communication style from the actor.

Step 2

Instructions on the ACA checklist, using oral presentations and written information (ACA booklet).

Step 3

Feedback according to the ACA checklist on GP performance during the videotaped GP-patient interview in step 1.

Step 4

Studying the ACA checklist, *discussing* this material with peers in small groups and *trying out* newly acquired skills in their own general practice to identify problem areas from their own experience.

Step 5

Formulating learning goals based on the previous steps.

Step 6

Role-play exercises tailored to the GP's individual learning goals.

Step 7

A second videotaped interview with an actor simulating a patient.

Step 8

Using the second videotaped interview and the ACA checklist as tools for *self-assessment* of their communication skills.

Box 2. The Availability, Current issues, Anticipation (ACA) checklist

Availability *(of the GP for the patient):*

1. Taking time
2. Allowing any subject to be discussed
3. Active listening
4. Facilitating behaviour (e.g. empathic, respectful, attentive, occasionally also phoning or visiting the patient spontaneously)
5. Shared decision-making with regard to diagnosis and treatment plan
6. Accessibility (e.g. phone numbers)

Current issues *(that should be raised by the GP):*

1. Diagnosis
2. Prognosis
3. Physical complaints and worries
4. Psychosocial complaints and worries
5. Spiritual/existential complaints and worries
6. Wishes for the present and the coming days
7. Unfinished business, bringing life to a close
8. Discussing treatment and care options (concerning 1-7)

Anticipating *(various scenarios):*

1. Offering follow-up appointments
2. Possible complications
3. Wishes for the coming weeks/months (personal wishes as well as preferences with regard to medical decisions)
4. The actual process of dying (final hours/days)
5. End-of-life decisions

Outcome measures

We asked the participating patients to complete the following questionnaires:

1. Palliative care outcome measures

The Palliative Care Outcome Scale (POS), a validated 10-item questionnaire, covers the main components of palliative care. Eight questions have a 5-point Likert-scale response from 0 ('not at all') to 4 ('overwhelming'), and two questions have 3-point Likert-scale responses (0-2-4). Patients were asked to answer the questions according to their experiences during the previous 3 days. Higher scores indicate more severe problems.[26-28]

The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative (EORTC QLQ-C15-PAL) measures the health-related quality of life of cancer patients in palliative care as experienced during the previous week. It consists of 15 questions organized into two function scales (physical and emotional), seven symptom scales (e.g. fatigue, nausea/vomiting and pain), and an overall quality of life scale. Responses to 14 questions are given on 4-point Likert scales ranging from 1 ('not at all') to 4 ('very much'), and to the 'overall quality of life' question on a scale from 1 ('very poor') to 7 ('excellent'). The scores are linearly converted to 0-100 scales, with higher values representing better functioning and quality of life, and greater symptom burden.[29-31]

The Rest & Peace Scale (RPS). In our qualitative study, we obtained information from patients, GPs, and end-of-life consultants about what they considered to be desired outcomes of palliative care.[8] We used the six most frequently reported indicators of successful palliative care as items for the RPS: My GP helped me to (1) feel comfortable; (2) feel at peace; (3) accept my advanced illness; (4) value the last period of my life; (5) experience that the GP respects me; and (6) find out my preferred place to die. All questions have 5-point Likert-scale responses from 1 ('strongly agree') to 5 ('strongly disagree'). Scores are transposed so that higher scores always indicate better palliative care outcome.

2. Satisfaction with the communication with the GP

From the validated Dutch version of the *Patient Satisfaction Questionnaire-III (PSQ-III)* we used the subscales interpersonal manner (7 items), communication (5 items) and time spent with GP (2 items). All questions have 5-point scale responses from 1 ('strongly agree') to 5 ('strongly disagree'). Scores were transposed so that higher scores always indicate greater patient satisfaction.[32,33]

3. GP's availability and discussed issues

The ACA scale measures the extent to which the GP was available for and discussed important issues with the patient. The ACA checklist consists of 19 items divided into three categories: Availability (6 items), Current issues (8 issues) and Anticipation (5 issues) (see Box 2). All questions have 5-point Likert-scale responses from 1 ('strongly agree') to 5 ('strongly disagree') with higher scores indicating that the GP was more available and discussed more issues.

Additionally, the patient and GP questionnaires contained items assessing their socio-demographic and other characteristics.

Statistical analysis

We assessed the comparability of GPs in the intervention and the control condition on socio-demographic and professional characteristics using chi-square for categorical variables and the Mann-Whitney test for interval level variables. Variables on which the two GP groups were not comparable at baseline were entered as covariates in subsequent analyses.

We calculated the sample size on the primary outcome measure at GP level 'number of 13 current and anticipated issues discussed' (see Box 2) and considered a 0.5 standard deviation (SD) difference (which corresponded with one issue more or less) between groups as clinically relevant. Such a difference can be detected with 64 GPs in each group (power 0.80, two-sided alpha 0.05).[24]

Due to poor prognosis, patients assessed at follow-up were different from those at baseline. Therefore, we present patient characteristics for all four groups. Missing data were minimal (0-4% missing items) and values for these missing data were estimated using single response function imputation.[34]

As the GP was the experimental unit of analysis and patients were nested within GP by time combinations, we used linear mixed models and accompanying effects to evaluate between-group differences over time for all outcome variables. In all analyses we used the GP's sex, age, practice location and percentage of full-time equivalent (FTE) working as covariates. Outcomes were presented as means, SDs and intervention effects. Between-group differences were first tested at the sum score/scale level. Where appropriate, analyses were conducted at the individual item level, but only when the results at the higher (scale) level were statistically significant. To adjust for multiple testing, the level of significance was set at 0.01. For all scales, we calculated internal consistency reliability using Cronbach's coefficient alpha. All analyses were conducted in SPSS 20.0 (SPSS, Inc., Chicago, IL).

Results

GP and patient characteristics

All 126 GPs eligible for the study agreed to participate. Sixty-two GPs ('Eindhoven' and 'Rotterdam') were assigned to the intervention group and 64 ('Amsterdam') to the control group. Of the 62 intervention GPs, 43 included one or more patients (30 GPs at baseline and 27 at follow-up). Of the 64 control GPs, 34 included patients (31 GPs at baseline and only 10 at follow-up) (see Figure 1). The primary reasons for not including patients were no patient needing palliative care in practice during inclusion periods, reluctance to ask a seriously ill patient to participate and the rapidly deteriorating condition of patients. Intervention GPs were more likely to practise in a rural location than control GPs. No further between-group differences were observed in the background characteristics of the GPs (Table 1). Also, the characteristics of those GPs who provided patients to the study were similar to those who did not.

In total, the participating GPs included 169 palliative care patients, of whom 157 (93%) completed the questionnaire. Reasons for non-response were: too weak to complete the questionnaire (8x), transfer to another setting (2x) and unknown (2x). We excluded 12 of 157 questionnaires because they were completed by a relative. The remaining 145 questionnaires (89 at baseline and 56 at follow-up) were included in the analysis.

Patient characteristics were comparable for all four groups. Almost all patients had cancer, but three patients had a neurological disease (see Table 2). At follow-up we collected only 12 questionnaires in the control group. As was to be expected, all patients at follow-up were other patients than those at baseline.

Outcomes

Primary outcomes

We found no significant effects of the ACA training programme on patients' ratings of palliative care outcomes (POS, QLQ-C15-PAL and RPS), satisfaction with the communication with their GP (PSQ-III) or GP's availability and discussed current and anticipated issues (ACA scale) (see Table 3).

Descriptive results

Most Rest and Peace items, all PSQ-III items, and most ACA items showed near-ceiling scores in all groups. For the QLQ-C15-PAL, the most prevalent symptoms were fatigue, appetite loss, and pain. For the RPS, lower scores were observed for 'my GP helped me to find out my preferred place to die'. For the ACA scale, lower values were observed for 'unfinished business', and to a lesser extent for 'prognosis and possible complications', 'the actual process of dying' and 'euthanasia'.

Figure 1. ACA trial flow diagram

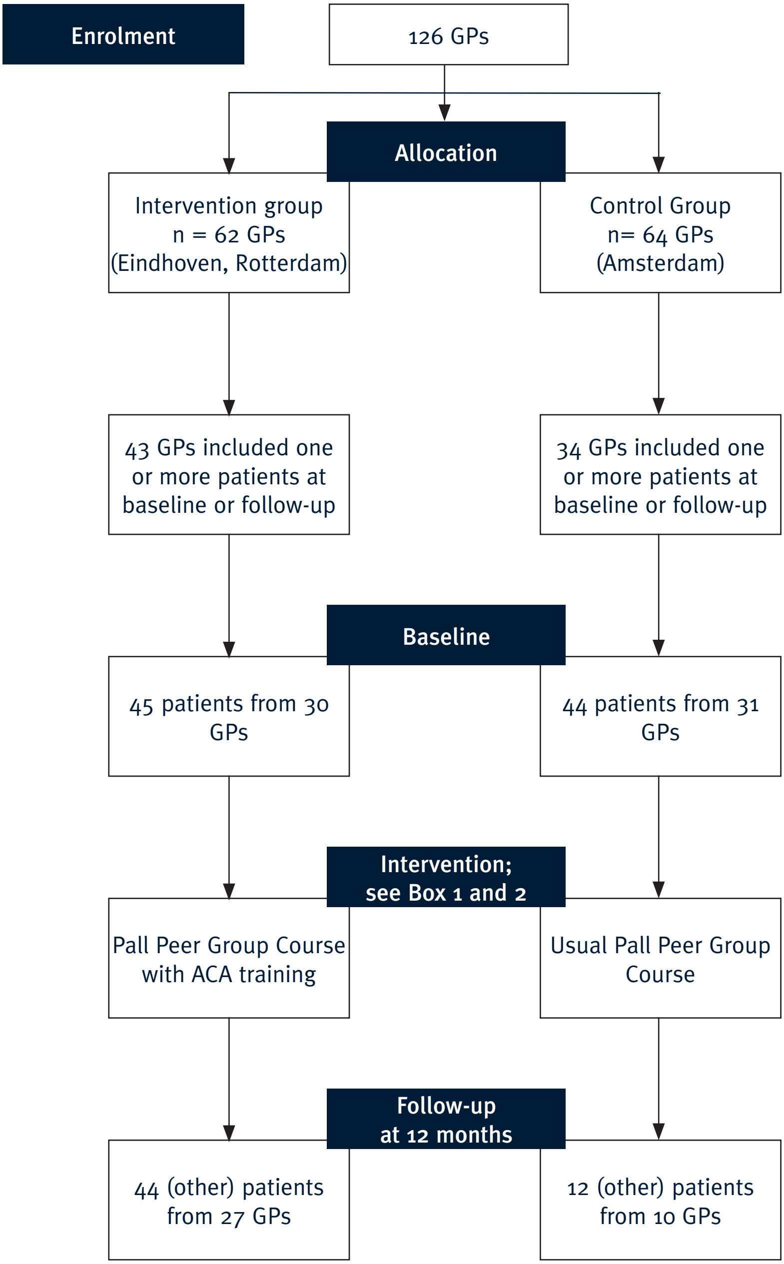

Table 1. Socio-demographic and professional characteristics of participating general practitioners (GPs)

Characteristics of participating GPs	**Intervention group; N=43 GPs**	**Control group; N=34 GPs**	**P-value***
Gender female, n (%)	21 (50%)	23 (68%)	0.10
Median age (range)	50 (35-60)	48 (33-61)	0.15
Median years of experience as a GP (range)	18 (1-32)	15 (2-31)	0.40
Type of practice			
Group practice, n (%)	16 (37%)	11 (32%)	
Duo practice, n (%)	15 (35%)	11 (32%)	
Solo practice, n (%)	12 (28%)	12 (35%)	
Practice location			**0.020**
Urban, n (%)	16 (37%)	22 **(64%)**	
Semi-rural, n (%)	13 (30%)	9 (27%)	
Rural, n (%)	14 **(33%)**	3 (9%)	
Percentage of FTE working	**0.90** (0.50-1.00)	**0.73** (0.50-1.00)	**0.050**
GP is vocational trainer, n (%)	14 (33%)	10 (29%)	0.77
Courses in palliative care attended by GP during the previous two years, n (%)	25 (60%)	22 (65%)	0.44

FTE: full-time equivalent.
* p-value using chi-square test or Mann-Whitney tests as appropriate.

Table 2. Socio-demographic and medical characteristics of 145 palliative care patients who were included by 43 intervention and 34 control general practitioners (GPs); the 56 patients at follow-up were other patients than the 89 patients at baseline

Characteristics of palliative care patients	Intervention group; n=45; Baseline	Control group; n=45; Baseline	Intervention group; n=44; Follow-up	Control group; n=12; Follow-up
Gender , n (%)				
- Female	23 (51%)	21 (48%)	23 (52%)	6 (50%)
Age (years), median (range)	67 (36-91)	70 (31-88)	65 (30-88)	67 (48-96)
Living situation, n (%)				
Alone	10 (22%)	10 (23%)	9 (20%)	5 (42%)
With partner, without children	30 (67%)	24 (55%)	22 (50%)	6 (50%)
With partner and child(ren)	3 (7%)	5 (11%)	10 (23%)	1 (8%)
With child(ren) (without partner)	1 (2%)	3 (7%)	-	-
Other	1 (2%)	2 (4%)	3 (7%)	-
Highest completed education, n (%)				
Primary school	13 (30%)	10(23%)	14 (34%)	3 (25%)
Secondary training	27 (61%)	21 (48%)	18 (44%)	6 (50%)
Post-secondary training	3 (7%)	11 (25%)	5 (12%)	3 (25%)
Other	1 (2%)	2 (4%)	4 (10%)	-
Diagnosis, n (%)				
Lung cancer	11 (24%)	10 (23%)	18 (41%)	4 (33%)
Gastrointestinal cancer	10 (22%)	14 (32%)	13 (29%)	4 (33%)
Gynaecological and urologic cancer	8 (18%)	4 (9%)	7 (16%)	1 (8%)
Breast cancer	8 (18%)	4 (9%)	2 (5%)	2 (17%)
Neurological cancer/disease	4 (9%)	3 (7%)	-	-
Cancer, other types	4 (9%)	9 (20%)	4 (9%)	1 (8%)
GP's expectations for the course of their patient's disease, n (%)				
Condition will remain stable at first	7 (16%)	3 (7%)	7 (16%)	1 (8%)
Condition will deteriorate gradually	10 (22%)	16 (36%)	9 (20%)	4 (34%)
Condition will deteriorate rapidly	28 (62%)	25 (57%)	28 (64%)	7 (58%)

Discussion

In this controlled trial, we found no significant differences over time between the intervention and control GPs in the patients' mean ratings on any of the five outcome measures. In general, patients greatly appreciated the palliative care provided by their GPs. They gave near maximum ratings for 'comfortable', 'at peace', 'acceptance', 'valuable last period of life', and 'respect' (RPS), for satisfaction with the communication with their GPs (PSQ-III), and for most items of the ACA scale. The lower scores we found in both groups for one RPS and a few ACA items suggest that GPs might take more initiative to discuss the following end-of-life issues: unfinished business, prognosis and possible complications, the actual process of dying, including the preferred place of death, and end-of-life decisions.

The study had a number of strengths and limitations worth noting. To our knowledge, this is the first study on effectiveness of a palliative care communication training programme for GPs using outcomes at patient-level.[21] Both the educational approach and content of the intervention are evidence-based. Patient-reported outcomes were quantitatively measured with three validated instruments (POS, QLQ-C15-PAL and PSQ-III) and two study-specific instruments (RPS and ACA scale). This study focused on GPs' performance, which is the (patient-reported) fourth level of Miller's pyramid model ('knows', 'knows how', 'shows' and 'does').[35]

Although we assigned participating GPs to either the intervention or the control condition without randomization, we carefully compared both groups and included significant between-group differences on background characteristics as covariates in subsequent analyses. However, the necessity of using different patients at baseline and follow-up complicated the design. The relatively modest sample size, particularly at follow-up, limited the power of the study. The recruiting of only 12 patients in the control group at follow-up compared to 44 in the intervention group may reflect a lower motivation to recruit patients by control GPs than by intervention GPs. Although only about half of the GPs included patients in the study, the response rate among patients was very high. Although the GPs were not blinded to the training condition, their patients were.

In our previous qualitative study,[8] we assumed that GP-patient communication in the palliative care setting was suboptimal. Yet, in the current trial, patients reported high levels of satisfaction with the communication and care provided by their GP. This discrepancy might reflect some level of selection bias (i.e. that GPs referred only certain patients to the study), some degree of reluctance on the part of patients to be critical of the care they received, limitations of the questionnaires used or a combination of these factors.

In a systematic review on communication training programmes for health care professionals (other than GPs) which focused on life-limiting conditions, a number of important features of a successful communication model were identified, including fo-

Table 3. Sum scores and effect of ACA communication training programme for the Palliative Care Outcome Scale (POS), the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative (QLQ-C15-PAL), the Rest & Peace Scale (RPS), the Patient Satisfaction Questionnaire–III (PSQ-III) and the ACA scale, based on ratings by 145 palliative care patients of intervention GPs (*n* = 43) and control GPs (*n* = 34), at baseline and at follow-up (the 56 patients at follow-up were other patients than the 89 patients at baseline)

Scale (range)	**Items n**	**Cron-bach's alpha**	**Baseline Intervention** n=45 patients	**Baseline Control** n=44 patients	**Follow-up Intervention** n=44 patients	**Follow-up Control** n=12 patients	**Effect (95% CI)**[a]	**P-value**
POS[b] (0-40)	10	0.66	10.14 (5.14)	12.14 (5.33)	9.34 (6.88)	10.25 (6.58)	-0.72 (-3.85; 5.30)	0.75
(see Appendix 1)								
EORTC QLQ-C15-PAL[c]**:**								
(see Appendix 2)								
-Overall QOL (0-100)	1	-	56.03 (22.47)	50.78 (23.25)	62.67 (27.50)	54.13 (22.61)	4.62 (-13.86; 23.10)	0.62
-Physical Functioning (0-100)	3	0.86	32.73 (31.03)	45.11 (32.12)	49.38 (30.67)	37.57 (29.40)	21.69 (-2.03; 45.40)	0.07
-Emotional Functioning (0-100)	2	0.78	69.82 (24.69)	62.80 (29.05)	77.09 (25.35)	56.26 (33.16)	16.06 (-5.15; 37.26)	0.14
Rest and Peace Scale[c] (6-30)	6	0.79	26.56 (3.88)	25.71 (4.72)	26.40 (3.82)	25.67 (3.55)	0.02 (-3.24; 3.28)	0.99
(see Appendix 3)								
-								

Continued

Table 3. Continued

Scale (range)	Items n	Cron-bach's alpha	Baseline Intervention n=45 patients	Baseline Control n=44 patients	Follow-up Intervention n=44 patients	Follow-up Control n=12 patients	Effect (95% CI)[a]	P-value
PSQ-III[c]:								
(see Appendix 4)								
-Interpersonal manner (7-35)	7	0.72	32.64 (3.89)	32.77 (4.57)	33.37 (2.65)	33.55 (1.81)	0.40 (-2.44; 3.25)	0.78
-Communication (5-25)	5	0.42	22.82 (2.71)	23.59 (2.29)	23.16 (2.19)	23.09 (1.64)	1.06 (-0.76; 2.88)	0.25
-Time spent with GP (2-10)	2	0.38	9.39 (1.51)	9.65 (1.00)	9.52 (1.11)	9.58 (1.16)	0.22 (-0.72; 1.16)	0.64
ACA scale[c]:								
(see Appendix 5)								
- Availability (5-25)	5	0.56	24.31 (1.33)	23.71 (2.47)	24.40 (1.29)	24.42 (1.38)	-0.58 (-1.93; 0.77)	0.40
- Current Issues (4-20)	4	0.43	17.07 (1.74)	16.71 (2.63)	17.00 (1.86)	16.58 (1.78)	0.08 (-1.55; 1.71)	0.92
- Anticipation (5-25)	5	0.76	21.07 (4.25)	21.00 (4.54)	21.34 (3.56)	19.75 (5.10)	1.76 (-1.56; 5.08)	0.30

ACA: Availability, Current issues, Anticipation; GP: general practitioner; CI: confidence interval; QOL: quality of life.
a Effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (urban, semi-rural or rural practice location and percentage of full-time equivalent (FTE) working) and for possible influences of the GP's sex and age.
b Higher scores indicate worse care outcomes.
c Higher scores indicate more favourable outcomes.

cused participant-led training and using effective communication to improve patient understanding and flexible patient-led 'Advance Care Planning'.[36] This is in line with the educational methods and content of the ACA training programme.

In a German study of the impact of a basic training course in palliative care for GPs, no significant training effect was found on the patient-reported outcomes (the POS and the QLQ-C15-PAL)[37] Similarly, although a Cochrane review on the effectiveness of communication skills training for medical specialists and oncology nurses in cancer care demonstrated moderate effects on health care professional communication behaviour, few effects were observed on patient-reported outcomes.[38]

We found no effect of the ACA training programme at either the GP or the patient level.[24] Although our findings indicate that the intervention is ineffective, there are other possible explanations that should be taken into consideration when interpreting the results. First, in comparison to medical specialists and oncology nurses, the GPs in our trial may have been so well trained in doctor-patient communication as part of their pre- and postgraduate education, that additional training in specific elements of communication in palliative care may not have added much to their communication skills. Moreover, by using PCPTCs for our study, we realized that we would be recruiting GPs with specific interest in palliative care. While this might have had implications for the generalizability of the results, it increased the feasibility of the project substantially. This may explain, at least in part, the high level of patient satisfaction with communication and palliative care provided by their GPs at baseline, which allowed little room for improvement on these outcomes over time.

Second, a study comparing the prevalence of GP-patient discussion of end-of-life topics across four countries found that Dutch GPs discussed more topics than GPs in Italy, Spain or Belgium.[39] This also may explain the high scores at baseline in our Dutch study.

Implications for clinical practice and future research

The descriptive results from our study suggest that although palliative care patients were generally quite satisfied with the care received from their GPs, GPs should take the initiative to discuss certain end-of-life issues, including unfinished business, prognosis and possible complications, the actual process of dying, and end-of-life decisions more often and/or more thoroughly. Future training programmes of this nature should give particular attention to these issues.

Future research on GP communication and care skills training programmes in the palliative care setting should include a broader sample of GPs, focusing on those professionals who have less experience (and perhaps less a priori interest) in palliative care issues. Although this may present real challenges in recruitment to such a programme, it may enhance the added value of the training experience considerably. Given international differences that have been reported in the literature on GPs palliative care-related communication behaviour, future efforts should be devoted to developing appropriate and effective training programmes in other countries as well. Hopefully, the lessons learned from our training programme can contribute to such efforts in the future.

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References

1 **Audit Commission:** What seems to be the matter? Communication between hospitals and patients. *(Report No 12). London: NHS*; 1993.

2 **Ford S, Fallowfield L, Lewis S.** Doctor-patient interactions in oncology. *Soc Sci Med* 1996; 42: 1511-1519.

3 **Lerman C, Daly M, Walsh WP, et al.** Communication between patients with breast cancer and health care providers. Determinants and implications. *Cancer* 1993; 72: 2612-2620.

4 **Razavi D, Delvaux N, Marchal S, et al.** Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators. *Psychooncology* 2000; 9: 293-302.

5 **Stewart MA.** Effective physician-patient communication and health outcomes: a review. *Can Med Assoc J* 1995; 152: 1423-1433.

6 **Turnberg L.** Improving communication between doctors and patients. *Improving Communication between Doctors and Patients: a report of a working party. London: Royal College of Physicians*; 1997.

7 **Korsch B, Putman SM, Frankel R, et al.** The medical interview: clinical care, education and research. Frontiers of Primary Care. *New York, NY, USA: Springer-Verlag*; 1995: 475-481.

8 **Slort W, Blankenstein AH, Deliens L, et al.** Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011; 61: 167-672.

9 **Baile WF, Lenzi R, Kudelka AP, et al.** Improving physician-patient communication in cancer care: outcome of a workshop for oncologists. *J Cancer Educ* 1997; 12: 166-173.

10 **Baile WF, Kudelka AP, Beale EA, et al.** Communication skills training in oncology. Description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer* 1999; 86: 887-897.

11 **Razavi D, Delvaux N, Marchal S, et al.** The effects of a 24-h psychological training program on attitudes, communication skills and occupational stress in oncology: a randomised study. *Eur J Cancer* 1993; 29A: 1858-1863.

12 **Razavi D, Delvaux N, Marchal S, et al.** Does training increase the use of more emotionally laden words by nurses when talking with cancer patients? A randomized study. *Br J Cancer* 2002; 87: 1-7.

13 **Razavi D, Merckaert I, Marchal S, et al.** How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of post training consolidation workshops. *J Clin Oncol* 2003; 21: 3141-3149.

14 **Fellowes D, Wilkinson S, Moore P.** Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev 2004; Art. No.:* CD003751. DOI: 10.1002/14651858.CD003751.pub2.

15 **Finset A, Ekeberg O, Eide H, et al.** Long term benefits of communication skills training for cancer doctors. *Psychooncology* 2003; 12: 686-693.

16 **Gysels M, Richardson A and Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Support Care Cancer* 2004; 12: 692-700.

17 **Gysels M, Richardson A and Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer 2005; 13: 356-366.*

18 **Wilkinson SM, Leliopoulou C, Gambles M and Roberts A.** Can intensive three-day programmes improve nurses' communication skills in cancer care? *Psychooncology* 2003; 12: 747-759.

19 **Fallowfield L, Jenkins V, Farewell V, et al.** Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled study. *Lancet* 2002; 359: 650-656.

20 **Shilling V, Jenkins V, Fallowfield L.** Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? *Psychooncology* 2003; 12: 599-611.

21 **Slort W, Schweitzer BPM, Blankenstein AH, et al.** Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliat Med* 2011; 25: 613-629.

22 **Alvarez MP, Agra Y.** Systematic review of educational interventions in palliative care for primary care physicians. *Palliat Med* 2006; 20: 673-683.

23 **Slort W, Blankenstein AH, Wanrooij BS, et al.** The ACA training programme to improve communication between general practitioners and their palliative care patients: development and applicability. *BMC Palliative Care* 2012; 11: 9. Doi:10.1186/1472-684X-11-9.

24 **Slort W, Blankenstein AH, Schweitzer BPM, et al.** Effectiveness of the ACA (Availability, Current issues and Anticipation) training programme on GP-patient communication in palliative care; a controlled trial. *BMC Fam Pract* 2013; 14: 93. Doi: 10.1186/10.1186/1471-2296-14-93.

25 **Kuin A, Wanrooij BS, Deliens L, et al.** Does the Palliative Care Peer Group Training project for GPs benefit the patients? 2006, unpublished paper.

26 **Hearn J, Higginson IJ.** Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Qual Health Care* 1999, 8: 219-227.

27 **Higginson IJ, Donaldson N.** Relationship between three palliative care outcome scales. *Health and Quality of Life Outcomes* 2004, 2: 68-75.

28 **Brandt HE, Deliens L, van der Steen JT, et al.** The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale. *Palliat Med* 2005;19: 334-342.

29 **Aaronson NK, Ahmedzai S, Bergman B, et al.** The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993; 85: 365-376.

30 **Fayers PM, Aaronson NK, Bjordal K, et al, on behalf of the EORTC Quality of Life Group.** The EORTC QLQ-C30 Scoring Manual (3rd Edition). *Brussels: European Organisation for Research and Treatment of Cancer;* 2001.

31 **Groenvold M, Petersen MA, Aaronson NK, et al.** The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. *Eur J Cancer* 2006; 42: 55-64.

32 **Ware JE, Snyder MK, Wright WR, et al.** Defining and measuring patient satisfaction with medical care. *Evaluation and Program Planning* 1983, 6: 247-263.

33 **Hagedoorn M, Uijl SG, Van Sonderen E, et al.** Structure and reliability of Ware's Patient Satisfaction Questionnaire III: patients' satisfaction with oncological care in the Netherlands. *Med Care* 2003, 41: 254-263.

34 **Sijtsma K, Van der Ark LA.** Investigation and treatment of missing item scores in test and questionnaire data. *Multivariate Behavioral Research* 2003; 38: 505-528.

35 **Miller GE.** The assessment of clinical skills/competence/performance. *Acad Med* 1990; 65: S63-S67.

36 **Barnes S, Gardiner C, Gott M, et al.** Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage* 2012; 44: 866-879.

37 **Hermann K, Engeser P, Szecsenyi J, et al.** Palliative patients cared for at home by PAMINO-trained and other GPs - health-related quality of life as measured by QLQ-C15-PAL and POS. *BMC Palliative Care* 2012; 11: 13. Doi:10.1186/1472-684X-11-13.

38 **Moore PM, Rivera Mercado S, Grez Artigues M, et al.** Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database of Systematic Reviews* 2013, Issue 3. Art. No.: *CD003751. DOI: 10.1002/14651858.CD003751.pub3.*

39 **Evans N, Costantini M, Pasman HR, et al. End-of-Life communication:** a retrospective survey of representative general practitioner networks in four countries. *J Pain Symptom Manage* 2014; 47: 604-619.

Appendix 1. Results of the Palliative Care Outcome Scale (POS) sum and item scores based on ratings by 145 palliative care patients of intervention GPs (n=43) and control GPs (n=34), at baseline and at follow-up; the 56 patients at follow-up were other patients than the 89 patients at baseline

	Baseline		Follow-up		Effect (95% confidence interval) [2]	P-value
	Intervention n=45 patients	Control n=44 patients	Intervention n=44 patients	Control n=12 patients		
POS sum score (higher scores indicate worse care outcomes) [1]	10.14 (5.14)	12.14 (5.33)	9.34 (6.88)	10.25 (6.58)	-0.72 (-3.85; 5.30)	0.75
Items [1]						
Pain	1.00 (1.06)	1.55 (1.06)	1.13 (1.26)	1.58 (1.44)	-0.11 (-0.99; 0.78)	0.81
Symptoms	1.20 (1.06)	1.16 (1.13)	0.75 (1.08)	1.00 (1.20)	-0.33 (-1.19; 0.52)	0.44
Anxiety	1.16 (1.24)	1.64 (1.34)	1.02 (1.20)	1.58 (1.38)	-0.14 (-.1.13; 0.86)	0.88
Family anxiety	2.26 (1.03)	2.54 (1.25)	1.83 (1.41)	2.25 (1.21)	-0.32 (-1.30; 0.65)	0.51
Information	1.11 (1.64)	1.27 (1.82)	1.27 (1.79)	0.89 (1.76)	0.70 (-0.83; 2.23)	0.37
Share feelings	0.59 (1.11)	0.50 (0.89)	0.45 (1.19)	0.67 (1.23)	-0.23 (-1.06; 0.60)	0.59
Life worthwhile	0.85 (0.94)	0.88 (0.98)	0.83 (1.21)	0.83 (1.03)	-0.04 (-0.86; 0.79)	0.93
Self-worth	1.35 (1.05)	1.29 (1.07)	0.81 (1.06)	1.00 (0.95)	0.42 (-1.24; 0.39)	0.30
Wasted time	0.36 (0.90)	0.68 (1.31)	0.40 (1.13)	0.17 (0.58)	0.53 (-0.32; 1.38)	0.22
Practical matters	0.51 (1.19)	0.68 (1.31)	0.60 (1.13)	0.60 (1.35)	0.17 (-0.83; 1.18)	0.73

[1] observed mean (and standard deviation) of the POS (sum and item scores); eight questions/items have a 5-point Likert-scale response from 0 (‘not at all’) to 4 (‘overwhelming’), and two questions have 3-point Likert-scale responses (0-2-4); higher scores indicate more severe problems; POS sum score ranges from 0 to 40 (=10x0 to 10x4); for calculating mean, standard deviation, and intervention effect for the POS sum score the incomplete dataset (because of missing values) was completed using (single) response function imputation.

[2] effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (urban, semi-rural or rural practice location and working percentage of FTE) and for possible influences of the GP’s sex and age.

Appendix 2. Results of the EORTC Quality of Life Questionnaire Core 15 Palliative (QLQ-C15-PAL) scores based on ratings by 145 palliative care patients of intervention GPs (n=43) and control GPs (n=34), at baseline and at follow-up; the 56 patients at follow-up were other patients than the 89 patients at baseline

EORTC QLQ-C15-PAL [1]	Baseline		Follow-up		Effect (95% confidence interval) [2]	P-value
	Intervention n=45 patients	Control n=44 patients	Intervention n=44 patients	Control n=12 patients		
Overall quality of life (a higher score indicates a higher quality of life)	56.03 (22.47)	50.78 (23.25)	62.67 (27.50)	54.13 (22.61)	4.62 (-13.86; 23.10)	0.62
Function scales (a higher score indicates a higher/healthier level of functioning)						
Physical functioning	32.73 (31.03)	45.11 (32.12)	49.38 (30.67)	37.57 (29.40)	21.69 (-2.03; 45.40)	0.07
Emotional functioning	69.82 (24.69)	62.80 (29.05)	77.09 (25.35)	56.26 (33.16)	16.06 (-5.15; 37.26)	0.14
Symptom scales (a higher score indicates a higher level of symptomatology/problems)						
Dyspnoea	22.97 (28.27)	28.69 (32.79)	24.63 (34.00)	39.41 (41.00)	-9.99 (-36.20; 16.23)	0.45
Pain	33.58 (32.20)	47.03 (34.45)	38.64 (33.56)	46.29 (38.66)	5.03 (-21.68; 31.74)	0.71
Insomnia	20.38 (28.84)	25.20 (32.40)	21.22 (29.50)	43.94 (34.37)	-19.60 (-44.06; 4.86)	0.11
Fatigue	67.04 (26.95)	65.38 (29.10)	57.07 (34.01)	75.01 (25.46)	-19.45 (-42.39; 3.50)	0.10
Appetite loss	41.86 (34.01)	37.70 (38.26)	37.89 (42.58)	50.00 (44.72)	-13.86 (-45.19; 17.46)	0.38
Nausea/Vomiting	25.56 (34.74)	19.78 (27.76)	18.94 (29.11)	15.29 (18.06)	-1.45 (-24.79; 21.90)	0.90

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[1] observed mean (and standard deviation) of the QLQ-C15-PAL scale and symptom scores; the QLQ-C15-PAL consists of 15 questions organized into two function scales (physical and emotional), seven symptom scales (e.g. fatigue, nausea/vomiting and pain), and an overall quality of life scale; scores are linearly converted to 0-100 scales, with higher values representing better functioning and quality of life, and greater symptom burden.

[2] effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (urban, semi-rural or rural practice location and working percentage of FTE) and for possible influences of the GP's sex and age.

Appendix 3. Results of the Rest & Peace Scale (RPS) sum and item scores based on ratings by 145 palliative care patients of intervention GPs (n=43) and control GPs (n=34), at baseline and at follow-up; the 56 patients at follow-up were other patients than the 89 patients at baseline

	Baseline		**Follow-up**		**Effect (95% confidence interval)** [2]	**P-value**
	Intervention n=45 patients	**Control n=44 patients**	**Intervention n=44 patients**	**Control**		
Rest&Peace sum score (higher scores indicate more favourable patient outcomes) [1]	26.56 (3.88)	25.71 (4.72)	26.40 (3.82)	25.67 (3.55)	0.02 (-3.24; 3.28)	0.99
Items [1] My GP helped me to:						
Feel comfortable	4.51 (0.73)	4.10 (1.21)	4.45 (0.74)	4.17 (0.94)	-0.15 (-0.88; 0.58)	0.68
Feel at peace	4.69 (0.70)	4.62 (0.99)	4.70 (0.64)	4.50 (0.80)	0.11 (-0.50; 0.73)	0.71
Accept my advanced illness	4.37 (1.02)	4.27 (1.01)	4.37 (0.89)	4.08 (1.08)	0.22 (-0.58; 1.01)	0.59
Value the last period of my life	4.29 (0.97)	4.00 (1.18)	4.24 (1.02)	4.58 (0.51)	-0.55 (-1.37; 0.28)	0.19
Experience that GP respects me	4.82 (0.58)	4.89 (0.62)	4.93 (0.34)	5.00 (0.00)	0.00 (-0.41; 0.42)	0.98
Find out my preferred place to die	3.53 (1.58)	3.59 (1.46)	3.70 (1.59)	3.25 (1.58)	0.64 (-0.79; 2.07)	0.38

[1] observed mean (and standard deviation) of the Rest & Peace Scale sum and item scores; all 6 questions have 5-point Likert-scale responses from 1 (‘strongly agree’) to 5 (‘strongly disagree’); these scores are transposed so that higher scores always indicate a more favourable palliative care outcome; Rest & Peace sum score ranges from 6 to 30 (=6x1 to 6x5); for calculating mean, standard deviation, and intervention effect for the Rest & Peace sum score the incomplete dataset (because of missing values) was completed using (single) response function imputation.

[2] effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (urban, semi-rural or rural practice location and working percentage of FTE) and for possible influences of the GP’s sex and age.

Appendix 4. Results of the Patient Satisfaction Questionnaire-III (PSQ-III) sum and item scores based on ratings by 145 palliative care patients of intervention GPs (n=43) and control GPs (n=34), at baseline and at follow-up; the 56 patients at follow-up were other patients than the 89 patients at baseline

PSQ-III items [1]	Baseline		Follow-up		Effect (95% confidence interval) [2]	P-value
	Intervention n=45 patients	Control n=44 patients	Intervention n=44 patients	Control n=12 patients		
Interpersonal manner, sum score (7-35) (higher scores indicate greater patient satisfaction)	32.64 (3.89)	32.77 (4.57)	33.37 (2.65)	33.55 (1.81)	0.40 (-2.44; 3.25)	0.78
Too business-like, impersonal	4.82 (0.61)	4.74 (0.90)	4.81 (0.86)	4.91 (0.30)	-0.23 (-0.83; 0.37)	0.45
Do best to keep me from worrying	4.69 (0.79)	4.41 (1.12)	4.74 (0.77)	4.82 (0.40)	-0.29 (-1.00; 0.41)	0.42
Should pay attention to privacy	4.28 (1.28)	4.53 (1.08)	4.53 (1.04)	4.60 (0.70)	0.35 (-0.57; 1.28)	0.45
Genuine interest in me	4.89 (0.32)	4.77 (0.86)	4.83 (0.66)	4.91 (0.30)	-0.16 (-0.66; 0.35)	0.54
Make me feel foolish	4.64 (0.98)	4.74 (0.95)	4.79 (0.86)	4.60 (1.26)	0.24 (-0.52; 1.01)	0.53
Very friendly and courteous	4.89 (0.61)	4.77 (0.89)	5.00 (0.00)	4.91 (0.30)	0.01 (-0.47; 0.49)	0.95
Should give me more respect	4.49 (1.27)	4.86 (0.56)	4.72 (0.96)	4.73 (0.65)	0.43 (-0.32; 1.19)	0.26
Communication , sum score (5-25) (higher scores indicate greater patient satisfaction)	22.82 (2.71)	23.59 (2.29)	23.16 (2.19)	23.09 (1.64)	1.06 (-0.76; 2.88)	0.25
Explain the reason for tests	4.07 (1.19)	4.37 (1.15)	4.29 (0.98)	3.60 (1.35)	1.04 (0.07; 2.01)	0.04
Use terms without explaining	4.20 (1.27)	4.53 (1.24)	4.53 (1.08)	4.90 (.32)	0.16 (-0.75; 1.06)	0.73
Say everything that's important	4.96 (0.21)	4.98 (0.15)	4.98 (0.15)	5.00 (0.00)	-0.01 (-0.14; 0.11)	0.83
Ignore what I tell them	4.60 (1.03)	4.88 (0.50)	4.47 (1.08)	4.92 (0.29)	-0.22 (-0.90; 0.46)	0.52
Listen carefully	4.96 (0.30)	4.89 (0.62)	4.88 (0.62)	5.00 (0.00)	-0.19 (-0.60; 0.22)	0.36

Continued

Appendix 4. Continued

Time spent with GP, sum score (2-10) (higher scores indicating greater patient satisfaction)	9.39 (1.51)	9.65 (1.00)	9.52 (1.11)	9.58 (1.16)	0.22 (-0.72; 1.16)	0.64
Spend plenty of time	4.89 (0.49)	4.95 (0.21)	4.98 (0.15)	5.00 (0.00)	0.07 (-0.17; 0.31)	0.56
Hurry too much when treat me	4.50 (1.13)	4.70 (0.89)	4.56 (1.10)	4.58 (1.16)	0.16 (-0.65; 0.97)	0.69

[1] observed mean (and standard deviation) of the PSQ-III ratings; we used the subscales interpersonal manner (7 items), communication (5 items) and time spent with GP (2 items); all questions have 5-point scale responses from 1 (‘strongly agree’) to 5 (‘strongly disagree’); scores were transposed so that higher scores always indicate greater patient satisfaction; for calculating mean, standard deviation, and intervention effect for the three sum scores the incomplete dataset (because of missing values) was completed using (single) response function imputation.

[2] effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (urban, semi-rural or rural practice location and working percentage of FTE) and for possible influences of the GP’s sex and age.

Appendix 5. Results of the ACA scale sum and item scores based on ratings by 145 palliative care patients of intervention GPs (n=43) and control GPs (n=34), at baseline and at follow-up; the 56 patients at follow-up were other patients than the 89 patients at baseline

ACA issues [1]		**Baseline**		**Follow-up**		**Effect (95% confidence interval)** [2]	**P-value**
in Box 2	**in Questionnaire**	**Intervention n=45 patients**	**Control n=44 patients**	**Intervention n=44 patients**	**Control n=12 patients**		
Availability items, sum score (5-25) (higher scores indicate that GP was more available)		24.31 (1.33)	23.71 (2.47)	24.40 (1.29)		-0.58 (-1.93; 0.77)	0.40
1	GP took time	4.89 (0.49)	4.95 (0.21)	4.98 (0.15)	5.00 (0.00)	0.07 (-0.16; 0.31)	0.54
2	GP allowed any subject to be discussed	4.96 (0.21)	4.98 (1.51)	4.98 (0.15)	5.00 (0.00)	-0.01 (-0.14; 0.11)	0.83
3	GP listened actively	4.93 (0.33)	4.86 (0.63)	4.95 (0.21)	5.00 (0.00)	-0.12 (-0.45; 0.20)	0.45
4	- (facilitating behaviour GP)	-	-	-	-	-	-
5	GP and I shared decision making with regard to starting treatments or not	4.71 (0.66)	4.40 (1.11)	4.79 (0.60)	4.83 (0.58)	-0.36 (-0.99; 0.27)	0.26
6	GP informed me about accessibility	4.82 (0.61)	4.45 (1.07)	4.61 (1.02)	4.58 (1.00)	-0.28 (-0.97; 0.42)	0.43
Current issues, sum score (4-20) (higher scores indicate that GP discussed more current issues)		17.07 (1.74)	16.71 (2.63)	17.00 (1.86)	16,58 (1.78)	0.08 (-1.55; 1.71)	0.92
1	- (diagnosis)	-	-	-	-	-	-
2	- (prognosis)	-	-	-	-	-	-
3, 4 and 5	GP discussed my questions, worries, and fears	4.82 (0.61)	4.91 (0.60)	4.93 (0.25)	4.92 (0.29)	0.10 (-0.29; 0.49)	0.62
6	GP discussed my wishes for present and coming days	4.78 (0.60)	4.57 (.73)	4.77 (0.57)	4.83 (0.39)	-0.31 (-0.79; 0.18)	0.21

Continued

Appendix 5. Continued

7	GP discussed my unfinished business	2.62 (1.23)	2.71 (1.23)	2.49 (1.44)	2.00 (1.35)	0.62 (-0.41; 1.65)	0.24
8	GP discussed treatment options clearly	4.84 (0.48)	4.45 (1.13)	4.81 (0.50)	4.83 (0.58)	-0.39 (-0.98; 0.20)	0.19
Anticipated issues, sum score (5-25) (higher scores indicate that GP discussed more anticipated issues)		21.07 (4.25)	21.00 (4.54)	21.34 (3.56)	19.75 (5.10)	1.76 (-1.56; 5.08)	0.30
1	GP offered follow-up appointments	4.56 (0.94)	4.60 (0.96)	4.58 (0.82)	4.08 (1.38)	0.57 (-0.18; 1.31)	0.13
2	GP discussed my prognosis and possible complications	4.02 (1.30)	3.98 (1.26)	4.16 (1.11)	3.58 (1.50)	0.63 (-0.34; 1.61)	0.20
3	GP discussed my wishes for the coming months	4.67 (0.78)	4.60 (0.73)	4.60 (0.82)	4.67 (0.65)	-0.16 (-0.77; 0.44)	0.60
4	GP informed me about the actual process of dying	4.00 (1.33)	3.83 (1.29)	4.05 (1.17)	3.75 (1.48)	0.25 (-0.75; 1.26)	0.62
5	GP discussed euthanasia	3.86 (1.60)	3.88 (1.48)	3.74 (1.51)	3.67 (1.56)	0.12 (-1.08; 1.32)	0.85

[1] observed mean (and standard deviation) of the ratings for the ACA scale; all questions have 5-point Likert-scale responses from 1 (‘strongly agree’) to 5 (‘strongly disagree’) with higher scores indicating that the GP was more available and discussed more issues; for calculating mean, standard deviation, and intervention effect for the sum scores of the three subscales the incomplete dataset (because of missing values) was completed using (single) response function imputation.

[2] effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (urban, semi-rural or rural practice location and working percentage of FTE) and for possible influences of the GP’s sex and age.

CHAPTER 7

Effectiveness of the ‘availability, current issues and anticipation’ (ACA) training programme for general practice trainees on communication with palliative care patients: A controlled trial

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Abstract

Objective

This study aimed to evaluate the effectiveness of a new palliative care ‘availability, current issues and anticipation’ (ACA) training programme to improve communication skills of general practice trainees (GPTs).

Methods

In a controlled trial among third-year GPTs, we videotaped one 20-min consultation between each GPT and a simulated palliative care patient at baseline and at six months follow-up. We measured the number of issues discussed and the quality of communication skills and analysed between-group differences using linear mixed models and logistic regression.

Results

Fifty-four GPTs were assigned to the intervention and 64 to the control group. We found no effect of the programme on the number of issues discussed or on the quality of GPT communicative behaviour. GPTs infrequently addressed ‘spiritual/existential issues’ and ‘unfinished business’. In a selection of the consultations, simulated patients brought up more issues than the GPTs did.

Conclusion

The ACA training programme was not effective in the way it was carried out and evaluated in this trial.

Practice implications

The ACA programme should focus on the issues that scored low in this trial. Future research on GPT-patient communication in palliative care should consider using real patients in a series of consultations to evaluate effectiveness.

The trial was registered in The Netherlands National Trial Register: NTR1271.

Introduction

Because general practitioners (GPs) play a central role in providing palliative care in many countries, their vocational general practice training should equip them to provide high quality palliative care. All eight vocational GP training institutes in the Netherlands provide educational palliative care programmes, but the content differs considerably between institutes.[1] Some institutes focus on medical aspects, others chiefly on communication. A survey among UK GP registrars showed that only half had received training in palliative care communication skills.[2]

Effective doctor-patient communication is widely accepted as an essential requirement for providing high-quality care.[3] Furthermore, communicating with palliative care patients is considered more difficult than communicating with patients with less serious conditions.[4] Several studies have demonstrated effectiveness of basic communication skills training programmes in improving oncologists' or oncology nurses' communication with oncology patients, including those receiving palliative care.[5,6] Although GPs are usually well trained in doctor-patient communication, this does not always cover training in communication with palliative care patients.[2] We did not identify any studies reporting effects of training general practice trainees (GPTs) in communicating with palliative care patients.[7]

To fill this gap, we designed a training programme for GPTs in communication with palliative care patients based on recent studies.[5,7-9] Our review and qualitative study yielded 19 relevant items, which we divided into three categories: *availability* of the GPT to the patient, *current issues* that the GPT should discuss with the patient and *anticipation* of various scenarios by the GPT (ACA).[7,9] This ACA training programme appeared to be applicable to both GPTs and GPs (see Box 1 and Box 2).[10] This paper reports on a controlled clinical trial which evaluated the effectiveness of the ACA training programme on GPT-patient communication in palliative care. Although health care professional-patient communication aims to impact health outcomes,[11,12] we deemed a trial using outcomes reported by real palliative care patients of GPTs unfeasible. Moreover, such patient-reported outcomes in this study would be strongly affected by the performance of the patients' own GP (being the GP vocational trainer of the GPT). Therefore, we decided only to measure outcomes at the level of GPT behaviour, using trained actors to simulate patients with advanced stage cancer. We hypothesized that GPTs exposed to the training programme would discuss more current and anticipated issues, become more skilled in their communication and gain more knowledge about medical aspects of palliative care compared with control GPTs.

Methods

Setting and participants

This controlled trial was conducted during the first six months of the third year of the GP vocational training programme at two Dutch GP vocational training institutes. In their final year GPTs work for 3-4 days per week in the practice of their GP trainer and one day per week they attend training programmes at the institute. Each training group consists of approximately 10 trainees, facilitated by two teachers (a GP and a behavioural scientist). All GPTs enrolled in 11 groups that started between June 2007 and July 2008 (six groups at the University Medical Centre in Utrecht and five at the VU University Medical Centre in Amsterdam) were invited to take part in the study. To avoid imbalance between intervention and control groups at the participating institutes, we assigned groups at each institute to the intervention or control condition alternately. GPTs enrolled in three groups in Utrecht and two in Amsterdam were assigned to the intervention condition in which the ACA training programme was integrated into the vocational training scheme. GPTs who enrolled in six other groups (three in Utrecht and three in Amsterdam) were assigned to the control condition without the ACA programme. Both intervention and control GPTs had received doctor-patient communication training during the first year of their curriculum. As their training and experience in palliative care may vary, this was measured at baseline (see Table 1).

Intervention

The ACA training programme consists of eight steps (see Box 1) and is supported by the ACA checklist (see Box 2).[10] Steps 1 and 2 took place on the first day. Within two months all participants received individual feedback on their videotaped simulated consultation (step 3). During the following months they had to complete step 4 in order to formulate their personal learning goals (step 5). Three to four months after the start, the GPTs participated in role-play exercises that were tailored to their learning goals (step 6). Finally, six months after the start a second consultation with an actor simulating a patient was videotaped (step 7) to allow participants to assess their communication skills against the ACA checklist (step 8).

To promote implementation of the ACA programme in the GP vocational training scheme, it was conducted by the regular teachers in the vocational GP training institutes, who had received detailed instructions about the training programme from the first author (WS).[13]

Box 1. The eight steps of the ACA (availability, current issues, anticipation) training programme for general practice trainees (GPTs)

Step 1
Videotaped GPT-patient interview with a trained actor simulating a patient in an advanced stage of lung (role A) or colon (role B) cancer, according to detailed scripts; immediately after the interview the participant receives general feedback on communication style from the actor (30 min).

Step 2
Instructions on the ACA checklist, using oral presentations and written information (ACA booklet) (30 min).

Step 3
Oral feedback according to the ACA checklist on GPT performance during the videotaped GPT-patient interview in step 1 from their peers and facilitators in small groups (60 min).

Step 4
Studying the ACA checklist, *discussing* this material with peers in small groups, and *trying out* newly acquired skills in the practice of their vocational GP trainer to identify problem areas from their own experience (60 min).

Step 5
Formulating learning goals based on the previous steps (30 min).

Step 6
Role-play exercises tailored to the GPT's individual learning goals: GPTs performed role-play with other participants in the course, which enabled them to experience the patient perspective (60 min).

Step 7 A
Second videotaped interview with an actor simulating a patient (30 min).

Step 8
Using the second videotaped interview and the ACA checklist as tools for *self-assessment* of their communication skills formulate new learning goals and start a new learning cycle (60 min).

The estimated total duration of all steps in the ACA training programme is 6 h.

Box 2. The ACA (availability, current issues, anticipation) checklist

Availability *(of the GPT for the patient):*

1. Taking time
2. Allowing any subject to be discussed
3. Active listening
4. Facilitating behaviour (e.g. empathic, respectful, attentive, occasionally also phoning or visiting the patient spontaneously)
5. Shared decision-making with regard to diagnosis and treatment plan
6. Accessibility (e.g. phone numbers)

Current issues *(that should be raised by the GPT):*

1. Diagnosis
2. Prognosis
3. Patient's physical complaints and worries
4. Patient's psychosocial complaints and worries
5. Patient's spiritual/existential complaints and worries
6. Wishes for the present and the coming days
7. Unfinished business, bringing life to a close
8. Discussing treatment and care options (concerning 1–7)

Anticipating *(various scenarios):*

1. Offering follow-up appointments
2. Possible complications
3. Wishes for the coming weeks/months (personal wishes as well as preferences with regard to medical decisions)
4. The actual process of dying (final hours/days)
5. End-of-life decisions

Sample size

For calculating sample size, we used the outcome measure 'number of issues discussed by the GPT' and considered a difference of 0.5 standard deviation (which corresponded with one extra issue discussed by the GPT) between intervention and control conditions as a clinically relevant difference. Such a difference can be detected with 64 GPTs in each group (power 0.80, two-sided alpha 0.05).

Outcome measures

Outcome measures were determined in discussion with a panel of experts in palliative care research. We decided to measure both how the GPT communicated with the patient and what was discussed. These outcomes fit in well with the content of the ACA training programme on how to communicate with the patient (availability items) and what to discuss (current and anticipated issues). Both 'how' and 'what' were measured quantitatively.

The number of issues discussed ('what') was defined as the total number out of 13 current and anticipated issues about which a GPT had made at least one utterance during the simulated consultation. Additionally, we calculated for each issue the percentage of consultations in which the GPTs discussed that issue.

The quality of a GPT's communicative behaviour ('how') was defined as his or her scores on the six availability items. Because this complex outcome consisted of several numbers and percentages its sub-scores could not be summed up and were reported separately. Additionally, verbal dominance was calculated to evaluate whether the programme influenced it. The GPT's knowledge about medical aspects of palliative care was measured with a 22-question test.

Measurement instruments

We measured the outcomes 'how' and 'what' from the videotaped consultations with the Roter Interaction Analysis System (RIAS).[14,15] The RIAS, which was developed in the United States, has been used successfully in previous studies in Dutch general practice settings.[16] It distinguishes mutually exclusive and exhaustive categories into which verbal utterances that convey a complete thought can be classified. A distinction is made between task-oriented and affective categories. Task-oriented categories refer to utterances that address a patient's physical or psychosocial problems. Affective categories carry explicit emotional content and refer to aspects of communication that are needed to establish a therapeutically effective relationship. The RIAS also rates 'global affects' on 6-point scales (e.g. friendliness/warmth).

For the outcome 'number of issues discussed' we added the current and anticipated issues to the task-oriented categories of the original RIAS. For the outcome 'communicative behaviour' we added several study-specific 6-point scales to the RIAS (e.g. the extent to which the GPT took time with the simulated patient). Four of the six availability items could be scored positively (e.g. 'taking time') as well as negatively (e.g. 'not taking time'). As we were specifically interested in communication by the GPTs, we only calculated scores for them and not for the simulated patient.

Knowledge about medical aspects of palliative care was assessed by a written test consisting of 15 patient cases followed by one or more questions of the true or false type with an additional 'don't know' option. We used 15 questions from the database of the 'National Knowledge Test for GPTs' and we constructed seven extra questions.

Measurement procedure

For each GPT participating in the study, we videotaped a 20-min consultation with an actor simulating a palliative care patient at baseline and at follow-up. Knowledge tests were also taken at baseline and at follow-up using the same set of questions. The baseline assessment took place on the first day of the course; the follow-up was six months later.

We developed a detailed patient role including medical, psychological, social and spiritual/existential information, and we instructed professionally trained actors to respond according to the role and depending on the questions of the GPTs. At baseline, half of the GPTs from all vocational training groups had a consultation with such a simulated patient (SiP) who role-played a patient with advanced stage lung cancer. The other 50% saw a SiP playing the role of a patient with advanced colon cancer. At the follow-up assessment, this was reversed. The setting was standardized to avoid any environmental variability. The mean number of issues discussed with the SiP was 8.3; the range was wide (5.7-9.7), mainly caused by one outlier (5.7).

The participating GPTs were aware of their group allocation but the SiPs and the raters of the videotaped GPT-simulated patient encounters were not.

Coding procedure

Coding was carried out directly from videotape by three trained raters using The Observer© software (www.noldus.com). Average coding time was three to four times the duration of the consultation. Throughout the coding period, all coders rated a random sample of 10% of the tapes to assess interrater reliability. Interrater reliability averaged 0.89 (range 0.71-0.99) for the ACA issues and 0.68 (range 0.51-0.87) for RIAS-utterances with a mean occurrence greater than 2%.[14,15] These reliability estimates are comparable to those achieved in other studies.[17-19]

Statistical analysis

We compared the socio-demographic and professional characteristics of the GPTs in the intervention and the control condition using the Chi-square statistic for categorical variables and the Mann-Whitney test for continuous variables. Variables on which the two groups were not comparable at baseline were entered as covariates in subsequent multivariable analyses.

We summed the number of 13 current and anticipated issues that were discussed by the GPT; for each issue we calculated the percentage of consultations in which that issue was discussed. For the outcome 'communicative behaviour' we calculated mean numbers and percentages of the several sub-scores. Verbal dominance was calculated by dividing the sum of all GPT utterances by the sum of all patient utterances. The knowledge test score was the number of correct answers minus the number of incorrect answers (the 'don't know' option counted for 0 points).

We used linear mixed models and accompanying effects to evaluate between-group differences over time for interval level outcome variables. For dichotomous outcome variables we used the logistic regression method of generalized estimating equations (GEE) to account for dependence of data due to repeated measures, yielding odds ratios. In all analyses we used the GPT's sex and age, the actual SiP, the actual training group of the GPT, and whether they were working in a group, duo or single-handed training practice as covariates. In order to adjust for multiple testing, the level of significance was set at 0.01. All data were entered and analysed in SPSS 20.0 (SPSS, Inc., Chicago, IL).

Results

GPT characteristics

From 108 GPTs eligible for this study 105 participated (one GPT was ill, two did not participate for unknown reasons). Fifty-four were assigned to the intervention and 51 to the control group. Videotapes were missing from seven intervention and four control GPTs at baseline, and from 17 (31%) intervention and 11 (22%) control GPTs at follow-up (see Fig. 1). GPTs in the intervention group were more likely to practise in a duo practice and less likely in a group practice. No further significant between-group differences were observed (Table 1).

Number of issues discussed ('what' 1)

We found no statistically significant differences over time between the intervention and control group in the mean total number of ACA issues, of current or anticipated issues discussed (Table 2). In the total study sample, GPTs discussed on average eight of the 13 ACA issues (4.5 current and 3.5 anticipated issues).

As we found that the covariate 'SiP' was significantly related to the outcome 'number of issues discussed', we re-observed the videotaped consultations with the highest scores

Fig. 1. ACA trial for general practice trainees (GPTs), flow diagram.

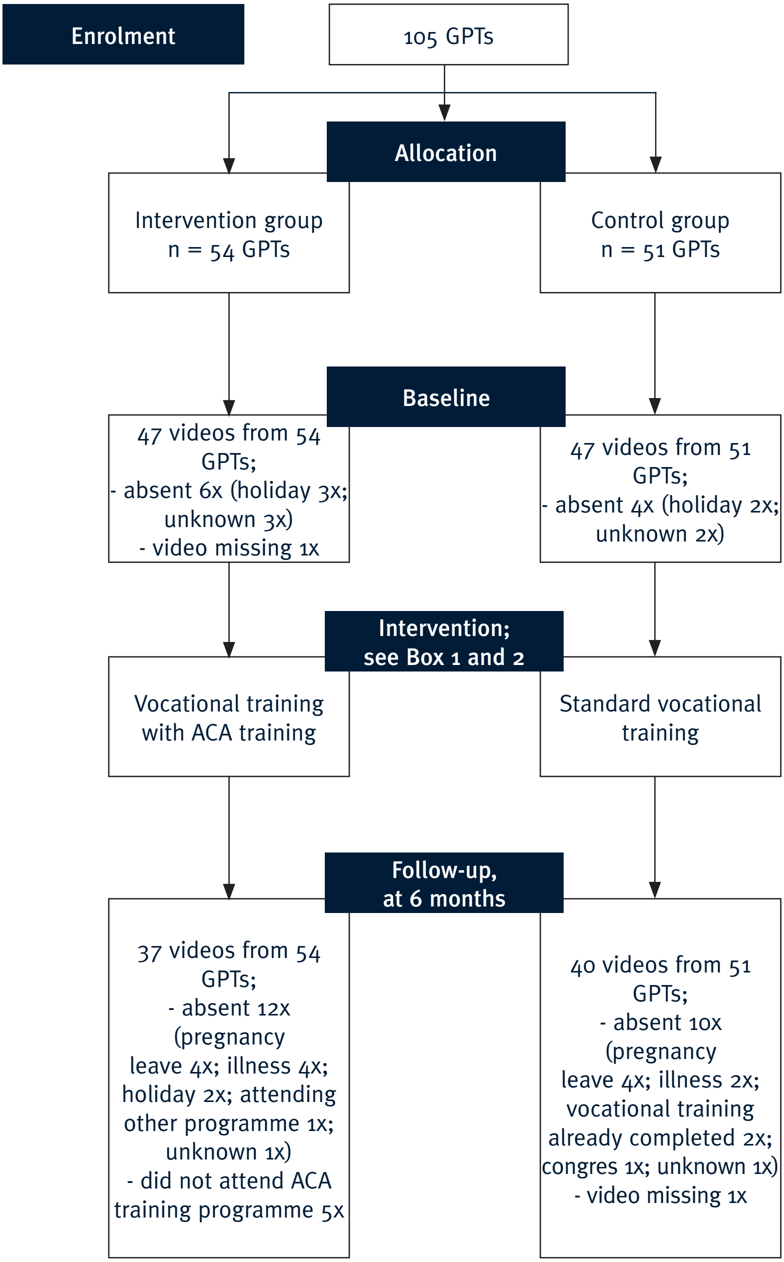

Table 1. Socio-demographic and professional characteristics of participating general practice trainees (GPTs) of the intervention and control group

Characteristics of participants	Intervention group; n = 54 GPTs	Control group; n = 51 GPTs	P
Gender and age:			
Gender female, *n* (%)	40 (74%)	31 (61%)	0.146
Age in years, mean (range)*	31.3 (26–47)	32.5 (26–47)	0.145
Experience in palliative care at baseline:			
Experience during work before vocational training, *n* (%)	16 (32%)	17 (35%)	0.776
Number of palliative care patients during first vocational training year, mean (range)*	2 (0–5)	3 (0–15)	0.328
Training or practical experience during second vocational training year, *n* (%)	37 (76%)	39 (80%)	0.223
Experiences outside training or work, *n* (%)	11 (22%)	7 (14%)	0.297
Knowledge test at baseline:			
22 questions, number of correct answers minus the number of incorrect answers, mean (range)*	12.6 (1–20)	13.1 (−3–21)	0.160
Vocational GP training institute:			0.818
- UMCU, Utrecht, *n* (%)	34 (63%)	31 (61%)	
- VUmc, Amsterdam, *n* (%)	20 (37%)	20 (39%)	
Vocational GP training practice:			
Group, duo or single-handed practice			**0.019**
- Group practice, *n* (%)	18 (33%)	28 (55%)	
- Duo practice, *n* (%)	21 (39%)	8 (16%)	
- Single-handed practice, *n* (%)	15 (28%)	15 (29%)	
Practice location area			0.958
- Urban, *n* (%)	28 (52%)	27 (53%)	
- Semi-rural, *n* (%)	14 (26%)	12 (23.5%)	
- Rural, *n* (%)	12 (22%)	12 (23.5%)	

Data are presented as number (percentage) or * mean (range); P = p-value using chi square test or Mann–Whitney test as appropriate.

(11 or 12 issues discussed) and this time we scored whether the GPT or the SiP initiated a certain issue. We found that GPTs brought up two to five issues while the SiPs brought up no less than six to nine issues.

Different issues discussed ('what' 2)

We found no significant between-group differences over time in the percentages of consultations in which the different issues were discussed (Table 2).

The four ACA issues physical complaints, psychosocial complaints, discussing treatment and care options and offering follow-up appointments were addressed in 95-100% of consultations in both groups at baseline and follow-up measurements; GPTs infrequently addressed spiritual/existential issues and 'unfinished business'.

Communicative behaviour, the availability items ('how')

We observed statistically significant between-group differences over time in a few availability outcomes: three types of affective utterances (back-channel responses, showing approval and verbal attention) and shared decision-making (Table 3). However, although the intervention GPTs scored slightly higher at follow-up on verbal attention and shared decision-making, the significant differences resulted mainly from changes in the control group.

Verbal dominance showed no significant between-group difference over time, with ($P = 0.07$) or without ($P = 0.02$) inclusion of the rather frequently scored back-channels (utterances indicating attentive listening, such as 'mmm-huh'). In both groups the verbal dominance was between 0.8 and 0.9 (i.e. SiPs made slightly more utterances than GPTs).

Knowledge test

The scores of both groups increased from 13 to 14 without a significant between-groups difference over time.

Discussion

Main findings

In this controlled trial we found no effect of the ACA training programme on the total number of current and anticipated issues that GPTs discussed in consultations, on the percentage of consultations in which they discussed issues, on the quality of their communicative behaviour or on their level of knowledge about medical aspects of palliative care.

Interpretation of findings

Although we developed an evidence based intervention and used sound methods to

Table 2. Number and type of current and anticipated issues that the general practice trainees (GPTs) addressed during the simulated consultations in intervention group (n = 54) and control group (n = 51)

ACA issues	Baseline		Follow-up		Effect (difference [c] or odds ratio [d]) (95% confidence interval)	P-value
	Intervention n = 47	Control n = 47	Intervention n = 37	Control n = 40		
All current and anticipated issues (0–13) [a]	8.43 (1.58)	8.22 (1.78)	8.65 (1.25)	7.92 (1.33)	0.50 (−0.47; 1.47)[c]	0.31
Current issues (0–8) [a]	4.74 (0.99)	4.85 (1.13)	4.81 (0.91)	4.58 (0.81)	0.30 (−0.29; 0.90)[c]	0.32
1. Diagnosis[b]	62	76	70	70	0.79 (0.07; 8.99)[d]	0.85
2. Prognosis[b]	60	48	68	60	0.87 (0.22; 3.44)[d]	0.85
3. Complaints, physical[b]	100	100	100	100	–[e]	–
4. Complaints, psychosocial[b]	100	100	100	100	–[e]	–
5. Complaints, spiritual/existential[b]	2	9	3	7	0.27 (0.05; 1.35)[d]	0.11
6. Wishes, at present[b]	38	41	43	17	2.01 (0.34; 12.00)[d]	0.44
7. Unfinished business[b]	13	15	3	5	0.77 (0.29; 2.01)[d]	0.61
8. Treatment and care options[b]	100	96	95	97	–[e]	–
Anticipated issues (0–5) [a]	3.68 (1.16)	3.37 (1.02)	3.84 (1.12)	3.35 (0.97)	0.21 (−0.49; 0.91)[c]	0.55
1. Follow-up appointments[b]	96	100	100	97	–[e]	–
2. Possible complications[b]	81	76	86	62	2.14 (1.09; 4.21)[d]	0.03
3. Wishes, for the coming months[b]	85	80	73	87	0.74 (0.35; 1.55)[d]	0.42
4. The actual process of dying[b]	60	35	76	40	4.40 (0.52; 36.99)[d]	0.17
5. End-of-life decisions[b]	47	46	49	47	1.87 (0.15; 23.25)[d]	0.63

[a] Observed mean (and standard deviation) of the number of issues the GPT addressed during the consultation by at least one utterance concerning an issue; interrater reliability for the ACA issues averaged 0.89 (range 0.71–0.99).

[b] Observed percentage of consultations in which a GPT made at least one utterance concerning this issue.

[c] Effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (group, duo or single-handed practice) and for possible influences of the GPT's sex and age, several actors simulating palliative care patients, and the actual training group of the GPT.

[d] Odds ratio (95% confidence interval) using a logistic regression (generalized estimating equations = GEE) model, adjusted for baseline differences (group, duo or single-handed practice) and for possible influences of the GPT's sex and age, several actors simulating palliative care patients, and the actual training group of the GPT.

[e] The logistic regression (GEE) model is not fit for results of binomial data close to 0 or 100% respectively.

Table 3. General practice trainee (GPT) scores on the availability items ('quality of communicative behaviour') during the simulated consultations in intervention group (n = 54) and control group (n = 51)

Availability items	**Baseline**		**Follow-up**		**Effect (difference [g] or odds ratio [h]) (95% confidence interval)**	**P-value**
Positive	**Intervention n = 47**	**Control n = 47**	**Intervention n = 37**	**Control n = 40**		
1. Taking time (3 GARs, 3–18) [a]	12.74 (1.76)	12.36 (2.85)	12.68 (2.20)	11.75 (2.01)	0.88 (−0.66; 2.42)[g]	0.26
2. Allowing any subject to be discussed (2 GARs, 2–12) [a]	7.77 (1.31)	7.72 (2.14)	8.19 (1.58)	7.18 (1.81)	1.01 (−0.16; 2.19)[g]	0.09
3. Active listening						
A. Open/closed questions ratio[b]	0.38 (0.25)	0.31 (0.19)	0.43 (0.38)	0.38 (0.27)	−0.03 (−0.20; 0.14)[g]	0.72
B. Affective utterances (RIAS):						
1. Back-channel responses [c]	37.23 (9.65)	33.27 (9.00)	37.15 (9.86)	35.58 (8.91)	5.50 (−9.53; −1.47)[g]	**0.008**
2. Shows approval (=approval +compliment)[d]	0.85 (1.10)	0.55 (.74)	0.50 (.69)	0.63 (1.01)	0.67 (−1.16; −0.19)[g]	**0.007**
3. Verbal attention (=empathy + legitimizes + partnership)[d]	4.33 (2.81)	4.99 (3.02)	5.12 (3.54)	3.85 (2.90)	2.21 (0.57; 3.85)[g]	**0.009**
4. Shows concern or worry[d]	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	–	–
5. Reassurance (e.g. reassures, encourages, shows optimism)[d]	2.32 (2.86)	1.56 (1.82)	1.83 (2.65)	1.26 (1.72)	0.11 (−1.49; 1.70)[g]	0.89
6. Agreement (shows agreement or understanding)[d]	1.97 (1.48)	2.10 (2.17)	2.21 (1.82)	2.18 (1.73)	−0.21 (−1.32; 0.91)[g]	0.71
7. Personal remarks, laughs[d]	4.14 (2.47)	4.27 (2.15)	4.44 (2.62)	4.06 (1.71)	0.09 (−1.19; 1.36)[g]	0.89
8. silence[e]	40	30	51	37	0.67 (0.12; 3.72)[h]	0.65
C. Task-focused utterances (RIAS):[d]						
1. Check (paraphrase/checks for understanding)	4.65 (2.93)	4.40 (2.98)	5.36 (3.35)	4.20 (1.91)	0.22 (−1.66; 2.11)[g]	0.81
2. Gives orientation, instructions, introduction	1.98 (1.51)	2.05 (1.44)	2.16 (1.70)	2.00 (1.84)	0.76 (−0.37; 1.88)[g]	0.19
3. Bids for repetition	0.13 (0.29)	0.06 (0.18)	0.17 (0.55)	0.07 (0.27)	−0.11 (−0.35; 1.37)[g]	0.38
4. Asks for understanding	0.04 (0.17)	0.04 (0.18)	0.08 (0.25)	0.00 (0.00)	0.04 (−0.07; 0.16)[g]	0.49
5. Asks for opinion	1.66 (1.41)	1.70 (1.04)	1.63 (1.18)	1.88 (0.97)	−0.17 (−0.96; 0.61)[g]	0.66
4. Facilitating behaviour						
A. Facilitating behaviour (5 GARs, 5–30)[a]	21.32 (3.60)	21.11 (4.84)	22.30 (3.28)	19.87 (4.68)	2.29 (−0.53; 5.12)[g]	0.11
B. Meta-communication [e]	6	15	3	7	0.36 (0.12; 1.09)[h]	0.07
5. Shared decision making with regard to diagnosis and treatment plan						
A. Shared Decision Making (3 GARs, 3–18)[a]	9.89 (2.68)	10.40 (3.03)	9.92 (2.52)	8.50 (2.84)	2.61 (0.69; 4.54)[g]	**0.008**
B. Extent of shared decision making (Range per topic 1–4)[f]	1.84 (.46)	2.02 (.65)	1.99 (0.49)	1.83 (0.54)	0.47 (0.12; 0.81)[g]	**0.009**
6. Accessibility[e]	2	9	13	7	0.84 (0.26; 2.74)[h]	0.77

Continued

Table 3. Continued

Availability items Negative	Baseline Intervention n =47	 Control n =47	Follow-up Intervention n =37	 Control n =40	Effect (difference [g] or odds ratio [h]) (95% confidence interval)	P-value
1. Not taking time Hurried/Rushed (1 GAR, 1–6)[a]	2.15 (1.10)	2.15 (1.27)	1.92 (.98)	2.43 (1.34)	–0.29 (–1.10; 0.52)[g]	0.48
2. Not allowing any subject to be discussed Disregard[e]	17	20	22	17	1.05 (0.54; 2.04)[h]	0.89
3. Not listening actively Disagreement (=shows disapproval, criticism)[e]	2	0	3	0	–[i]	–[i]
4 Not facilitating behaviour (2 GARs, 2–12)[a]	3.19 (1.17)	2.91 (1.02)	3.14 (.98)	3.18 (1.06)	–0.66 (–1.31; –0.02)[g]	0.04

a Observed mean rating (and standard deviation) of a (or of the sum of some) global affect rating(s) (GARs) for the GPT; the scale of each global affect rating ranges from 1 to 6; interrater reliability of the GARs averaged 0.12 (range 0–0.28; these ICCs were rather low due to low variances in the GARs between consultations); 3 GARs 'taking time': calmness, speaking quietly, and showing involvement; 2 GARs 'allowing any subject to be discussed': GP's open attitude and allowing any subject to be discussed; 5 GARs'facilitating behaviour': interest/attentiveness, friendliness/warmth, responsiveness/engagement, sympathetic/empathetic, and respectfulness; 3 GARs 'shared decision making': with regard to treatment and care options taking patient's quality of life and meaningfulness into consideration, informing patient adequately, and involving patient in decisions about treatment and care options; 1 GAR 'not taking time': (hurried/rushed); and 2 GARs 'not facilitating behaviour': anger/irritation and anxiety/nervousness.

b Observed mean ratio (and standard deviation) of the total number of GPT's open questions divided by the total number of GPT's closed questions during a consultation.

c Observed mean percentage (and standard deviation) of the total number of back channels by the GPT divided by the total number of all utterances (including the backchannels) by the GPT during a consultation; interrater reliability of the scores on the RIAS utterance back channel was 0.87.

d Observed mean percentage (and standard deviation) of the total number of this type of utterance by the GPT divided by the total number of all utterances (with the exception of the back-channels) by the GPT during a consultation (the back-channels were excepted to prevent dominance of all results by the rather high en variable numberof back-channels that were scored during the consultations when compared to the numbers of all other utterances); interrater reliability of the scores on the four RIAS utterances with a mean occurrence greater than 2% (verbal attention, agreement, personal remarks, check, and giving orientation) averaged 0.64 (range 0.51–0.86).

e Observed percentage of consultations of the intervention and control group at baseline and post-measurement in which the GPT made at least one utterance concerningthis issue.

f Observed mean ratio (and standard deviation) of the sum of the ratings for the extent to which the GPT had discussed the treatment or care options concerning the addressed problems with the patient (=shared decision making, rating 1–4) divided by the number of problems that were addressed during the consultation.

g Effect of intervention (95% confidence interval) using a linear mixed model, adjusted for baseline differences (group, duo or single-handed practice) and for possible influences of the GPT's sex and age, several actors simulating palliative care patients, and the actual training group of the GPT.

h Odds ratio (95% confidence interval) using a logistic regression (GEE) model, adjusted for baseline differences (group, duo or single-handed practice) and for possible influences of the GPT's sex and age, several actors simulating palliative care patients, and the actual training group of the GPT.

i The logistic regression (GEE) model is not fit for results of binomial data close to 0 or 100% respectively.

evaluate its effectiveness, we found no effect on how and what the GPT discussed with the simulated palliative care patient in this trial. In addition, we found no effect in a similar trial among experienced GPs.[20] While this most obviously indicates that the intervention is not effective, we will nevertheless reflect on specific circumstances in our trials which might explain our negative findings and on possibilities for improving the programme.

Third-year GPTs and GPs might have been so well trained in doctor-patient communication as part of their pre- and postgraduate education that training in specific elements of communication in palliative care would not add much to their communication skills (ceiling effect). However, in spite of the high total number of issues discussed in a consultation, there seems to be room for improvement on the scores in current issues 1, 2, 5, 6, and 7 and anticipated issues 4 and 5 (see Table 2). Since we know from the results of these trials that GP(T)s already discuss certain issues in almost every consultation at baseline, the effectiveness of the programme might be increased by focusing on the issues with the lowest scores.

With regard to the intervention, we are not sure if the teachers at the vocational training institutes carried out the programme as intended, since some GPTs reported as an inhibiting factor that not all steps had been addressed in their group.[10] Furthermore, the extent to which GPTs have discussed the ACA checklist and booklet with their GP trainers is unknown.[10]

With regard to outcome measurement, a possible explanation for our findings might be that we measured the outcomes in one 20-min consultation with a SiP of each GPT at baseline and one at follow-up, whereas in daily practice Dutch GPs visit their palliative care patients frequently at home and thus discussion of the 13 issues will be spread over several visits. Using SiPs for outcome measurement is probably more appropriate to studying aspects of care restricted to one consultation than to studying care situations in which diagnostic and therapeutic interventions are spread over several occasions.[21] Post hoc, we found in the consultations with the highest scores that SiPs brought up more issues than GPTs did. Some GPTs achieved high scores by asking adequate open questions, while others achieved them by apparently ‘not knowing what to say’ and waiting for the patient to speak. It seemed that allowing the patient room to raise their problems was enough to achieve a high score. This probably also happens with real patients in daily practice, but our SiPs, knowing their role well and having played it many times, might have influenced the scores more than real patients would have done. The feasibility of a study design observing a series of GP(T) consultations with real palliative care patients might be reconsidered.

Furthermore, our quantitative content analysis (RIAS) of the consultations, solely relying on frequency of communication behaviours, might not have been sensitive enough to assess changes in overall quality of the GPT’s communication with the patient.[22] Future research with real patients might consider including, in addition to intervention studies, qualitative studies that do not aim to evaluate specific interventions but to describe which GP(T) communication skills influence palliative care patient outcomes in a positive or negative way. Qualitative methods seek a patient's view of which aspects of GP communication help and which block him/her. By combining quantitative and qualitative methods, a degree of comprehensiveness may be achieved that neither approach, if used alone, can achieve. Finally, while each intervention GPT exercised a few specific communication skills, we only measured the summed scores of whole intervention and control groups, thereby maybe missing higher scores at follow-up on individual learning points. Future research might benefit from evaluating each individual GP's learning goals, thus facilitating more targeted interventions and more specific outcome assessment.

Strengths and limitations of this study

Both the educational approach and content of the intervention are evidence-based.[5,7-9] Outcomes were based on behavioural observations of simulated GPT-patient consultations assessed by a validated quantitative instrument (RIAS).

We evaluated consultation skills of GPTs by measuring their competence in managed circumstances, which is the third level according to the pyramid model of Miller (knows, knows how, shows, does).[23]

As we had to assign GPTs to either the intervention or the control condition without randomization, we carefully compared both groups and included significant between-group differences in background characteristics as covariates in the subsequent analyses. The GPTs were not blind to their training condition. The loss to follow-up, although rather high, was due to pregnancy leave, illness, holiday and organizational reasons; these reasons were not related to the study and therefore probably not selective. We have no data about the extent to which the training programme was carried out as intended. The SiPs received detailed instructions but a specific training programme for the actors was not included and we did not determine the validity and reliability of their performance.[24,25] Variability in how many issues the SiPs brought up might have influenced our results.

Comparison with existing literature

Recently, effectiveness of communication skills training for health care professionals in cancer care was assessed in a Cochrane review.[26] Meta-analyses based on 10 studies among medical specialists and oncology nurses revealed that trained professionals were more likely to use open questions and to show empathy towards patients than the control group. We found in our trial that intervention GPTs scored higher on 'verbal attention' and control GPTs lower at follow-up, while the open/closed questions ratio increased in both groups without a between-groups difference. In our trial among experienced GPs the score on ‘verbal attention’ remained the same and the open/closed questions ratio decreased slightly in both groups.[20] We have no explanation for our findings other than that these are probably coincidental.

Barnes et al. performed a systematic review on communication training programmes for health care professionals, which focused on life-limiting conditions. One of three themes that emerged from this review was ‘using education to enhance professional communication skills’.[27] They report an improvement in the way physicians delivered bad news and responded to patients’ emotional clues. In contrast to those trials, we included GPTs rather than medical specialists and oncology nurses and the steps of our intervention were spread over a longer period. In addition, we did not measure GPTs’ responses to patients’ clues.

In comparison to experienced GPs, the GPTs in this trial scored higher on ‘silences’ and lower on ‘allowing any subject to be discussed’, ‘open/closed questions ratio’, ‘back channel responses’, ‘check’, ‘giving orientation’, ‘meta-communication’, ‘shared decision making’, and verbal dominance.[20] These results suggests that the GPTs were silent and hesitant and were following the patient in comparison with the experienced GPs who actively guided the patient.

Conclusion

The ACA training programme was not effective in the way it was carried out and evaluated in this trial.

Practice implications

This study revealed possibilities for improving the way in which the ACA training programme should be carried out and evaluated. Firstly, the content of the programme should focus on the issues that scored low in our two trials (current issues 1, 2, 5, 6, and 7 and anticipated issues 4 and 5; see Table 2). Secondly, in order to carry out the programme as intended, both the GP trainers at the institutes and those in the vocational training practices should receive more instructions and be more involved in the training programme.

Future experimental research on GP(T)-patient communication in palliative care might consider a study design using real palliative care patients at home and measuring outcomes spread over a series of visits. Besides, including qualitative research methods, in addition to intervention studies, might add in-depth information to quantitative outcome measures.

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References

1 **Inventarisatie van onderwijs in palliatieve zorg.** Een signaleringsrapport. *De kenniscentra palliatieve zorg (UMC St Radboud, VUmc, Erasmus MC, UMCU) en de vereniging van integrale kankercentra (VIKC)*; 2009 (in Dutch).

2 **Low J, Cloherty M, Wilkinson S, Barclay S, Hibble A.** A UK-wide postal survey to evaluate palliative care education amongst General Practice Registrars. *Palliat Med* 2006;20:463-9.

3 **Frank J, editor.** The CanMeds 2005 physician competency framework. Better standards. Better physicians. Better care. *Ottawa: The Royal College of Physicians and Surgeons of Canada;* 2008 p. 1-40. http://rcpsc.medical.org/ canmeds/CanMEDS2005/CanMEDS2005_e.pdf.

4 **Korsch B, Putman SM, Frankel R, Roter D.** The medical interview: clinical care, education and research. *Frontiers of primary care. New York, NY, USA: Springer- Verlag;* 1995. p. 475-81.

5 **Gysels M, Richardson A, Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer* 2005;13:356-66.

6 **Fellowes D, Wilkinson S, Moore P.** Communication skills training for health are professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004. http://dx.doi.org/10.1002/14651858. CD003751.pub2.

7 **Slort W, Schweitzer BPM, Blankenstein AH, Abarshi EA, Riphagen II, Echteld MA, et al.** Perceived barriers and facilitators for general practitioner-patient communication in palliative care: a systematic review. *Palliat Med* 2011;25:613-29.

8 **Alvarez MP, Agra Y.** Systematic review of educational interventions in palliative care for primary care physicians. *Palliat Med* 2006;20:673-83.

9 **Slort W, Blankenstein AH, Deliens L, Van der Horst HE.** Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011;61:167-672.

10 **Slort W, Blankenstein AH, Wanrooij BS, Van der Horst HE, Deliens L.** The ACA raining programme to improve communication between general practitioners and their palliative care patients: development and applicability. *BMC Palliat Care* 2012;11:9. http://dx.doi.org/10.1186/1472-684X-11-9.

11 **Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, et al.** The impact of patient-centered care on outcomes. *J Fam Pract* 2000;49: 796-804.

12 **Street Jr RL, Makoul G, Arora NK, Epstein RM.** How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns* 2009;74:295-301.

13 **Reinders ME, Blankenstein AH, Marwijk HWJ, Schleypen H, Schoonheim PL, Stalman WAB.** Development and feasibility of a patient feedback programme to improve consultation skills in general practice training. *Patient Educ Couns* 2008;72:12-9.

14 **Roter DL.** The Roter Method of Interaction Process Analysis: RIAS Manual. *Baltimore: Johns Hopkins University;* 1993.

15 **Roter D, Larson S.** The Roter Interaction Analysis System (RIAS): utility and flexibility for analysis of medical interactions. *Patient Educ Couns* 2002;46:243-51.

16 **Bensing JM.** Doctor-patient communication and the quality of care. An observational study into affective and instrumental behavior in general practice. *[Doctoral dissertation] Utrecht: NIVEL; 1991.*

17 **Timmermans LM, Van der Maazen RWM, Verhaak CM, Van Roosmalen MS, Van Daal WAJ, Kraaimaat FW.** Patient participation in discussing palliative radiotherapy. *Patient Educ Couns* 2005;57:53-61.

18 **Verhaak CM, Kraaimaat FW, Staps ACJ, Van Daal WAJ.** Informed consent in palliative radiotherapy: participation of patients and proxies in treatment decisions. *Patient Educ Couns* 2000;41:63-71.

19 **Ong LM, Visser MR, Kruyver IP, Bensing JM, Van den Brink-Muinen A, Stouthard JM, et al.** The Roter Interaction Analysis System (RIAS) in oncological consultations: psychometric properties. *Psychooncology* 1998;7:387-401.

20 **Slort W, Blankenstein AH, Schweitzer BPM, Knol DL, Deliens L, Aaronson NK, et al.** Effectiveness of the ACA (availability, current issues and anticipation) training programme on GP-patient communication in palliative care; a controlled trial. *BMC Fam Pract* 2013;14:93.

21 **Buellens J, Rethans JJ, Goedhuys J, Buntinx F.** The use of standardized patients in research in general practice. *Family Practice 1997*;14:58-62.

22 **van Dulmen S.** The key to good healthcare communication. *Patient Educ Couns* 2002;46:233-4.

23 **Miller GE.** The assessment of clinical skills/competence/performance. *Acad Med* 1990;65:S63-7.

24 **Wallace J, Rao R, Haslam R.** Simulated patients and objective structured clinical examinations: a review of their use. *Adv Psychiatr Treat* 2002;8:342-8.

25 **Churchouse C, McCafferty C.** Standardized patients versus simulated patients: is there a difference? *Clin Simul Nurs* 2012;8:e363-5. http://dx.doi.org/ 10.1016/j.ecns.2011.04.008.

26 **Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA.** Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev* 2013. http://dx.doi.org/10.100214651858.CD003751.pub3. Issue 3, Art. no.: CD003751.

27 **Barnes S, Gardiner C, Gott M, Payne S, Chady B, Small N, et al.** Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage* 2012;44:866-79. http://dx.doi.org/10.1016/j.jpainsymman.2011.11.009.

CHAPTER 8

General discussion

Introduction

In this chapter, we present the main findings of our research project reported in chapters 2 to 7. The meaning of the results and a number of methodological issues are discussed, the implications of the findings for general practice and GP vocational training are addressed, and recommendations for future research are given.

Background

Several studies have demonstrated effectiveness of basic communication skills training programmes in improving oncologists' or oncology nurses' communication with oncology patients, including those receiving palliative care.[1,2] Although GPs are usually well-trained in doctor-patient communication, this does not always cover training in communication with palliative care patients.[3] We did not identify any such studies reporting effects of training GP or general practice trainees (GP trainees) in communicating with palliative care patients.[4] Consequently, for our research project focusing on GP-patient communication in palliative care, we formulated the following questions:

I. How and what should GPs communicate with palliative care patients?
II. Which problems in GP-patient communication in palliative care (in the Netherlands) do patients, GPs and end-of-life consultants report?
III. Does the ACA training programme improve the GP (trainee)'s communication skills and patient outcomes?

Main findings and discussion

In this section, we present and discuss the main findings chronologically, following the three parts of this thesis: (1) explorative studies; (2) development of the ACA training programme; and (3) experimental studies.

(1) Explorative studies

The two exploratory studies were intended to address the first two aforementioned questions of our project and thereby to obtain detailed information on the perceived facilitators of and barriers to GP-patient communication in palliative care. This information was important for developing a palliative care communication training programme for specifically GP and GP trainees.

In our systematic review **(chapter 2)** we summarized and categorized barriers and facilitators for GP-patient communication at the end of life, based on available results of qualitative and quantitative questionnaire studies.[4] We found evidence of ambivalence among both patients and GPs about discussing the prognosis. The skills required to deal effectively with their own and the patient's ambivalence regarding discussing sensitive end-of-life issues appears to be a major challenge for GPs providing palliative care. The results of our review suggest that, to be effective communicators in the palliative care setting, GPs should be available for their patients, and take the initiative to talk honestly about the several end-of-life issues. Although the life expectancy of palliative care patients may be rather short, we identified several relevant factors concerning the future of the patient. These factors emphasize the importance of anticipating various scenarios when GPs are providing palliative care.

In our qualitative study on facilitators and barriers to GP-patient communication in palliative care **(chapter 3)**, we identified possible facilitators and barriers, in addition to those identified in our systematic review.[5] Almost all participating end-of-life consultants had observed problems in GP-patient communication in the past year (e.g., GP failing to clarify the patient's problems and concerns sufficiently, GP not anticipating various scenarios). In the focus groups, GPs 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. The results of the qualitative study suggested that the quality of the GP-patient communication in palliative care could be improved. More specifically, to communicate effectively GPs should pay attention to how they communicate with their palliative care patients, and they should take the initiative to discuss the several end-of-life issues.

Discussion (1)

With our review we originally intended to identify quality indicators of GP-patient communication in palliative care. We classified the identified factors as barriers or facilitators for communication, according to the description of the separate factors in the article, and as related to structure, process or outcome.[6] In our study, process refers to factors influencing the communication during the actual consultation. These factors assess the topics that the GPs and patients address in palliative care consultations, and how well this is done ('how' factors). However, none of the studies reported on the development of such quality indicators. Furthermore, none of the studies included in our review reported factors related to the outcome of GP-patient communication in palliative care, and none of these studies evaluated the possible effects of structural and process factors on existing palliative care outcome measures, for example, the Palliative Care Outcome Scale (POS)[7] and the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C15-PAL.[8] Because we did not identify any studies that evaluated relations between barriers or facilitators of communication and outcomes of palliative care, this review became a synthesis of the perspectives of patients and GPs on barriers and facilitators for GP-patient communication in palliative care rather than a review on the effectiveness of communication.

To determine which perceived barriers and facilitators are specific for palliative care we compared our findings on GP-patient communication in palliative care with the findings of previous studies on GP-patient communication in general.[9-11] The majority of our findings were also found in the literature on GP-patient communication in general (e.g. giving the patient room to tell his story, expressing empathy, exploring emotions, discussing diagnosis and prognosis, shared decision making and discussing alternative treatment options). Therefore, we conclude that the key features of GP-patient communication in palliative care are very similar to those of GP-patient communication, in general.

A few of our findings could not be found in these articles on GP-patient communication, in general, and thus may be specific to the palliative care setting. A barrier related to structure at the patient level that seems typical for GP-patient communication in palliative care is the unpredictability of the clinical course. Because of this unpredictability, in the palliative care situation GPs have to deal more with uncertainty of the prognosis and need to anticipate various scenarios before they unfold. From the 'how' factors, the ambivalence of the patients and the GPs in dealing with the bad prognosis seems to play a major role in communication in the final phase of life. Although this ambivalence plays a role in almost all doctor-patient communication, in palliative care this may be even more important because the relevant issues - somatic, psychological, social and spiritual - come into play in the context of impending death.

Patients' ideas and preferences may change over time as the disease progresses, which is another 'how' factor especially important in palliative care. Therefore, GPs need to continually re-appraise the needs of patients and their families with regard to the disclosure of information, and to tailor the information and care accordingly.[12,13] In addition, GPs should distinguish between the problems of their patients and their needs; patients may not wish to discuss or to be helped with all of their problems.[14-16]

Among the topics that we found, specific palliative care issues are the explanation of the final stage of the patient's disease, strong patient emotions, end-of-life preferences, spiritual concerns, medical futility, life-prolonging treatment options, end-of-life decisions (e.g. living wills) and the patient's belief in afterlife.

To determine which perceived barriers to and facilitators of communication in palliative care are specific for GPs we compared our findings with those of the extensive monograph on patient-centred communication in cancer care by Epstein and Street, based on a critical synthesis of existing literature, the authors' personal research experience, as well as discussions with a number of internationally recognized experts in the area of communication, oncology, health care delivery, quality of care assessment, and patient advocacy who participated in a symposium on patient-centred communication in cancer care.[17] The few differences that we found were the possibility for GPs to make home visits and a stronger emphasis on anticipating various scenarios in our findings.

In a systematic review, Hancock et al. showed that many health care professionals avoid discussing the actual prognosis.[18] These results are in line with our finding that, ambivalence of patients and GPs in dealing with the prognosis appears to be an important barrier to open and honest communication about end-of-life issues. In another review, Clayton et al. found that the majority of patients prefer honest information, and that they seem to be able to maintain a sense of hope despite acknowledging the terminal nature of their illness.[19] These conclusions are in line with our findings that patients appreciate their GP being honest and straightforward, taking the initiative to talk about end-of-life issues and providing all the necessary information in a paced, gradual and tailored way. Moreover, the results of our review indicate that, in order to be able to maintain hope, patients prefer that their GPs do not discuss the (poor) prognosis too often, that they are also willing to talk in everyday language about any day-to-day topic that the patient wishes to discuss, that they give encouragement and hope and are humorous. The findings of these two reviews and our review emphasize that dealing with ambivalence seems to be one of the most serious challenges GPs and other health care professionals face in palliative care.

Although, in our qualitative study, patients, GPs and consultants reported problems in GP-patient communication in palliative care, the results of this study are based only on the experiences and opinions of small samples of GPs, patients, and end-of-life consultants. From this qualitative study, no conclusions can be drawn about the incidence of problems in GP-patient communication in daily palliative care. In our opinion, it is rather difficult to design an appropriate study to enable reliable conclusions on this issue. Large scale quantitative studies (e.g., questionnaire studies) among patients will probably not be able to identify problems in GP-patient communication in palliative care as patients tend to score very high on (satisfaction with) communication and care outcomes. On the other hand, in-depth, qualitative interview methods, which might provide better insight in patient's perception of problematic communication in palliative care, may be difficult to generalize.

(2) Development and applicability of the ACA training programme

In **chapter 4** we described the development of a new palliative care specific communication training programme for GPs. To support the new communication training programme, we incorporated the GP-related facilitators identified in the explorative studies into the 19-items ACA checklist, divided into three categories: the *availability* of the GP for the patient; *current issues* that should be raised by the GP; and the GP *anticipating* various scenarios (ACA).

To assess the applicability of the ACA training programme, all participating GPs and GP trainees were asked to complete an evaluation form at the end of the programme. This evaluation showed that the programme appeared to be applicable to practicing GPs who attended a 2-year Palliative Care Peer Group Training Course and to (inexperienced) third-year GP trainees from five vocational training groups. The ACA checklist was appreciated by GPs as useful both in practice and as a learning tool, whereas GP trainees mainly appreciated the list for use in practice. A quarter of the GPs and a third of the GP trainees spontaneously reported the ACA checklist to be a useful guide for communication with palliative care patients.

Discussion (2)

To our knowledge, this is the first evidence-based palliative care specific training programme specifically targeted at the GP (trainee)'s communication with palliative care patients.[4] Both the content and the educational approach of the ACA training programme are evidence-based. The content of the ACA training programme is based on the results of recent exploratory studies among palliative care patients, their relatives, GPs, and end-of-life consultants.[4,5] The educational approach was derived from two systematic reviews of methods in training programmes for communication in palliative and cancer care.[21,22]

We evaluated the rate of attendance of GPs and GP trainees and their appreciation of the different steps of the programme. This evaluation of the first experiences with the programme was quantitative in nature. A qualitative study might have given additional insight in factors that would facilitate or inhibit application of this training programme.

The newly developed training programme was assessed among practising GPs and inexperienced GP trainees. The GPs participated in a two-year Palliative Care Peer Group Training Course, and probably had a greater than average commitment to palliative care, unlike the GP trainees, who participated as part of their vocational training, with no special commitment. Although we evaluated the applicability of the ACA training programme in two different settings, our results can only be generalised with caution for use in other settings.

In their review of educational interventions in palliative care for primary care physicians, Alvarez et al. state that key elements of GP-patient communication in palliative care should be designed more specifically to obtain favourable results, and that effective training methods in key communication skills for doctors should be addressed in three phases: cognitive input, modelling, and practising key skills with feedback about performance.[21] These statements are in line with our findings that the GPs and GP trainees appreciated the checklist with the 19 items and also the several educational methods incorporated in the ACA training programme. We were surprised that even a well-known communication skill such as 'active listening' was chosen by several experienced GPs as their main individual learning goal. We consider the opportunities for GP (trainee)s to assess their individual shortcomings in communication skills and to participate in role-play exercises tailored to their own learning goals as strong characteristics of the ACA training programme. The use of a checklist to clarify individual learning goals to facilitate the learning process might be extended to other topics and educational areas.

(3) Experimental studies

To answer question III, we conducted two related controlled trials to evaluate the effectiveness of the ACA training programme, one among GPs who attended a two-year Palliative Care Peer Group Training Course and the second among third-year GP trainees. To determine outcomes at GP (trainee) level, we performed a quantitative content analysis of one videotaped consultation of each GP (trainee) with a simulated palliative care patient conducted at baseline, and one at follow-up **(chapter 5 and 7).**[23,24] In the trial among GPs we also measured the following outcomes reported by real patients of the participating GPs: palliative care outcomes, patient satisfaction with the communication with their GP, and patient perception of their GP's availability, and discussion of current and anticipated issues **(chapter 6).**[25] In the trial among GP trainees we also measured the knowledge about medical aspects of palliative care (chapter 7).[24] In both trials we found no effect of the ACA communication training programme on the total number of current and anticipated issues that GPs and GP trainees discussed in simulated consultations, or on the quality of their communicative behaviour. In the trial among GPs we also found no effect of the ACA training programme on real patient reported outcomes. In the trial among GP trainees we found no effect of the ACA communication training programme on their knowledge about medical aspects of palliative care.

The descriptive results from the controlled trials suggest that, although palliative care patients were generally quite satisfied with the communication and palliative care provided by their GPs, GPs should take the initiative to discuss certain end-of-life issues, including spiritual/existential issues, unfinished business, prognosis and possible complications, the actual process of dying, and end-of-life decisions more often and/or more thoroughly. Future training programmes of this nature should give particular attention to these issues.

Discussion (3)

To our knowledge, these were the first studies on effectiveness of a communication training programme specifically targeted at GP-patient communication in palliative care.[4] Although we developed an evidence- based intervention and used sound methods to evaluate its effectiveness, we found no effect on how and what the GP (trainee) discussed with the simulated palliative care patient nor on any of the patient reported outcomes. Besides the intervention being not effective, we considered several methodological issues as possible explanations for these negative results; see our reflections in the paragraph 'methodological considerations' (setting and participants; sample size; non-randomized assignment to groups; content and educational approach of intervention; way of carrying out the intervention; outcome measurement).

The results of our previous qualitative study suggest that GP-patient communication in the palliative care setting might be suboptimal.[5] Yet, in the trial among GPs, patients reported high levels of satisfaction with the communication and care provided by their GP. This discrepancy might reflect some level of selection bias (i.e., that GPs referred especially the more satisfied patients to the study), some degree of reluctance on the part of patients to be critical of the care they received, limitations of the questionnaires used, or a combination of these factors. Another possible explanation is that the frequency of problematic GP-patient communication in palliative care as identified in our qualitative study is so low, that the patient-reported outcomes in our trial among GPs were hardly influenced by these infrequent cases.

The total number of issues discussed by the GPs and GP trainees was eight out of 13 before and after the training in both intervention and control groups. We consider this a rather high number during a 15 or 20-minute consultation. In spite of the high total number of issues discussed in a consultation, there seems to be room for improvement on the scores in current issues 1, 2, 5, 6, and 7 and anticipated issues 2, 3, 4 and 5 (see ACA checklist, page 185). The following issues were discussed in almost all consultations: patient's physical complaints and worries, patient's psychosocial complaints and worries, treatment and care options, and offering follow-up appointments. The following issues were discussed in about 60-85% of the consultations: possible complications and wishes for the coming weeks/months. The following issues were discussed least often: diagnosis, prognosis, patient's spiritual/existential complaints and worries, wishes at present, unfinished business, the actual process of dying, and end-of-life decisions. Probably GPs and GP trainees always discuss with their patients the physical and psychosocial aspects of a complaint, the treatment options, and the follow-up after this actual consultation, irrespective of the type of complaint and consultation, so also in palliative care consultations. Since we know from the results of our trials that GP (trainee)s discuss certain issues in almost every consultation already at baseline, the effectiveness of the ACA training programme might be increased by focusing on the issues that were discussed less often in our trials.

We found it remarkable that, already at baseline, the GP trainees discussed as many issues with the simulated palliative care patients as the (experienced) GPs did.[23,24] We analysed the scores of the GP trainees and GPs to explore similarities and differences in the 'how' and 'what' outcomes between both groups, because from possible differences in their outcomes we might derive learning objectives for the GP trainee, or for the GP. By pooling all GP trainee and GP consultations we had 170 GP trainee versus 239 GP consultations for analysis. The mean duration of the GP trainee consultation was 18 minutes and of the GP consultation 15,5 minutes. In comparison to experienced GPs, the GP trainees scored higher on 'silences' and lower on 'allowing any subject to be discussed', 'open/closed questions ratio', 'back channel responses', 'check', 'giving orientation', 'meta-communication', 'shared decision making', and verbal dominance.[23,24] The results suggest that the GP trainees were silent and hesitant and were following the initiatives of the patient in comparison with the experienced GPs who actively guided the patient. In order to communicate optimally as a GP (trainee) with a patient receiving palliative care, he should be available (e.g. taking time, listening actively) and he should anticipate various scenarios, including initiating discussions about several end-of-life issues. Perhaps GP trainees learn more easy how to listen emphatically to the patient than how to actively guide the patient and initiate discussion about end-of-life issues. This assumption might be explored further and communication training programmes for GP trainees might focus on this aspect.

After the start of our research project in 2006, several other studies on communication skills training programmes to improve health care provider-patient communication in palliative care (or cancer care) have been published. We found only one trial evaluating a training programme in palliative care for GPs; most of the trials evaluated communication skills training courses for medical specialists and oncology nurses.

Hermann et al. evaluated the impact of a 40-hour basic training course in palliative care for GPs in Germany (PAMINO) on the care of palliative patients and their health-related quality of life, using the POS en QLQ-C15-PAL.[26] Their training course did not solely cover communication skills and attitudes as in our study, but covered a broad variety of issues: psychology of pain, legal aspects, dialogues of clarification with patients, ethics and attitudes, symptom control and pain therapy, dying and the requirements of dying people, communication and burn-out, palliation in geriatrics, and palliative care. They used the same inclusion criteria for patients as in our trial, but their patients were asked to complete a questionnaire once a month and for analyses they used the last questionnaire received, i.e. shortly before their death or at the end of the 6-months observation period. Like in our study, only half of the participating GPs included patients. On the POS sum and item scores their patients reported a higher burden than did our patients. On the QLQ-C15-PAL their patients scored lower on overall quality of life and on physical and emotional scales, and higher on the symptom scales. These differences might be explained by the assumption that their patients probably completed the (latest) questionnaire later in their illness trajectory. On the POS, both their patients and ours scored ‘family anxiety’ highest and ‘time wasted’ lowest. On the QLQ-C15-PAL all patients scored emotional functioning higher than physical functioning, and fatigue as the most frequently present symptom. Like us, Hermann et al. did not detect an effect from their training course on patient outcomes.

In a recent systematic review on effectiveness of communication training programmes for health care professionals (other than GPs) which focused on life-limiting conditions, a number of important features of a successful communication model were identified, including focused participant-led training, and using effective communication to improve patient understanding and flexible patient-led ‘Advance Care Planning’.[27] This is in line with the educational methods and content of the ACA training programme.

In a recent Cochrane review, effectiveness of communication skills training for health care professionals in cancer care was assessed.[28] None of these intervention studies focused on GPs. Meta-analyses based on 10 studies among medical specialists and oncology nurses revealed that trained professionals were more likely to use open questions and to show empathy towards patients than the control group were. These health professionals (not GPs) had probably received less extensive training in doctor-patient communication as part of their educational curriculum, and therefore the baseline level of their communication skills might have allowed more room for improvement compared with the GPs, who might have been already trained so well in doctor-patient communication as part of their pre- and postgraduate education, that training them in specific elements of communication in palliative care might not add much to their communication skills (ceiling effect).

Two studies included in this Cochrane review contributed data to each of the outcomes ’patient perception of health care professional communication skills’[29,30] and ’patient satisfaction with communication’.[31,32] There were no statistically significant differences in either of these patient outcomes between the groups, which is consistent with our findings.

In a paper from the Cancer Research UK communication skills training study, Shilling et al. aimed to identify factors that influence patient and clinician satisfaction with the cancer consultation and whether satisfaction can be improved with communication skills training.[33] Half of the 160 participating doctors were randomized to attend a communication skills training course. Communication skills training showed a non-significant positive effect on patient satisfaction. The authors suggest that subtle benefits of improved communication may be overshadowed by practical problems such as waiting too long to see the doctor. The authors discussed that patient satisfaction is a very difficult concept to measure in oncology, as patients place tremendous faith in the treating clinician and may be reluctant to criticize practice out of fear that it might jeopardize their treatment or care. Hence satisfaction scores tend to be very high.[34] Previous analyses have shown that clinicians who participated in a communication skills training course demonstrated more patient-centred behaviours compared to those who did not attend the course.[31,35] Like Hulsman et al., they found no significant increase in patient satisfaction as a result of clinician communication skills training.[36] The absence of training effects on patient satisfaction suggests that either improvement in communicating behaviour is too small for patients to perceive or that the ceiling effects for satisfaction scores seen in this and similar studies may leave little room for any positive training effect.

Besides the Cochrane review, Barth and Lannen performed a systematic review and meta-analysis on the efficacy of communication skills training courses in oncology.[37] Their literature search was updated until the summer of 2008. Their meta-analysis showed a moderate effect of communication skills training on communication behaviour. They concluded that communication skills training of health professionals (other than GPs) is a promising approach to change communication behaviour and attitudes. They state that patients might also benefit from specifically trained health professionals, but that strong studies are lacking.

Another review formulated an almost identical conclusion. Uitterhoeve et al. conducted a review to determine whether communication training for health care professionals, including nurses and medical doctors in cancer care, improves patient outcomes.[38] Regarding patient satisfaction outcomes, they found slight estimated effects in favour of communication training. The authors concluded that the current review revealed inconclusive evidence for the effectiveness of communication training on patient satisfaction. They stated that more high quality studies are needed on this issue.

A recent study by Johnson et al. evaluated whether advanced communications skills training for health care professionals working in oncology and palliative care services from the North East of England improves patients' experience of consultations.[39] Interactions between 21 health care professionals and 1103 patients were evaluated using the Consultation and Relational Empathy (CARE) Measure, which is a 10-item questionnaire designed to assess patient perceptions of relational empathy in the consultation. Health care professionals (other than GPs) were either part of the intervention group who attended a 3-day communication skills training course or part of the control group who were on the waiting list for training. They found no significant differences over time in the patients' ratings on the CARE measure.

In another recent trial, Fallowfield et al. evaluated an evidence-based training programme for health care professionals (other than GPs) that aimed at enhancing communication with patients about early-phase trial participation.[40] The following improvements in communication were found after the workshop: establishing the patient's knowledge of their prognosis, discussing symptomatic care, the aims of the trial, and the unlikelihood of medical benefit. Patient simulator ratings showed improvements in: the awareness of palliative care and symptom control, the voluntariness of participation, the opportunity to ask questions, and the time to consider participation. The authors concluded that the short, intensive workshop changed communication skills competency in ways likely to promote valid, ethically informed consent from patients contemplating trial entry.

We compared the findings and discussions of the many aforementioned studies on effectiveness of communication skills training among oncologists and oncology nurses with our results. Most studies found moderate effects of communication skills training on health care professional level but only few effects on patient-reported outcomes. We found no effect of the ACA training programme at either the GP (trainee) or the patient level. Already at baseline, we found high scores in most of our outcomes at the GP (trainee) and the patient level. Our skewed data allowed little room for improvement on these outcomes. For patient-reported outcomes, we did not perform subgroup analyses as reported by Shilling et al.[33], mainly because we did not plan this before data collection and because our trial was not powered for subgroup analyses.[41]

Finally, another recent study examined the prevalence of GP-patient discussion of end-of-life topics (according to the GP) in Italy, Spain, Belgium, and The Netherlands, and associated patient and care characteristics.[42] This cross-sectional, retrospective survey was conducted with representative GP networks. Of all patients who died under their care, GPs recorded the health and care characteristics in the last three months of life, and the discussion of ten end-of-life topics (primary diagnosis, incurability of disease, life expectancy, possible medical complications, physical complaints, psychological problems, social problems, spiritual/existential problems, options for palliative treatment, and the possible burden of treatments). The mean number of topics discussed, the prevalence of discussion of each topic, and patient and care characteristics associated with discussions were estimated per country. In total, 4396 non-sudden deaths were included. On average, more topics were discussed in the Netherlands (mean = 6.37) than in Belgium (4.45), Spain (3.32), and Italy (3.19). The topics most frequently discussed in all countries were ‘physical complaints’ and the ‘primary diagnosis’, whereas ‘spiritual and existential issues’ were the least frequently discussed. While Evans et al. used a list of 10 issues, we used a checklist containing 13 issues. Issues identically present on both lists were (5x): primary diagnosis, physical complaints, psychological and social problems, spiritual/existential problems, and possible medical complications. Evans’ ‘incurability of disease’ and ‘life expectation’ are similar to our ‘prognosis’. Evans’ ‘options for palliative treatment’ and ‘burden of treatment’ are similar to our ‘discussing treatment and care options’. Issues that are on the ACA checklist and not on Evan’s list include (6x): ‘wishes for the present and coming days’, ‘unfinished business, bringing life to a close’, ‘offering follow-up appointments’, ‘wishes for the coming weeks/months’, the actual process of dying', and 'end-of-life decisions'. Like Evans, we found that the topic 'physical complaints' was frequently discussed, whereas 'spiritual/ existential issues' were the least frequently discussed. 'Primary diagnosis' was less often discussed by the GP (trainee)s with simulated patients in our trials, probably because of the way they were instructed for the role-play ('this is a patient who you know well and you have discussed the diagnosis already many times with him'). We did not ask the real patients if their GP discussed the diagnosis with them. It is noteworthy that a relatively high number of end-of-life issues is discussed in the Netherlands. This may, at least in part, explain the high scores at baseline in our trials.

Methodological considerations

In this paragraph we discuss the following methodological issues:

(1) assessment of the quality of qualitative studies;
(2) adaptation of the RIAS to this study;
(3) methodological considerations on the negative outcomes of both trials.

(1) Assessment of the quality of qualitative studies (chapter 2, review)

We aimed to gain more knowledge on GP-patient communication in palliative care by performing a systematic review **(chapter 2)**. Because we anticipated identifying primarily qualitative studies on the subject of our review, we oriented towards methods applicable to this type of study to assess the quality of studies. Our orientation revealed that, although qualitative research methods are widely used and increasingly accepted in health research, there was no universally accepted set of criteria with which to assess the quality of qualitative studies. Which criteria are appropriate, and how they should be assessed has been debated in several journals.[43-48] We collected articles and checklists addressing how to assess the quality of qualitative papers (e.g., the qualitative research checklist that BMJ editors use when appraising papers presenting original qualitative research) and in this way we found many criteria to assess the methodological quality of qualitative studies in various methodological publications on qualitative research.[49-57] In the most recent study, Harden et al. applied 12 criteria.[57] For our review, we combined the three criteria for assessing the extent to which the study findings reflected the perspectives and experiences of the population studied into one criterion. To the remaining 10 criteria we added six criteria derived from the other methodological studies focusing on qualitative research. In this way, we assessed each qualitative study according to 16 criteria, sub-divided into two dimensions. The first dimension was *clarity of reporting:* a clear description of the context, study aims, research question, choice of specific study design, sampling, data collection and analysis, and findings. The second dimension was the *robustness of the study methods*: a comprehensive sampling strategy, reliability and validity of the data collection and analysis, rooting of the findings in the perspectives and experiences of the respondents, logically proceeding from data to interpretation, and reflexivity.

Additionally, for the critical appraisal of the quantitative questionnaire studies we used the same set of criteria, but omitted the following four criteria that were not applicable to quantitative studies: 'Were the findings really rooted in the perspectives and experiences of the population studied?'; 'Was evidence of reflexivity in the process reported?'; 'Did the research move logically from a description of the data to analysis and interpretation?'; 'Were various methods used to establish the validity of the data analysis?'. We added 'a sufficient response rate' as a criterion for the second dimension, resulting in a 13-item list. For the assessment instruments used in our review, see Table 1 in chapter 2 of this thesis. Each criterion was rated 'yes' or 'no'. If there was insufficient information the score was 'no'. Equal weights were applied, resulting in a total quality score, ranging from zero to 16 for qualitative studies, and from zero to 13 for quantitative questionnaire studies.

For our study, two reviewers (WS and BS) independently applied the aforementioned sets of 16 criteria for qualitative studies and 13 criteria for quantitative questionnaire studies. The reviewers found both sets of criteria to be applicable to the included studies. Few discrepancies could be resolved by discussion.

Recently, Antunes et al. used the same criteria as proposed in our review.[58] We recommend using these sets of criteria to assess the quality of all types of qualitative research papers and quantitative questionnaire research papers.

(2) Adaptation of the RIAS to this study (chapter 5 and 7)

To measure the quality of the GP's and GP trainee's communication skills during his (videotaped) consultations with a simulated palliative care patient, we used the Roter Interaction Analysis System (RIAS).[59,60] The RIAS is a method of coding doctor-patient interaction during the medical visit. Since coding is done directly from audio- or videotapes, rather than transcripts, assessment of the tonal and non-verbal qualities of interaction is possible. The RIAS, which was developed in the United States, has been used successfully in previous studies in Dutch general practice settings.[61] It distinguishes mutually exclusive and exhaustive categories into which verbal utterances that convey a complete thought can be classified. A distinction is made between instrumental or task-oriented categories, and affective or socio-emotional categories. Task-oriented categories refer to utterances that address a patient's physical or psychosocial problems. Affective categories carry explicit emotional content and refer to aspects of communication that are needed to establish a therapeutically effective relationship. The RIAS also rates 'global affects' on 6-point scales (e.g. friendliness/warmth).

Adaptations are made, to some extent, to the original RIAS coding scheme for almost all studies. Typically, a study is designed to investigate a particular topic of interest. Specially designed coding forms (or software) are used, in addition to the RIAS frequencies forms (or software), to allow for elaboration of these topics (e.g., to note whether or not particular questions are asked, specific information given, or to assign ratings for certain behaviours). For example, information given to the patient regarding his or her diagnosis may be of interest.

For our study, RIAS coding resulted in the analysis of the verbal content of the GP's and GP trainee's (videotaped) consultations with a simulated palliative care patient.[24,25] We determined outcome measures of this study in discussion with a panel of experts in palliative care research. We decided to measure both how the GP communicated with the patient and what he discussed with him. Using the RIAS, both 'how' and 'what' were measured quantitatively. Additionally, coders maintained a log of each consultation (generated simultaneously with RIAS coding) consisting of a listing of the problems which were discussed and a rating for the extent to which the GP had discussed the treatment or care options concerning the addressed problems with the patient (= shared decision making). We also wanted to code who initiated each discussed issue (patient or GP/ GP trainee), but eventually we did not as this proved to be rather difficult. Sometimes, we saw patients giving clear clues, but not mentioning an issue explicitly. In such cases it was difficult to decide who initiated discussing that issue. Besides, a GP asking really good open questions, as such encouraging a patient to start talking about an issue, would not receive a score for that issue. Therefore, we could not analyse the number of issues about which the GP initiated to discuss them meaningfully.

For the outcome 'number of issues discussed' we added the 8 current and 5 anticipated issues to the task-oriented categories of the original RIAS. For the outcome quality of GP's communicative behaviour we added several study-specific 6-point scales to the RIAS (e.g. the extent to which the GP took time with the simulated patient). Four of the six availability items could be scored positively (e.g. 'taking time') as well as negatively (e.g. 'not taking time'). As we were especially interested in the communication by the GPs, we only calculated scores for the GPs (and not for the simulated patient). Besides, as we decided to calculate scores only for the GPs, we did not analyse scores for the simulated patients, nor did we apply sequence analysis to RIAS, thereby leaving other possible outcomes unknown.[62] We defined the number of issues discussed ('what') as the summed number of 13 current and anticipated issues about which the GP made at least one utterance concerning that issue, during the simulated consultation. In this respect, the occurrence or non-occurrence of discussing a particular issue by the GP was our main interest, not the frequency of discussing the issue. Additionally, we calculated for each issue the percentage of consultations in which the GPs discussed that issue.

The quality of a GP's communicative behaviour ('how') was defined as their scores on the six availability items. Because this complex outcome consisted of several numbers and percentages its sub-scores could not be summed up.

After making the aforementioned study-specific adaptations to the original RIAS, the instrument appeared to be applicable for analysis of consultations between GPs or GP trainees with simulated palliative care patients. Average coding time was three to four times the duration of the consultation. We succeeded in achieving interrater reliabilities that are comparable to those achieved in other studies using the RIAS. Although the RIAS is a quantitative method mainly relying on frequencies of communication behaviours, it is a feasible method that produced reliable results for our study.

(3) Methodological considerations on the negative outcomes of both trials (chapter 5-7)

In our two trials among GPs and GP trainees we found no significant effect at GP (trainee) level of the palliative care ACA training programme on the total number of current and anticipated issues that GP (trainee)s discussed in consultations with simulated palliative care patients, or on the quality of their communicative behaviour.[23,24] In the trial among GPs we also found no significant effects at patient level of the ACA communication training programme on patient ratings for palliative care outcomes, satisfaction with the communication with their GP, and GP's availability and discussed current and anticipated issues (ACA scale).[25] Although these findings indicate that the intervention is ineffective, there are methodological issues that should be taken into consideration when interpreting these findings. We will reflect on some of these methodological issues.

(3.1) Setting and participants; high scores at baseline (ceiling effects)

We included GPs who already had chosen to participate in a two-year Palliative Care Peer Group Training Course.[63] By using these Peer Group Training Courses for our study, we realized that we would be recruiting GPs with specific interest in palliative care. Similarly, third years GP trainees were already well trained in communication skills during the first two years of their vocational training. While these choices might have implications for the generalizability of the results, using existing courses increased the feasibility of the project substantially. This selection bias may explain, at least in part, the high level at baseline of most of our outcomes at GP (trainee) and patient level, which allowed little room for improvement on these outcomes over time.

The aforementioned international study comparing the prevalence of GP-patient discussion of end-of-life topics across four countries, found that Dutch GPs discussed more topics than GPs in Italy, Spain or Belgium.[42] This may also be reflected in our results, where we observed high scores at baseline.

Future research on GP communication and care skills training programmes in the palliative care setting should include a broader sample of GPs, focusing on those professionals who have less experience and less a priori interest in palliative care issues. Although this may present real challenges in recruitment to such a programme, a possible lower level of outcomes at baseline would allow room for improvement over time. Given international differences that have been reported in the literature on GPs palliative care-related communication behaviour, future efforts should be devoted to developing appropriate and effective training programmes in other countries as well.

(3.2) Sample size

The power of our trials might have been too low to demonstrate effectiveness of the ACA training, because of relatively low numbers of participants, high loss to follow-up among the GP trainees, only half of the GPs having included patients, and patients at baseline being different than those at follow-up (necessitating less sensitive methods of analysis). Moreover, although we used the actual training group of the GP trainees as a covariate in all analyses, and patients were nested within GP by time combinations, the study was not sufficiently powered to enable multilevel analyses. However, since we found no relevant effects at all, we assume that the problem of low power was not a critical issue in our trials.

(3.3) Non-randomized assignment to groups

As our intervention for GPs was added to an existing Palliative Care Peer Group Training Course and for GP trainees to the regular GP vocational training programme, we had to assign whole existing groups to either the intervention or the control condition. All GPs enrolled in four Palliative Care Peer Group Training Courses in 2006 and 2007 participated in the study. Because we wanted to start with an intervention group in 2006, and to prevent contamination between the two groups starting about the same time in Amsterdam, GPs enrolled in the courses conducted in Eindhoven (2006) and Rotterdam (2007) were assigned to the intervention condition, while GPs who enrolled in the courses in Amsterdam (both 2007) were assigned to the control condition. All GP trainees enrolled in 11 groups that started between June 2007 and July 2008 at the University Medical Centre in Utrecht and at the VU University Medical Center in Amsterdam participated in the study. Because we wanted to avoid imbalance between intervention and control groups at the participating institutes, we assigned groups at each institute to the intervention or control condition alternately. Thus, because of the setting of our trial and the small number of groups, we chose to assign groups of participants to the intervention or control condition, in order to enlarge the chance of getting comparable intervention and control groups. As we had to assign GPs and GP trainees to either the intervention or the control condition without randomization, we carefully compared both groups and included significant between-group differences in background characteristics as covariates in the subsequent analyses. We assume that the way of assigning small numbers of groups of participants to either the intervention or the control condition helped us to achieve comparable groups and did not bias our results. However, we cannot exclude the possibility that there were differences between the groups on characteristics that were not measured.

(3.4) Content and educational approach of intervention

We designed a new training programme for GP-patient communication in palliative care including the following educational components deduced from two recent reviews: the programme is learner-centred, using several methods, carried out over a longer period of time, mostly in small groups to encourage more intensive participation, combining theoretical information with practical rehearsal and constructive feedback from peers and skilled facilitators, thus providing a balance between cognitive learning and experiential learning.[21,22] To support this new training programme, we developed a checklist, based on the results of a systematic review[4] and qualitative study[5] which we have conducted previously to identify factors reported by palliative care patients, their relatives, GPs or end-of-life consultants as relevant for GP-patient communication in palliative care. Although the ACA checklist provides a concise summary of the essential factors for GP-patient communication in palliative care, all separate items (‘how’) and issues (‘what’) are not new, especially not for experienced GPs.

From the results of our trials we know that GP (trainee)s already discuss certain issues in almost every consultation, so the effectiveness of the programme might be increased by focusing on the palliative care specific issues that were discussed less often in our trials.[23,24] We consider the opportunities for GP (trainee)s to assess their individual shortcomings in communication skills and to participate in role-play exercises tailored to their own learning goals as strong characteristics of the ACA training programme. Nevertheless, as we did not record these process outcomes, it is unknown if GP (trainee)s focused their learning activities on their individual shortcomings. Moreover, we do not know if their individual learning goals were related to their (lowest) scores on the ACA items in their simulated consultations. It might be that assessment of individual communication skills at the start of the programme and, consequently, training tailored to individual lowest scores, might increase the effectiveness of the training programme.

Like most other communication skills training programmes for oncologists and oncological nurses that were solely focused on communication skills, the ACA training programme for GP (trainee)s also focuses solely on communications skills.[27-40] However, oncologists and oncology nurses are sometimes already specialized in palliative medicine, while GP (trainee)s are generalists, mostly without special training in palliative medicine. In the trial among GPs, the training was added to the regular content of the Palliative Care

Peer Group Training Course: symptom control, ethical and spiritual/existential issues, and management of care. In the trial among GP trainees, the training was not combined with education in palliative medicine. Future research might explore if training programmes for GP (trainee)s combining palliative medicine issues and communication skills are more effective than interventions focusing on communication skills alone.

(3.5) Way of carrying out the intervention

In order to facilitate implementation of the ACA training programme in future Palliative Care Peer Group Training Courses and in the GP vocational training scheme, the intervention in our trials was carried out by the regular teachers of the Peer Group Training Courses and of the vocational GP training institutes who had received detailed instructions about the training programme. A disadvantage of this choice is that we are not sure if the palliative care consultants in the peer groups (GPs) and the teachers at the vocational training institutes (GP trainees) carried out the programme as intended, since some GPs reported that the ACA checklist was not used during their peer group sessions and GP trainees reported that not all steps of the ACA training programme had been addressed in their group.[20] Furthermore, after the start of the training programme, the GPs and GP trainees were asked to enhance their understanding of the ACA checklist and their insight into their own communication skills by studying the written information, discussing this material with their peers in small groups, and trying out newly acquired skills in their own general practice to identify problem areas from their own experience. However, the extent to which GPs and GP trainees have actively carried out these steps of the programme is unknown. This also holds for the extent to which GPs and GP trainees (explicitly) formulated individual learning goals for their communication skills, and for the extent to which they exercised their individual learning goals in role-plays. Moreover, the extent to which GP trainees have discussed the ACA checklist and booklet with their GP trainers in their vocational training practices is unknown.

Future research on GP-patient communication in palliative care might consider training teachers better, registering learning activities of each individual participant in more detail during the training programme (instead of only interviewing participants afterwards), and ensuring that GP trainers in the vocational training practices are also involved in carrying out the ACA training programme for GP trainees.

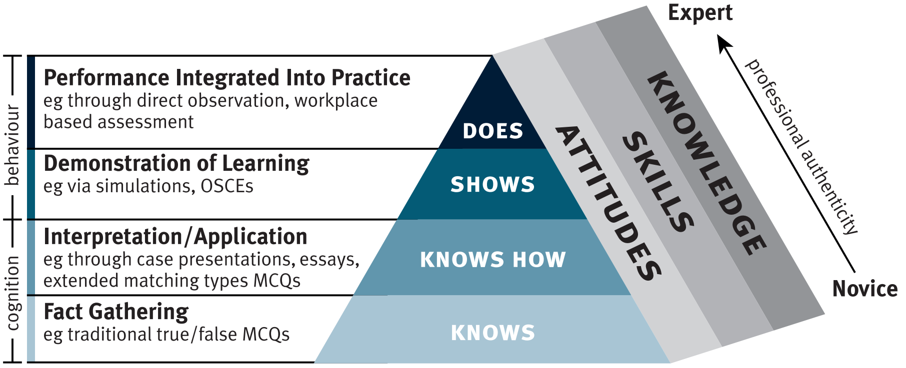
(3.6) Outcome and outcome measurement

Although we discussed extensively the best way to measure effectiveness of the ACA training programme, in retrospect, we consider several issues concerning outcome measurement as possible explanations for our negative results.

(3.6.1) Measurement levels according to the pyramid of Miller

Training effects can be measured on the four levels of competence according to the pyramid model of Miller; 1. knows (knowledge), i.e. recall of basic facts, principles, and theories; 2. knows how (applied knowledge), i.e. ability to solve problems, make decisions, and describe procedures; 3. shows how (competence), i.e. demonstration of skills in a controlled setting; and 4. does (performance), i.e. behaviour in real practice.[64]

Miller's Prism of Clinical Competence (aka Miller's Pyramid)



Based on work by Miller GE, The Assessment of Clinical Skills/Competence/Performance; Acad. Med. 1990; 65(9); 63-67
Adapted by Drs. R. Mehay & R. Burns, UK (Jan 2009)

On the first level of Miller's model the physicians' subjective evaluations about training effects are measured. These evaluations generally focus on the physicians' knowledge, skills and attitudes. Training effects on this level are important but not sufficient determinants of actual behavioural changes. The third level focuses on independent behavioural observations of doctor-patient interactions. Behavioural observations can be regarded as the most important indicator of training effects, since the interventions' aim to improve communication behaviours is tested most directly. The final level involves measurement of outcome effects of the improved interaction with the patient.[65]

In order to clarify what happens during medical encounters and, subsequently, whether the behaviour displayed by the physician is effective, De Haes et al. proposed a framework of functions and endpoints in medical communication research.[66,67] In their framework immediate, intermediate and long-term outcomes are distinguished on the one hand and patient-, provider- and process outcomes on the other. Such 'immediate endpoints' are relevant within the medical encounter and may refer to behaviour of the patient or the provider. Effective doctor-patient communication should contribute to better objective health 'long-term endpoints' for patients.

In our trial among GP trainees (chapter 7), on the first level according to the pyramid model of Miller we used a written knowledge test to assess the knowledge of the GP trainees about medical aspects of palliative care. In chapters 5 and 7 we reported on the effectiveness of the ACA communication training programme at the level of the GP (trainee) competence, which is the third level according to the pyramid model of Miller. These 'how' and 'what' measures are 'immediate endpoints' according to the framework as proposed by de Haes et al. These outcome were measured at the training institute in a consultation with a simulated palliative care patient. In chapter 6 we reported on the outcomes reported by real palliative care patients of the participating GPs. This is the GP performance as perceived by his patient, which is the (patient-reported) fourth level of Miller's pyramid model. These palliative care, quality of life, and patient satisfaction measures are 'long-term endpoints' according to the framework as proposed by de Haes et al.

Considering the possible measures for evaluating effects of communication training programmes, the weakest effects are to be expected on the highest measurement levels according to the pyramid of Miller (i.e. level 3 (competence) and 4 (performance)). In a review, Hulsman et al. showed that training effects on physicians' communication behaviour (i.e. the third level according to Miller) are generally rather limited. Additionally, they found that in studies with the most adequate research designs, the fewest results are reported concerning improvements of communication behaviours.[65] In a Cochrane review by Fellowes et al. on randomized controlled trials on effectiveness of communication skills training for health care professionals (not GPs) working with people who have cancer, such courses also appeared to have only limited effects on outcomes at the third and fourth level according to Miller.[1] Considering these previous findings, from the start of our research project we anticipated the serious challenge of proving effects of the ACA training programme at the highest levels according to Miller, even though we developed an evidence based intervention and used sound methods to evaluate its effectiveness.

High percentages of intervention GPs and GP trainees participating in our trials reported self-perceived effects of the ACA training programme. They reported that they had learned certain issues from the ACA training programme (86 and 89%, respectively) and they experienced changes in their communication in consultations with palliative care patients in their (vocational) general practice (73 and 53%, respectively). These high positive self-reported effects of the ACA training programme are remarkable, as we found no changes in the behavioural observations and patient reported outcomes in our trials. These different results of our measurements on different levels indicate the limited relevance of finding positive training effects on self-reported measures only, as was discussed by Davies et al. in a review.[68]

(3.6.2) Quantitative outcome measures

Our quantitative content analysis (RIAS) of the GP (trainee) consultations, solely relying on frequency of communication behaviours, might not have been sensitive enough to assess changes in overall quality of the GP (trainee)'s communication with the patient.[69]

Future research using real palliative care patients might consider combining quantitative and qualitative research methods. Qualitative methods might seek a patient's view of which GP (trainee) skills and attitudes facilitate and hinder the communication process. In addition to quantitative intervention studies, qualitative studies might aim to describe which GP (trainee) communication skills influence palliative care patient outcomes.

(3.6.3) Number of issues discussed by the GP

In retrospect, we question whether the 'number of issues discussed by the GP' was an appropriate indicator of quality of communication in palliative care. However, we failed to find an effect on either the 'how' of GP (trainee)-patient communication or on any of the patient reported outcomes. On the other hand, the international study of Evans et al. compared the prevalence of GP-patient discussion of end-of-life topics across four countries.[42] This study, which compared the number of discussed topics, suggests, nonetheless, that the authors considered this measure as a relevant outcome of palliative care.

Another aspect of the outcome 'number of topics discussed by the GP' is that we wanted to measure how many issues that were discussed were initiated by the GP. However, it proved difficult to develop a reliable way of coding who initiated each discussed issue (patient or GP/ GP trainee). Eventually, we defined the 'number of issues discussed by the GP' ('what') as the sum of 13 current and anticipated issues about which the GP made at least one utterance concerning that issue during the simulated consultation, irrespective of who initiated the discussion of the issue. Therefore, it is still unknown how often discussion of issues was initiated by the patient and by the GP (trainee). In this way, we may have missed a possible increase in the 'number of discussed issues initiated by the GP'.

(3.6.4) One simulated consultation at baseline and follow-up

Because we did not consider a trial design using a series of (videotaped) consultations of GP (trainee)s with real palliative care patients to be feasible, we measured the outcomes at GP level in one simulated consultation for each GP and GP trainee at baseline and one at follow-up (chapter 5 and 7, 'in vitro'). Because we used only one consultation per GP (trainee) at baseline and follow-up, the setting in which these consultations took place was standardized to avoid any environmental variability, thereby increasing the comparability between the consultations. Nevertheless, these 'in vitro' assessments are different from daily practice, where Dutch GPs visit their palliative care patients frequently at home and thus discussion of the 13 ACA issues will be spread over several visits.

For this reason, in the trial among GPs, we also measured outcomes reported by real palliative care patients of the participating GPs (chapter 6, 'in vivo'). Although these patient-reported outcomes do not have the aforementioned restrictions of one simulated consultation per measurement moment, we did not find any effects of the ACA training programme at patient level either.

Future experimental research on GP (trainee)-patient communication in palliative care might reconsider the feasibility of a study design using real palliative care patients at home and measuring outcomes spread over a series of visits.

(3.6.5) Simulated patients

In order to standardize the assessments we developed two detailed patient roles including medical, psychological, and social information, and we instructed professionally trained actors to respond according to the role and depending on the questions of the GP (trainee)s. At baseline, half of the GP (trainee)s of all groups had a consultation with such a simulated patient (SiP) who role-played a patient with advanced stage lung cancer. The other 50% saw a SiP playing the role of a patient with advanced colon cancer. At the follow-up assessment, this was reversed.

It may be that using SiPs for outcome measurement is more appropriate for studying aspects of care restricted to one consultation than to studying care situations in which diagnostic and therapeutic interventions are spread over several contacts.[70]

Post hoc, in the trial among GP trainees we found in the consultations with the highest scores that SiPs brought up more issues than GP trainees did. Some GP trainees achieved high scores by asking adequate open questions, while others achieved them by apparently 'not knowing what to say' and waiting for the patient to speak. It seemed that allowing the patient room to raise their problems was enough to achieve a high score. This probably also happens with real patients in daily practice, but our SiPs, knowing their role well and having played it many times, might have initiated discussion of more issues than real patients would have done. While we wanted to test how many and which issues would be brought up by the GPs and GP trainees as a result of the programme, the results were probably influenced by the behaviour of the actors. Additionally, although the SiPs received detailed instructions, a specific training programme for the actors was not included and we did not determine the validity and reliability of their performance.[71,72] Variability in how many issues the SiPs brought up might also have influenced our results.

Future experimental research on GP (trainee)-patient communication in palliative care might reconsider the feasibility of a study design observing a series of GP (trainee) consultations with real palliative care patients.

(3.6.6) Effect of communication skills training over time

In our trial among GPs, the follow-up measurement was performed 12 months after baseline, this was 6 months after the last step of the training. In our trial among GP trainees, the follow-up measurement was performed 6 months after baseline, this was 3 months after the last step of the training. We had to use slightly different timetables for the two trials, because the intervention had to fit in existing courses. Other studies (not among GP (trainee)s) showed that some effects of communication skills training in cancer care maintained while other outcomes changed over time.[31,73,74] This matter might have influenced our results. It is unknown how much time the integration process of the newly acquired behaviours may take.[65] Incorporation of follow-up measurements in future study designs may provide more insight in the course of palliative care communication skills training effects among GP (trainee)s over time.

Implications for general practice

At the start of our research project we aimed to determine how and what GPs should communicate with palliative care patients (question I.). From all identified factors in the explorative studies, we selected the facilitating items regarding the communicative behaviour of a GP providing palliative care and the issues that should be raised by the GP, and we summarized these factors into the 19 items of the ACA checklist. We divided these items into three categories: [1] the *availability* of the GP for the patient, [2] *current issues* that should be raised by the GP, and [3] the GP *anticipating* various scenarios (ACA).

We recommend the GP to apply all six items concerning availability during each visit, because these items can be considered as necessary conditions for effective communication. The eight items for 'current issues' and the five items for 'anticipating' should be explicitly addressed by the GP, but not necessarily all during one visit. It seems even preferable to spread discussion about these 13 issues over several visits, allowing GP and patient to take the necessary time for each issue. During every visit the GP and the patient can identify and discuss those issues on the ACA checklist that are most relevant for the patient at that moment. GPs can use the ACA checklist in practice in the following ways: [1] before and during a palliative care consultation to obtain an overview of the issues that can be addressed; [2] after a series of consultations to check if all essential issues have been discussed with the patient; [3] to detect possible causes of problems in communication.

The descriptive results from our experimental studies at the GP and the patient level suggest that, although palliative care patients were generally quite satisfied with the care received from their GPs, GPs should take the initiative to discuss certain end-of-life issues with their patients, including spiritual/existential issues, unfinished business, prognosis and possible complications, the actual process of dying, and end-of-life decisions more often and/or more thoroughly.

Implications for GP vocational training

Our applicability study revealed possibilities to improve the implementation of the ACA training programme in GP vocational training. Because the GP trainees appreciated using the ACA checklist in practice more than using it as a learning tool, we recommend that they first try out the checklist in practice or role-play and afterwards reflect on their experiences with peers or their GP trainer. Therefore, the GP trainers in the vocational training practices should receive detailed instructions about the ACA training programme like the regular teachers in the vocational GP training institutes.

We consider the opportunities for GP trainees to assess their individual shortcomings in communication skills and to participate in role-play exercises tailored to their own learning goals as strong characteristics of the ACA training programme. The use of a checklist to clarify individual learning goals to facilitate the learning process might be extended to other topics and educational areas.

Future research

In the introduction we questioned the quality of communication by GPs with their patients receiving palliative care. As we found somewhat conflicting results from our qualitative and experimental studies, future research might explore the quality of GP-patient communication in palliative care further. Such an investigation will present real challenges in recruitment of palliative care patients who are willing and able to report about unsatisfactory communication or care by their GP. Such recruitment should especially avoid selection bias by GPs including patients. Besides, interviewing patients will probably bring about more in-depth information on this delicate issue than questionnaires will produce.

Our applicability and effectiveness studies mainly used quantitative measurements. Counting attendance and appreciation scores assessed the applicability of the programme. Effectiveness was assessed by counting GP (trainee) behaviours and patient-reported ratings. Especially when studying a complex intervention, future research, preferably using real palliative care patients, might consider combining quantitative and qualitative methods in order to achieve more differentiated results that neither approach, if used alone, could achieve.

In this thesis, we have discussed our experimental studies and compared them to other studies on effectiveness of communication skills training programmes in palliative and cancer care. These studies reported small or no effects at behavioural level and hardly any studies demonstrated an impact upon patient outcomes. These results show that future research will still meet the challenge of developing effective communication training programmes and appropriate designs to assess their effects. Regarding the ACA training programme, we are not sure whether the programme is not effective or whether the used methods to assess its effectiveness were insufficient for this aim, or both. Considering the high scores at baseline in our studies and in several others, we suggest to use the baseline outcomes to focus subsequent training programmes on the parts of the programme with the lowest scores. Within the context of a trial, however, it is hardly possible to conduct a proper evaluation of baseline scores before defining the content of the intervention. Hence, we advocate to plan an observational study in which the actual levels of outcome variables are assessed in the study population as an intermediate step between explorative and experimental studies.

Future research on effectiveness of GP communication and care skills training programmes in the palliative care setting should include a broader sample of GPs than in our study, focusing on those professionals who have less experience (and perhaps less a priori interest) in palliative care issues. Although this may present real challenges in recruitment to such a programme, a possible lower level of outcomes at baseline would allow room for improvement over time. Given international differences that have been reported in the literature on GPs palliative care-related communication behaviour, future efforts should be devoted to developing appropriate and effective training programmes in other countries as well. Such future research might aim to conduct highly powered trials by including larger numbers of GP (trainee)s and patients. Furthermore, the long-term effectiveness of the communication skills training programme might be studied. Moreover, process outcomes should be recorded during the programme to know if GP (trainee)s focus their learning activities on their individual shortcomings, and if their individual learning goals were related to their (lowest) scores on the ACA items in their simulated consultations. Future experimental research on GP (trainee)-patient communication in palliative care might reconsider the feasibility of a study design using real palliative care patients at home and measuring outcomes spread over a series of visits (instead of using simulated patients). Hopefully, the lessons learned from our studies evaluating the effectiveness of the ACA training programme can contribute to such efforts in the future.

Conclusion

Based on best available evidence, we developed a training programme intended to improve GP-patient communication in palliative care. Unfortunately, we did not succeed in demonstrating its effectiveness in trials among GPs and GP trainees. Future research is needed to determine if the effectiveness of the ACA training programme can be improved by focusing more on specific palliative care issues and by broadening the target population of GPs to include those with less experience or affinity with palliative care.

References

1 **Fellowes D, Wilkinson S, Moore P.** Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004; Art. No.: CD003751. DOI: 10.1002/14651858.CD003751.pub2.

2 **Gysels M, Richardson A, Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Support Care Cancer* 2004; 12: 692-700.

3 **Low J, Cloherty M, Wilkinson S, Barclay S, Hibble A.** A UK-wide postal survey to evaluate palliative care education amongst General Practice Registrars. *Palliat Med* 2006; 20: 463-469.

4 **Slort W, Schweitzer BPM, Blankenstein AH, Abarshi EA, Riphagen II, Echteld MA, Aaronson NK, Van der Horst HE, Deliens L.** Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliat Med* 2011; 25: 613-629.

5 **Slort W, Blankenstein AH, Deliens L, Van der Horst HE.** Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011; 61: 167-672.

6 **Grunfeld E, Lethbridge L, Dewar R, Lawson B, Paszat LF, Johnston G, Burge F, McIntyre P, Earle CC.** Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. *Palliat Med* 2006; 20: 769-777.

7 **Hearn J, Higginson IJ.** Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Palliative Care Core Audit Project Advisory Group. Qual Health Care* 1999; 8: 219-227.

8 **Groenvold M, Petersen MA, Aaronson NK, Arraras JI, Blazeby JM, Bottomley A, Fayers PM, de Graeff A, Hammerlid E, Kaasa S, Sprangers MA, Bjorner JB; EORTC Quality of Life Group.** The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. *Eur J Cancer* 2006; 42: 55-64.

9 **Van den Brink-Muinen A, Verhaak PF, Bensing JM, Bahrs O, Deveugele M, Gask L, Mead N, Leiva-Fernandez F, Perez A, Messerli V, Oppizzi L, Peltenburg M.** Communication in general practice: differences between European countries. *Fam Pract* 2003; 20: 478-485.

10 **Hobma SO, Ram PM, Muijtjens AM, Grol1 RP, van der Vleuten CP.** Setting a standard for performance assessment of doctor patient communication in general practice. *Med Educ* 2004; 38: 1244-1252.

11 **Deveugele M, Derese A, de Bacquer D, van den Brink-Muinen A, Bensing J, de Maeseneer J.** Consultation in general practice: a standard operating procedure? *Patient Educ Couns* 2004; 54: 227-233.

12 **Deschepper R, Bernheim JL, Stichele RV, Van den Block L, Michiels E, Van Der Kelen G, Mortier F, Deliens L.** Truth-telling at the end of life: A pilot study on the perspective of patients and professional caregivers. *Patient Educ Couns* 2008; 71: 52-56.

13 **Michiels E, Deschepper R, Bilsen J, Mortier F, Deliens L.** Information disclosure to terminally ill patients and their relatives: self-reported practice of Belgian clinical specialists and general practitioners. *Palliat Med* 2009; 23: 345-353.

14 **Osse BH, Vernooij-Dassen MJ, Schade E, Grol RP.** The problems experienced by patients with cancer and their needs for palliative care. *Support Care Cancer* 2005; 13: 722-732.

15 **Osse BHP, Vernooij-Dassen MJFJ, Schade E, de Vree B, van den Muijsenbergh ME, Grol RP.** Problems to discuss with cancer patients in palliative care: A comprehensive approach. *Patient Educ Couns* 2002; 47: 195-204.

16 **Van den Muijsenbergh M. Palliatieve zorg: De persoonlijke specialiteit van elke huisarts.** *Huisarts Wet* 2003; 46: 80-85.

17 **Epstein RM, Street RL, Jr.** Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. *Bethesda: National Cancer Institute, 2007,* NIH Publication No. 07-6225.

18 **Hancock K, Clayton JM, Parker SM, Wal der S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH.** Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007; 21: 507-517.

19 **Clayton JM, Hancock K, Parker S, Butow PN, Walder S, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Olver IN, Tattersall MH.** Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psychooncology* 2008; 17: 641-659.

20 **Slort W, Blankenstein AH, Wanrooij BS, Van der Horst HE, Deliens L.** The ACA training programme to improve communication between general practitioners and their palliative care patients: development and applicability. *BMC Palliat Care* 2012;11:9. Doi:10.1186/1472-684X-11-9.

21 **Alvarez MP, Agra Y.** Systematic review of educational interventions in palliative care for primary care physicians. *Palliat Med 2006,* 20:673-683.

22 **Gysels M, Richardson A, Higginson IJ.** Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer* 2005, 13: 356-366.

23 **Slort W, Blankenstein AH, Schweitzer BPM, Knol DL, Deliens L, Aaronson NK, Van der Horst HE.** Effectiveness of the ACA (Availability, Current issues and Anticipation) training programme on GP-patient communication in palliative care; a controlled trial. *BMC Fam Pract* 2013; 14: 93.

24 **Slort W, Blankenstein AH, Schweitzer BPM, Deliens L, Van der Horst HE.** Effectiveness of the ‘availability, current issues and anticipation’ (ACA) training programme for general practice trainees on communication with palliative care patients: A controlled trial. *Patient Education and Counseling* 2014; 95: 83-90.

25 **Slort W, Blankenstein AH, Schweitzer BPM, Knol DL, Van der Horst HE, Aaronson NK, Deliens L.** Effectiveness of the palliative care ‘Availability, Current issues and Anticipation’ (ACA) communication training programme for general practitioners on patient outcomes: A controlled trial. *Palliat Med* 2014, June 20, doi: 10.1177/0269216314538302.

26 **Hermann K, Engeser P, Szecsenyi J, Miksch A.** Palliative patients cared for at home by PAMINO-trained and other GPs - health-related quality of life as measured by QLQ-C15-PAL and POS. *BMC Palliat Care* 2012; 11: 13. Doi:10.1186/1472-684X-11-13.

27 **Barnes S, Gardiner C, Gott M, Payne S, Chady B, Small N, Seamark D, Halpin D.** Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage* 2012; 44: 866-879. Doi: 10.1016 /j.jpainsymman.2011.11.009.

28 **Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA.** Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database of Systematic Reviews* 2013, Issue 3. Art. No.: CD003751. DOI: 10.1002/14651858.CD003751.pub3.

29 **Razavi D, Delvaux N, Marchal S, Durieux J-F, Farvacques C, Dubus L, Hogenraad R.** Does training increase the use of more emotionally laden words by nurses when talking with cancer patients? A randomised study. *Br J Cancer* 2002; 87: 1-7.

30 **Razavi D, Merckaert I, Marchal S, Libert Y, Conradt S, Boniver J, Etienne AM, Fontaine O, Janne P, Klastersky J, Reynaert C, Scalliet P, Slachmuylder JL, Delvaux N.** How to optimize physicians’ communication skills in cancer care: results of a randomized study assessing the usefulness of post-training consolidation workshops. *J Clin Oncol* 2003; 21: 3141-3149.

31 **Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R.** Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled study. *Lancet* 2002 ;359: 650-656.

32 **Wilkinson S, Perry R, Blanchard K, Linsell L.** Effectiveness of a three-day communication skills course in changing nurses’ communication skills with cancer/palliative care patients: a randomised controlled trial. *Palliat Med* 2008; 22: 365-375.

33 **Shilling V, Jenkins V, Fallowfield L.** Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? *Psychooncology* 2003; 12: 599-611.

34 **Sitzia J.** How valid and reliable are patient satisfaction data? An analysis of 195 studies. *Int J Qual Health Care* 1999; 11: 319-328.

35 **Jenkins V, Fallowfield L.** Can communication skills training alter physicians’ beliefs and behavior in clinics? *J Clin Oncol* 2002; 20: 765-769.

36 **Hulsman RL, Ros WJ, Winnubst JA, Bensing JM.** The effectiveness of a computer-assisted instruction programme on communication skills of medical specialists in oncology. *Med Educ* 2002; 36: 125-134.

37 **Barth J, Lannen P.** Efficacy of communication skills training courses in oncology: a systematic review and meta-analysis. *Ann Oncol* 2011; 22: 1030-1040.

38 **Uitterhoeve R, Bensing J, Grol R, de Mulder P, Van Achterberg T.** The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. *Eur J Cancer Care* 2010; 19: 442-457.

39 **Johnson LA, Gorman C, Morse R, Firth M, Rushbrooke S.** Does communication skills training make a difference to patients' experiences of consultations in oncology and palliative care services? *Eur J Cancer Care* 2013; 22: 202-209.

40 **Fallowfield LJ, Solis-Trapala I, Jenkins VA.** Evaluation of an Educational Program to Improve Communication with Patients About Early-Phase Trial Participation. *Oncologist* 2012; 17: 377-383.

41 **Brookes ST, Whitley E, Peters TJ, Mulheran PA, Egger M, Davey Smith G.** Subgroup analyses in randomised controlled trials: quantifying the risks of false-positives and false-negatives. *Health Technol Assess* 2001; 5: 1-56.

42 **Evans N, Costantini M, Pasman HR, Van den Block L, Donker GA, Miccinesi G, Bertolissi S, Gil M, Boffin N, Zurriaga O, Deliens L, Onwuteaka-Philipsen B.** End-of-Life Communication: A Retrospective Survey of Representative General Practitioner Networks in Four Countries. *J Pain Symptom Manage.* 2013 Aug 7. pii: S0885-3924(13)00331-X. doi: 10.1016/j.jpainsymman.2013.04.008.

43 **Mays N, Pope C.** Assessing quality in qualitative research. *BMJ* 2000; 320: 50-52.

44 **Thomas J, Harden A, Oakley A, Oliver S, Sutcliffe K, Rees R, Brunton G, Kavanagh J.** Integrating qualitative research with trials in systematic reviews. *BMJ* 2004; 328: 1010-1012.

45 **Dixon-Woods M, Shaw RL, Agarwal S, Smith JA.** The problem of appraising qualitative research. *Qual Saf Health Care* 2004; 13: 223-225.

46 **Eakin JM, Mykhalovskiy E.** Reframing the evaluation of qualitative health research: reflections on a review of appraisal guidelines in the health sciences. *J Eval Clin Pract.* 2*003; 9: 187-194.*

47 **Horsburgh D.** Evaluation of qualitative research. *J Clin Nurs.* 2003; 12: 307-312.

48 **Treloar C, Champness S, Simpson PL, Higginbotham N.** Critical appraisal checklist for qualitative research studies. *Indian J Pediatr.* 2000; 67: 347-351.

49 **Popay J, Rogers A, Williams G.** Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998; 8: 341-351.

50 **Hawker S, Payne S, Kerr C, Hardey M, Powell J.** Appraising the evidence: reviewing disparate data systematically. *Qual Health Res* 2002; 12: 1284-1299.

51 **Vermeire E, Van Royen P, Griffiths F, Coenen S, Peremans L, Hendrickx K.** The critical appraisal of focus group research articles. *Eur J Gen Pract* 2002; 8: 104-108.

52 **Dixon-Woods M, Fitzpatrick R, Roberts K.** Including qualitative research in systematic reviews: opportunities and problems. *J Eval Clin Pract* 2001; 7: 125-133.

53 **Dixon-Woods M, Sutton A, Shaw R, Miller T, Smith J, Young B, Bonas S, Booth A, Jones D.** Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *J Health Serv Res Policy* 2007; 12: 42-47.

54 **Oliver S, Harden A, Rees R, Shepherd J, Brunton G, Oakley A.** Young people and mental health: novel methods for systematic review of research on barriers and facilitators. *Health Educ Res* 2008; 23: 770-790.

55 **Noyes J, Popay J, Pearson A, Hannes K, Booth A, on behalf of the Cochrane Qualitative Research Methods Group.** Qualitative research and Cochrane reviews. *In: Higgins JPT and Green S (eds).* Cochrane handbook for systematic reviews of interventions. *5.0.2* [updated September 2009], http://www.cochranehandbook. org. The Cochrane Collaboration, 2009.

56 **Harden A, Garcia J, Oliver S, Rees R, Shepherd J, Brunton G, Oakley A.** Applying systematic review methods to studies of people's views: an example from public health research. *J Epidemiol Community Health* 2004; 58: 794-800.

57 **Harden A, Brunton G, Fletcher A, Oakley A.** Teenage pregnancy and social disadvantage: systematic review integrating controlled trials and qualitative studies. *Br Med J* 2009; 339: b4254.

58 **Antunes B, Harding R, Higginson IJ, on behalf of EUROIMPACT.** Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Palliat Med* 2013; DOI: 10.1177/0269216313491619.

59 **Roter DL.** The Roter Method of Interaction Process Analysis: RIAS Manual. *Baltimore: Johns Hopkins University;* 1993.

60 **Roter D, Larson S.** The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Educ Couns* 2002, 46: 243-251.

61 **Bensing JM.** Doctor-Patient Communication and the Quality of Care. An observational study into affective and instrumental behavior in general practice. *Doctoral Dissertation. NIVEL: Utrecht;* 1991.

62 **Eide H, Quera V, Graugaard P, Finset A.** Physician-patient dialogue surrounding patients' expression of concern: applying equence analysis to RIAS. *Soc Sci Med.* 2004; 59: 145-155.

63 **Kuin A, Wanrooij BS, Deliens L, Willems DL, Van der Wal, G.** Does the Palliative Care Peer Group Training project for GPs benefit the patients? 2006, unpublished paper.

64 **Miller GE.** The assessment of clinical skills/competence/ performance. *Acad Med* 1990; 65: S63-7.

65 **Hulsman RL, Ros WJG, Winnubst JAM, Bensing JM.** Teaching clinically experienced physicians communication skills. A review of evaluation studies. *Medical Education* 1999; 33: 655-668.

66 **de Haes H, Bensing J.** Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient Educ Couns.* 2009; 74: 287-294. Doi: 10.1016/j.pec.2008.12.006.

67 **Street RL Jr, De Haes HC.** Designing a curriculum for communication skills training from a theory and evidence-based perspective. *Patient Educ Couns.* 2013; 93: 27-33. Doi: 10.1016/j.pec.2013.06.012.

68 **Davis DA, Mazmanian PE, Fordis M, Van Harrison R, Thorpe KE, Perrier L.** Accuracy of physician self-assessment compared with observed measures of competence: a systematic review. *JAMA.* 2006; 296: 1094-1102.

69 **Dulmen, S. van.** The key to good healthcare communication. *Patient Educ Couns* 2002; 46: 233-234.

70 **Buellens J, Rethans JJ, Goedhuys J, Buntinx F.** The use of standardized patients in research in general practice. *Family Practice* 1997; 14: 58-62.

71 **Wallace J, Rao R, Haslam R.** Simulated patients and objective structured clinical examinations: a review of their use. *Advances in Psychiatric Treatment* 2002; 8: 342-348.

72 **Churchouse C, McCafferty C.** Standardized patients versus simulated patients: Is there a difference? Clinical *Simulation in Nursing* 2012; 8: e363-e365. doi:10.1016/j.ecns.2011.04.008.

73 **Fallowfield L, Jenkins V, Farewell V, Solis-Trapala I.** Enduring impact of communication skills training: results of a 12-month follow-up. *Br J Cancer* 2003; 89: 1445-1449.

74 **Butow P, Cockburn J, Girgis A, Bowman D, Schofield P, D'Este C, Stojanovski E, Tattersall MH; CUES Team.** Increasing oncologists' skills in eliciting and responding to emotional cues: evaluation of a communication skills training program. *Psychooncology* 2008; 17: 209-218.

Summary, including the ACA checklist

Summary

General practitioners (GPs) play a central role in providing palliative care in many countries. In order to provide high-quality care, effective communication between health care professionals and patients is considered to be an essential requirement. GP-patient communication in palliative care will often be difficult, due to the severity and complexity of this situation, involving a mix of medical, psychological, social and spiritual/existential issues. If the communication is not effective, some, if not many, of the problems that patients are facing might not be identified by GPs. Consequently, it is likely that GPs will not be able to take the appropriate actions, and the patient's quality of life may be unnecessarily impaired. Knowledge about factors that hinder or facilitate GPs in their communication with patients in palliative care is needed for the development of effective training programmes to equip GPs to be effective communicators, and ultimately to improve the quality of the palliative care they provide and the quality of life of their patients.

The aim of the research project described in this thesis was to develop and test a communication training programme for GPs and GP trainees providing care to patients in palliative care, in order to improve health-related patient outcomes. The project comprised three parts: (1) explorative studies; (2) development of a communication training programme; and (3) experimental studies.

(1) The explorative studies

In **chapter 2** we reported on a systematic **review** of the literature aimed at identifying facilitators of and barriers to GP-patient communication in palliative care based on a search in seven computerized databases. The most frequently reported facilitators were: the availability of the GP, longstanding GP-patient relationships, GPs showing commitment, being open and allowing any topic to be discussed, being honest and friendly, listening actively and taking patients seriously, taking the initiative to talk about end-of-life issues, not withholding information, negotiating palliative care options, being willing to talk about the diagnosis and prognosis, preparation for death, the patient's psychological, social and spiritual issues and the patient's end-of-life preferences. The most frequently reported barriers were: the GP's lack of time, the patient's ambivalence or unwillingness to be informed about the prognosis, and the GP not talking honestly about the diagnosis or prognosis. The results of our review suggest that, to be effective communicators in the palliative care setting, GPs should be available for their patients, and take the initiative to talk honestly about the many relevant end-of-life issues.

In **chapter 3** we presented the results of a **qualitative study** on facilitators of and barriers to GP-patient communication in palliative care. For this study, we interviewed palliative care patients, asked GPs to discuss this issue in focus groups, and asked end-of-life consultants to complete a questionnaire. Patients as well as GPs valued accessibility, taking time, showing commitment, and listening carefully as facilitators. 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. Almost all participating end-of-life consultants had observed problems in GP-patient communication in the past year (e.g., GP failing to clarify the patient's concerns sufficiently, GP not anticipating various scenarios). The results of the qualitative study suggested that the quality of the GP-patient communication in palliative care could be improved. More specifically, 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), and they should take the initiative more often to discuss several end-of-life issues (e.g., the unfavourable prognosis, unfinished business, end-of-life preferences).

(2) The development of the ACA communication training programme

In **chapter 4** we described the **development** of a new palliative care specific communication training programme for GPs and evaluated the **first experiences** of a group of GPs and a group of GP trainees with this new training programme. To support this new training programme we developed the 19-items checklist which summarized the GP-related facilitators identified in the explorative studies, divided into three categories: [1] the *availability* of the GP for the patient, [2] *current issues* that should be raised by the GP, and [3] the GP *anticipating* various scenarios (ACA). To assess the applicability of the programme we evaluated the rate of attendance of GPs and GP trainees and their appreciation of the different steps of the programme. The ACA checklist was appreciated by GPs as useful both in practice and as a learning tool, whereas GP trainees mainly appreciated the list for use in practice.

(3) The experimental studies

In **chapter 5** we reported on a controlled **trial** that evaluated the effectiveness of the ACA training programme on outcomes at the GP level. To determine these outcomes, we performed a quantitative content analysis (Roter Interaction Analysis System = RIAS) of one videotaped consultation of each GP with a simulated palliative care patient conducted at baseline, and one at twelve months follow-up. Both how the GP communicated with the patient ('availability') and the number of current and anticipated issues the GP discussed with the patient were measured. We found no effect of the ACA communication training programme on the total number of current and anticipated issues that GPs discussed in the simulated consultations, or on the quality of their communicative behaviour.

In **chapter 6** we presented the same controlled **trial** to evaluate effectiveness of the

ACA training programme but reporting outcomes at patient level. We asked real palliative care patients of the participating GPs to complete a questionnaire at baseline and at 12 months follow-up. Outcomes were: palliative care outcomes (the Palliative Care Outcome Scale [POS], the EORTC Quality of Life Questionnaire Core 15 Palliative [QLQ-C15-PAL] and the Rest & Peace Scale); satisfaction with the communication with their GP (the Patient Satisfaction Questionnaire-III [PSQ-III]); and the patient's perception of the GP's availability and the extent to which current and anticipated issues were discussed (the ACA scale). We also found no effect of the ACA training programme on these patient reported outcomes.

In **chapter 7** we reported on a similar controlled **trial** to evaluate the effectiveness of the ACA training programme but among third years GP trainees. For each GP trainee, we videotaped a consultation with a simulated palliative care patient at baseline and at six months follow-up. Outcomes were the same as used in chapter 5. We found no effect of the ACA communication training programme on the total number of current and anticipated issues that GP trainees discussed in the simulated consultations, or on the quality of their communicative behaviour.

The descriptive results from both controlled trials suggest that, although palliative care patients were generally quite satisfied with the communication and palliative care provided by their GPs (chapter 6), GPs and GP trainees should take the initiative more often to discuss certain end-of-life issues, including spiritual/existential issues, unfinished business, prognosis and possible complications, the actual process of dying, and end-of-life decisions (chapter 5-7).

Finally, in **chapter 8** we summarized the main findings of our studies and discussed methodological considerations and the implications of our results for general practice, GP vocational training, and future research.

While many studies on effectiveness of communication skills training among oncologists and oncology nurses found positive effects on health care professional level and only few effects on patient-reported outcomes, we found no effects of the ACA training programme at GP (trainee) and patient level. Including GPs who already had chosen to participate in a two-year Palliative Care Peer Group Training Course and third years GP trainees may explain, at least in part, the high level at baseline of most of our outcomes at GP (trainee) and patient level, which allowed little room for improvement on these outcomes over time (ceiling effect). Besides, in spite of the high total number of issues discussed in a consultation, there seems to be room for improvement on the scores in some current and anticipated issues. The effectiveness of the programme might be increased by including a broader sample of GPs and by focusing on the issues which were discussed less often in our studies.

The ACA checklist

Availability (of the GP for the patient)

(1) Taking time
(2) Allowing any subject to be discussed
(3) Active listening
(4) Facilitating behaviour (e.g. empathic, respectful, attentive, occasionally also phoning or visiting the patient spontaneously)
(5) Shared decision-making with regard to diagnosis and treatment plan
(6) Accessibility (e.g. phone numbers)

Current issues (that should be raised by the GP)

(1) Diagnosis
(2) Prognosis
(3) Patient's physical complaints and worries
(4) Patient's psychosocial complaints and worries
(5) Patient's spiritual/existential complaints and worries
(6) Wishes for the present and the coming days
(7) Unfinished business, bringing life to a close
(8) Discussing treatment and care options (concerning current issues 1-7)

Anticipating (various scenarios)

(1) Offering follow-up appointments
(2) Possible complications
(3) Wishes for the coming weeks/months (personal wishes as well as preferences with regard to medical decisions)
(4) The actual process of dying (final hours/days)
(5) End-of-life decisions

Samenvatting, met de AAA checklist

Huisarts-patiënt communicatie in de palliatieve zorg

Aanwezigheid, actuele onderwerpen en anticiperen

Huisartsen spelen in veel landen een centrale rol in de palliatieve zorg. Om zorg van hoge kwaliteit te kunnen verlenen, wordt effectieve communicatie tussen hulpverlener en patiënt als noodzakelijke voorwaarde beschouwd. Binnen de palliatieve zorg is de communicatie tussen huisarts en patiënt vaak niet gemakkelijk door de ernst en complexiteit van de situatie aan het einde van het leven. Hierbij zijn zowel lichamelijke als psychosociale en spirituele/existentiële aspecten sterk met elkaar verweven. Pas wanneer al deze aspecten ter sprake komen, kan de huisarts in overleg met de patiënt het best passende beleid kiezen. Voor het ontwikkelen van effectieve trainingsprogramma's op dit gebied was meer kennis nodig over factoren die huisartsen helpen of juist hinderen in hun communicatie met patiënten in de palliatieve fase. Dergelijke trainingsprogramma's zouden huisartsen in staat moeten stellen effectiever te communiceren om daarmee de kwaliteit van de verleende palliatieve zorg en de kwaliteit van leven van patiënten te verbeteren.

Het doel van ons onderzoek was om een trainingsprogramma voor huisartsen en aios huisartsgeneeskunde (een aios is een arts in opleiding tot specialist) specifiek over communicatie in de palliatieve zorg te ontwikkelen en te testen. Het achterliggende doel was om daarmee de gezondheid van patiënten te verbeteren. Het onderzoek bestaat uit drie delen: (1) explorerende studies, (2) ontwikkeling van een trainingsprogramma en (3) experimentele studies.

(1) Explorerende studies

In **hoofdstuk 2** rapporteerden we een systematische **review** met het doel factoren te verzamelen die de communicatie tussen huisarts en patiënt in de palliatieve zorg helpen of juist hinderen. Helpende factoren waren bijvoorbeeld dat huisarts 'er is' voor de patiënt (= 'aanwezigheid'), dat de huisarts goed luistert en zich betrokken, open en eerlijk opstelt, daarbij ruimte gevend om alle onderwerpen te kunnen bespreken. Verder helpt het wanneer de huisarts initiatief neemt om te praten over onderwerpen als diagnose en prognose, psychosociale en spirituele/existentiële vragen van de patiënt en het levenseinde. Hinderende factoren waren bijvoorbeeld dat de huisarts te weinig tijd neemt, dat de patiënt niet 'alle details' wil weten over zijn prognose en dat de huisarts niet eerlijk spreekt over diagnose en prognose.

In **hoofdstuk 3** presenteerden we een **kwalitatieve studie** over helpende en hinderende factoren voor de huisarts-patiënt communicatie in de palliatieve zorg. Voor deze studie interviewden we patiënten die palliatieve zorg kregen van hun huisarts, nodigden we huisartsen uit om het onderwerp te bespreken in focusgroepen en vroegen we levenseinde-consulenten om een vragenlijst in te vullen. Huisartsen en patiënten noemden als helpende factorenen: bereikbaarheid, de tijd nemen, betrokkenheid tonen en zorgvuldig luisteren. Huisartsen en levenseinde-consulenten noemden als hinderende factorenen: de huisarts heeft moeite met het omgaan met een 'delay' of mogelijke fout en met eisende familieleden van patiënten. Bijna alle levenseinde-consulenten waren in het afgelopen jaar betrokken geweest bij een situatie waarbij de huisarts-patiënt communicatie problematisch verliep (bijvoorbeeld door het onvoldoende verhelderen van de zorgen van de patiënt door de huisarts, of doordat de huisarts onvoldoende anticipeerde op mogelijke problemen).

Op basis van de explorerende studies concludeerden we dat de kwaliteit van de communicatie tussen huisarts en patiënt in de palliatieve zorg nog verbeterd kon worden. Met name zouden huisartsen meer aandacht moeten geven aan hoe ze communiceren met hun patiënten (bijvoorbeeld de tijd nemen, zorgvuldig luisteren, over elk gewenst onderwerp willen spreken, ook eens spontaan de patiënt bellen of bezoeken) en huisartsen zouden vaker het initiatief moeten nemen om met de patiënt te spreken over diverse onderwerpen die spelen rond het levenseinde (bijvoorbeeld een ongunstige prognose, 'unfinished business', mogelijke complicaties, en wensen over het levenseinde).

(2) Ontwikkeling van het AAA-trainingsprogramma

In **hoofdstuk 4** beschreven we de **ontwikkeling** van een nieuw trainingsprogramma voor huisartsen specifiek over communicatie in de palliatieve zorg. Tevens evalueerden we de **eerste ervaringen** van een groep huisartsen en een groep aios huisartsgeneeskunde met dit programma. Als hulpmiddel ontwikkelden we een checklist, bestaande uit 19 items, waarin de helpende factoren uit de explorerende studies werden samengevat. Deze checklist is onderverdeeld in drieën: (1) de ***a**anwezigheid* van de huisarts voor de patiënt, (2) de ***a**ctuele onderwerpen* die door de huisarts aan de orde gesteld moeten worden, en (3) het ***a**nticiperen* door de huisarts op diverse scenario's (AAA-checklist).

We evalueerden de uitvoerbaarheid van het trainingsprogramma door te kijken hoeveel huisartsen en aios deelnamen aan de diverse onderdelen en hoe zij die waardeerden. Het trainingsprogramma bleek goed uitvoerbaar in de groep huisartsen en de groep aios. De huisartsen waren positief over het gebruik van de AAA-checklist zowel in de praktijk als bij het onderwijs, terwijl de aios vooral het gebruik van de checklist in de praktijk waardeerden.

(3) De experimentele studies

In **hoofdstuk 5** presenteerden we een gecontroleerde interventiestudie om de effecten van het AAA-trainingsprogramma op huisartsniveau te onderzoeken. De effecten werden gemeten door een kwantitatieve analyse (RIAS = 'Roter Interactive Analysis

System') van een op video opgenomen consult van elke huisarts met een gesimuleerde palliatieve zorg patiënt voor de start van de training, en een consult een jaar later. We maten hoe de huisarts met de patiënt communiceerde ('aanwezigheid') en hoeveel actuele en anticipatie onderwerpen de huisarts met de patiënt besprak. Op beide uitkomsten vonden we geen effect van het AAA-trainingsprogramma.

In **hoofdstuk 6** presenteerden we een ander onderdeel van dezelfde interventiestudie als in hoofdstuk 5, namelijk met uitkomsten op patiëntniveau. We vroegen aan patiënten die palliatieve zorg van de deelnemende huisartsen kregen een vragenlijst in te vullen voor de start van de training, en een jaar later. De vragenlijst mat uitkomsten van palliatieve zorg (the Palliative Care Outcome Scale [POS], the EORTC Quality of Life Questionnaire Core 15 Palliative [QLQ-C15-PAL] and 'the Rest & Peace Scale'), tevredenheid over de communicatie met de huisarts (the Patient Satisfaction Questionnaire-III [PSQ-III]) en de door de patiënt ervaren aanwezigheid van de huisarts en besproken actuele en anticipatie onderwerpen. We vonden ook op deze door de patiënten gerapporteerde uitkomsten geen effect van het AAA-trainingsprogramma.

In **hoofdstuk 7** rapporteerden we een vergelijkbare gecontroleerde interventiestudie om de effectiviteit van het AAA-trainingsprogramma te onderzoeken, maar nu onder derdejaars aios huisartsgeneeskunde. Ook van elke aios werd een consult met een gesimuleerde palliatieve zorg patiënt opgenomen voor de start van de training, en zes maanden later. De uitkomsten waren hetzelfde als beschreven in hoofdstuk 5. Maar in deze studie maten we geen gegevens bij patiënten. We vonden ook bij de aios geen effect van het AAA-trainingsprogramma op het aantal door de aios besproken onderwerpen en eveneens niet op hoe de aios met de patiënt communiceerde.

In de interventiestudies zagen we enerzijds dat de patiënten in het algemeen zeer tevreden zijn over de palliatieve zorg verleend door hun huisarts en over de communicatie (hoofdstuk 6). Aan de andere kant laten de uitkomsten zien dat er ruimte voor verbetering is bij huisartsen en aios als het gaat om het bespreken van levenseinde-onderwerpen met de patiënt, zoals spirituele/existentiële vragen, 'unfinished business', prognose en mogelijke complicaties, het feitelijke stervensproces en beslissingen rond het levenseinde (hoofdstuk 5-7).

Ten slotte, in **hoofdstuk 8** hebben we de voornaamste bevindingen van ons gehele onderzoek samengevat en bespraken we methodologische aspecten. Ook kwamen de gevolgen van onze resultaten aan bod voor de palliatieve zorg door huisartsen, voor onderwijs aan aios huisartsgeneeskunde over communicatie met patiënten in de palliatieve zorg en voor toekomstig onderzoek.

Veel onderzoeken naar de effecten van communicatietrainingen in de oncologische of palliatieve setting laten wel geringe positieve resultaten zien op hulpverlenersniveau, maar niet of nauwelijks op patiëntniveau. Wij vonden in onze studies echter op beide niveaus geen effect. Werkt de AAA-training nu wel of niet? Ook na ons onderzoek kunnen we deze vraag niet met zekerheid beantwoorden. Konden we geen effect aantonen doordat de training niet goed is of doordat onze meetmethodes ontoereikend zijn, of door een combinatie van beide? Mogelijk speelde het ook een rol dat we ons onderzoek uitvoerden onder huisartsen die deelnamen aan een uitgebreide cursus over palliatieve zorg en derdejaars aios huisartsgeneeskunde. Deze twee groepen scoorden bij de voormeting al zo hoog op de verschillende uitkomsten, dat er weinig ruimte overbleef voor verbetering (plafondeffect). Verder bleek dat, ondanks de hoge totaalscores, sommige onderwerpen veel minder vaak door de huisartsen/aios werden besproken met de patiënten. Mogelijk kan het AAA-trainingsprogramma wel effectief zijn als een bredere groep huisartsen zou meedoen en als de training zich vooral zou richten op de onderwerpen die het minst vaak werden besproken.

De AAA-checklist

Aanwezigheid (van de huisarts voor de patiënt)

(1) De tijd nemen
(2) Ruimte geven om alle onderwerpen te kunnen bespreken
(3) Actief luisteren
(4) Faciliterend gedrag (bijvoorbeeld empathisch, respectvol, voorkomend, ook eens spontaan de patiënt opbellen of bezoeken)
(5) Gezamenlijk besluiten nemen (over diagnostiek en behandelplan)
(6) Bereikbaarheid (bijvoorbeeld telefoonnummers)

Actuele onderwerpen (die de huisarts aan de orde moet stellen):

(7) Diagnose
(8) Prognose
(9) Lichamelijke klachten en zorgen van de patiënt
(10) Psychosociale klachten en zorgen van de patiënt
(11) Spirituele/existentiële klachten en zorgen van de patiënt
(12) Wensen voor nu en de komende dagen
(13) Unfinished business, afronding van het leven
(14) Bespreken van opties voor behandeling en zorg naar aanleiding van de genoemde onderwerpen (7-13)

Anticiperen (op diverse scenario's)

(15) Vervolgafspraken aanbieden
(16) Mogelijke complicaties
(17) Wensen voor de komende weken of maanden (zowel persoonlijke wensen als voorkeuren ten aanzien van medische beslissingen)
(18) Het feitelijke stervensproces (laatste uren of dagen)
(19) Beslissingen rond het levenseinde

APPENDIX

Communiceren met palliatieve patiënten

Willemjan Slort
Peter Pype
Myriam Deveugele

Huisarts en Wetenschap 2011; 54: 614-617 (nascholing) (dutch paper)

Samenvatting

Dit artikel geeft aan de hand van een casus praktische aanbevelingen voor de communicatie met patiënten in de palliatieve fase. De aanbevelingen vormen samen de AAA-checklist: aanwezigheid, actuele onderwerpen, anticiperen. Door tijd te nemen, ruimte te bieden, actief te luisteren, zich faciliterend te gedragen, samen besluiten te nemen en bereikbaar te zijn is de huisarts gedurende de palliatieve fase *aanwezig* voor de patiënt. Daarbij stelt de huisarts proactief enkele *actuele onderwerpen* aan de orde: diagnose en prognose, klachten en zorgen, wensen voor de korte termijn, unfinished business, behandeling en zorg. Bovendien *anticipeert* de huisarts op diverse scenario's door vervolgafspraken aan te bieden en door mogelijke complicaties, wensen voor de langere termijn, het feitelijke sterven en beslissingen rond het levenseinde te bespreken.

De kern

- De huisarts kan in de palliatieve fase een belangrijke bondgenoot zijn voor de patiënt en diens naasten.

- Goed communiceren met de patiënt aan het einde van het leven is vaak niet zo makkelijk.

- Goede communicatie met patiënten in de palliatieve fase stoelt op drie aandachtspunten: aanwezig zijn voor de patiënt, actuele onderwerpen aan de orde stellen en anticiperen op diverse scenario's.

Inleiding

Huisarts Peter Valentijn komt in gedachten verzonken thuis. Hij heeft net in het verzorgingshuis zijn laatste bezoek van de dag afgelegd bij Jette Vanderkinderen, een dame van 82 jaar. Voor haar komt het einde van het leven nu snel dichterbij, sinds deze morgen is ze comateus. Peter kijkt met voldoening terug op de lange periode dat hij haar zorg kon bieden en op de vele gesprekken die ze samen hebben gevoerd. Gisteren bedankte ze hem nog voor de goede zorg die hij haar man had gegeven. En hij begreep dat ze daarmee veel meer bedoelde...

In veel landen krijgt palliatieve zorg de laatste jaren meer aandacht, in Nederland onder andere door het verschijnen van het NHG-Standpunt Palliatieve zorg in 2009.[1] In dit artikel geven we praktische aanbevelingen voor de communicatie tussen huisarts en patiënt in de palliatieve fase. Dat de arts-patiënt-communicatie belangrijk is, is terdege aangetoond. Effectieve communicatie levert een positieve bijdrage aan het effect van pijnbehandeling, aan therapietrouw en aan het psychologisch functioneren van patiënten. Omgekeerd blijkt ineffectieve communicatie samen te hangen met meer angst, onzekerheid en ontevredenheid over de ontvangen zorg.[2] De arts-patiënt-communicatie is de afgelopen tientallen jaren aan grote veranderingen onderhevig geweest. Allereerst heeft een verschuiving plaatsgevonden van paternalistische naar patiëntgerichte zorg, waarbij de autonomie van de patiënt en *shared decision making* centraal kwamen te staan. Ook de wijze waarop de arts de patiënt een ernstige diagnose meedeelt, is veranderd. Waar vroeger de nadruk lag op het verzachten en verzwijgen van diagnose en prognose, is het tegenwoordig goed gebruik de waarheid te vertellen.[3] Het lijkt logisch dat bovengenoemde veranderingen ook gelden voor communicatie aan het einde van het leven. Goed communiceren met de patiënt en diens naasten aan het einde van het leven is vaak niet gemakkelijk. In deze fase ontstaat meestal een complexe situatie waarin lichamelijke, psychosociale en spirituele aspecten nauw verweven zijn. Vaak ook zijn er sterke emoties bij zowel de patiënt en diens naasten als de zorgverleners.

De praktische aanbevelingen in deze nascholing zijn gebaseerd op de resultaten van een recent verschenen systematische review en een kwalitatief onderzoek van de eerste auteur (WS).[4,5] Daaruit kwamen drie categorieën aandachtspunten naar voren, waarvan de eerste letters de zogeheten AAA-checklist vormen **[tabel]**:

- *aanwezigheid* voor de patiënt;
- *actuele onderwerpen* die aan de orde gesteld moeten worden;
- *anticiperen* op diverse scenario's.

Aanwezigheid van de huisarts voor de patiënt

Peter Valentijn is huisarts. Hij is 45 jaar en werkt samen met een vrouwelijke collega in een duopraktijk in een plattelandsdorp waar het aangenaam leven en werken is. Hij is al jaren de huisarts van mevrouw Jette Vanderkinderen, die hij Jetje mag noemen. Jarenlang ging hij driemaandelijks bij haar langs om een vinger aan de pols te houden, de bloeddruk te controleren en herhaalrecepten te verzorgen. Dikwijls mondden deze bezoekjes uit in een gezellige babbel waar zowel Jetje als hijzelf prijs op stelden. Vijf jaar geleden is Jetjes man thuis overleden aan prostaatkanker. Die laatste maanden van intense zorg voor haar man hebben tussen Peter en Jetje een band geschapen die de huisarts-patiëntrelatie heeft verdiept. Na het overlijden was er even sprake van dat Jetje zou verhuizen naar een verzorgingshuis, maar uiteindelijk besliste ze toch om thuis te blijven, gesteund door haar kinderen en 'haar' dokter. Negen maanden geleden werd ze ernstig ziek. De longarts naar wie ze door Peter was verwezen, stelde de diagnose grootcellige longtumor. De behandeling doorliep verschillende fasen: longoperatie zonder nabehandeling, chemotherapie na een recidief in de andere long en recent werd nieuwe activiteit van de tumor vastgesteld. Gedurende deze hele periode bleef Peter in overleg met Jetje en met de behandelend specialist.

Een maand geleden ging Jetjes conditie flink achteruit. Haar dochter bood aan haar moeder in huis te nemen; het alternatief was verhuizen naar het verzorgingshuis. Jetje koos voor het verzorgingshuis. Peter bezoekt haar daar nu elke week. Tijdens de wekelijkse visites gaat er altijd iemand van de verpleging mee. Peter vindt het plezierig over de professionele zorg te kunnen overleggen met de specialist ouderengeneeskunde van de palliatieve afdeling in het nabijgelegen verpleeghuis. Daardoor kan hij voor zijn gevoel nog wat rustiger bij Jetje aanwezig zijn en gesprekken voeren, ook over alledaagse dingen, over haar leven en het naderende einde.

In de palliatieve fase zal het leven voor de patiënt en diens naasten in relatief korte tijd sterk veranderen. De ziekte wordt ernstiger en de uiteindelijke vooruitzichten zijn ongunstig. Dat kan onzekerheid en ontreddering met zich meebrengen. Juist in deze periode kan de huisarts door zijn ervaring met het begeleiden van patiënten in de palliatieve fase een bondgenoot zijn die de patiënt en diens naasten helpt deze periode zo goed mogelijk vorm te geven.[6] De huisarts is hierbij als professional en als persoon aanwezig voor de patiënt.[7] We onderscheiden daarin zes aandachtspunten.

Tijd nemen

De huisarts dient voldoende tijd te nemen voor de patiënt. Sommige gespreksonderwerpen zijn emotioneel en vragen meer tijd voor een zorgvuldige bespreking. Verschillende non-verbale aspecten van het gedrag (blijven staan of gaan zitten, jas aanhouden of uitdoen, lichaamshouding, spreektempo) kunnen de indruk wekken dat de huisarts rustig de tijd neemt of daarentegen juist gehaast is.

Ruimte geven om alle onderwerpen te kunnen bespreken

De huisarts dient de patiënt voldoende ruimte te geven, zodat alle onderwerpen die de patiënt van belang acht aan de orde kunnen komen. Voor een deel zal de huisarts actief naar bepaalde onderwerpen vragen en daarop ingaan, maar daarnaast moet hij op open wijze exploreren of de patiënt ook andere onderwerpen wil bespreken. Veel patiënten vinden het belangrijk als zij met de huisarts ook over alledaagse dingen kunnen praten, en gepaste humor wordt daarbij gewaardeerd.

Voor Jetje was het telkens opnieuw bespreken van haar klachten, de resultaten van onderzoeken, en de kansen op een gunstig effect van behandelingen vermoeiend. In die periode werd haar eerste achterkleinkind geboren en dat was voor haar een welkome aanleiding om het eens over iets anders te hebben. Het gebeurde zelfs een keer dat huisarts Peter op huisbezoek kwam zonder dat er over haar ziekte gesproken werd.

Actief luisteren

De soms snelle achteruitgang roept vaak (levens)vragen en emoties op bij de patiënt en diens naasten. In deze zware periode willen patiënten graag dat de huisarts luistert met een open en respectvolle houding, dat hij ingaat op non-verbale signalen en dat hij op die manier thema’s aan de orde krijgt waarover de patiënt zelf niet makkelijk spontaan zal beginnen

Faciliterend gedrag

Een spontaan telefoontje of bezoekje van de huisarts wordt gewaardeerd en gezien als uiting van persoonlijke betrokkenheid. Vaardigheden om op empathische wijze te communiceren op meta-niveau (over de onderliggende betekenis van een onderwerp of de relatie) zijn ook in de palliatieve zorg belangrijk om de relatie met de patiënt en diens naasten zo goed mogelijk te houden én om voor zichzelf een gezonde balans te bewaren. Immers, problemen in de communicatie tussen huisarts en patiënt kunnen de hulpverlening hinderen. Een blokkade kan bijvoorbeeld ontstaan door vertraging in de diagnostiek, waarbij de huisarts de klacht aanvankelijk als onschuldig inschatte terwijl later blijkt dat het toch om een ernstige diagnose ging. Als huisarts en patiënt dit niet uitpraten, kan dat leiden tot boosheid bij de patiënt en/of schuldgevoelens bij de huisarts. Metacommunicatie kan de huisarts-patiëntrelatie juist verdiepen, maar het vraagt moed van de huisarts om dergelijke zaken aan de orde te stellen.

Tabel. De AAA-checklist

1 **Aanwezigheid** (van de huisarts voor de patiënt)

- Tijd nemen
- Ruimte geven om alle onderwerpen te kunnen bespreken
- Actief luisteren
- Faciliterend gedrag (bijvoorbeeld empathisch, respectvol, voorkomend, ook eens spontaan de patiënt opbellen of bezoeken)
- Gezamenlijk besluiten nemen (over diagnostiek en behandelplan)
- Bereikbaarheid (bijvoorbeeld telefoonnummers)

2 **Actuele onderwerpen** (die door de huisarts aan de orde gesteld moeten worden):

- Diagnose
- Prognose
- Klachten en zorgen van de patiënt (lichamelijk, psychosociaal en spiritueel)
- Wensen voor nu en de komende dagen
- Unfinished business, afronding van het leven
- Bespreken van opties voor behandeling en zorg naar aanleiding van de genoemde onderwerpen

3 **Anticiperen** (op diverse scenario’s)

- Vervolgafspraken aanbieden
- Mogelijke complicaties
- Wensen voor de komende weken of maanden (zowel persoonlijke wensen als voorkeuren ten aanzien van medische beslissingen)
- Het feitelijke stervensproces (laatste uren of dagen)
- Beslissingen rond het levenseinde

Gezamenlijk besluiten nemen (over diagnostiek en behandelplan)

De huisarts is de centrale persoon die met de patiënt over diens klachten spreekt en hem optimaal dient te informeren over de diagnostische en therapeutische mogelijkheden, zodat de patiënt kan meebeslissen over het beleid. In de palliatieve fase is het samen met de patiënt besluiten nemen over diagnostiek en behandelplan nog belangrijker dan in andere situaties, omdat in deze fase meer nadruk komt te liggen op ‘wat nog zinvol is’ en op de kwaliteit van leven. Vanzelfsprekend is het vooral de patiënt die bepaalt wat in de concrete situatie ‘zinvol’ is en wat ‘kwaliteit’ inhoudt.

Bereikbaarheid

Veel patiënten zullen in de palliatieve fase vaker contact zoeken met hun huisarts dan daarvoor. Patiënten vinden het belangrijk dat ze hun huisarts goed (telefonisch) kunnen bereiken, dat ze op korte termijn een afspraak kunnen krijgen met de huisarts van hun keuze, dat de huisarts visites aan huis wil komen afleggen en dat de continuïteit van de zorg is gewaarborgd. De huisarts dient de patiënt uit te leggen via welk nummer hij voor welke vragen bereikbaar is tijdens praktijkuren en buiten praktijkuren.

Actuele onderwerpen die aan de orde gesteld moeten worden

Toen huisarts Peter Valentijn van de radioloog gehoord had dat de afwijkingen op de longfoto van Jetje zeer waarschijnlijk op longkanker duidden, ging hij naar Jetje toe met veel twijfels. Hij wist dat hij haar moest doorverwijzen, maar wist niet goed hoe hij het zou aanpakken. Zou hij spreken over een ‘ontsteking’ of een ‘plek op de longen’? Wat zou ze vragen? Hij herinnerde zich nog hoe ontredderd ze was door de diagnose uitgezaaide prostaatkanker bij haar man, en ook hoe ze een jaar lang voor depressie werd behandeld toen haar jongste dochter ging scheiden. Zou ze opnieuw instorten als hij haar het slechte nieuws zou vertellen? Wie weet zou het achteraf helemaal niet om een maligne tumor blijken te gaan.

Peter bleek bezorgder dan Jetje zelf. ‘Jette, ik moet je iets zeggen’, begon hij. Hij schrok ervan dat hij haar ‘Jette’ noemde in plaats van ‘Jetje’. Ze had het ook gehoord. En ook de ernstige ondertoon in zijn stem. ‘Doe maar, Peter’, zei ze, ‘zeg het maar’. Er volgde een rustig en open gesprek waarbij het woord ‘tumor’ niet viel, maar wel het woord ‘ernstig’. Samen besloten ze dat Jetje het zelf aan haar dochters zou vertellen en dat Peter naar de zoon zou telefoneren. Toen hij naar huis reed, had Peter het gevoel dat Jetje het gesprek had geleid. En het voelde goed aan.

Het hoort bij het voeren van de regie dat de huisarts proactief een aantal zaken aan de orde stelt om te exploreren welke daarvan voor de patiënt belangrijk zijn. We onderscheiden zes actuele onderwerpen.

Diagnose en prognose

Diagnose en prognose zijn juist in de palliatieve zorg zo nauw met elkaar verbonden dat we ze hier samen bespreken. Over het meedelen van slecht nieuws is men het in de recente literatuur eens: de patiënt heeft het recht om diagnose en prognose te kennen. Dit recht is in Nederland en België wettelijk vastgelegd.[8,9] Onderzoek toont aan dat artsen veel minder informatie geven dan ze zelf denken, en dat de informatie vaak niet volledig begrijpelijk is voor de patiënt. Daarnaast blijkt de arts vooral geneigd om feitelijke medische informatie te geven, terwijl de patiënt vaak ook behoefte heeft aan inzicht over de gevolgen van de ziekte voor de eigen leefsituatie.

De ambivalente wijze waarop de patiënt en diens naasten, en soms ook artsen, kunnen omgaan met 'de waarheid' heeft grote invloed op de communicatie in de gehele palliatieve fase. De meeste patiënten willen dat hun huisarts eerlijk is over de diagnose en prognose, maar ze wensen ook dat de huisarts ruimte laat voor hoop. Soms zijn huisartsen zo bezorgd over het nadelige effect van hun eventuele openheid over de prognose op de hoop van de patiënt, dat ze de prognose maar liever niet open en accuraat bespreken. Verder is het belangrijk dat de huisarts geregeld expliciet checkt wat de behoefte is van de patiënt en diens naasten aan informatie over hun ziekte en vooruitzichten, omdat deze behoefte kan veranderen gedurende de progressie van de ziekte.

Klachten en zorgen van de patiënt

De palliatieve fase wordt gekenmerkt door een telkens verslechterende conditie. De Wereldgezondheidsorganisatie onderscheidt hier vier probleemcategorieën: lichamelijk, psychisch, sociaal en spiritueel.[10] Het door de huisarts actief exploreren van mogelijke klachten, zorgen en angsten op deze gebieden leidt tot grotere patiënttevredenheid Bepaalde klachten kunnen door behandelingen en specifieke zorg (gedeeltelijk) verholpen worden. Bij andere klachten realiseren patiënten zich dat de huisarts niet veel aan hun situatie kan veranderen, maar ook dan hebben ze er meestal wel behoefte aan om over hun klachten te praten.

Wensen voor nu en de komende dagen

Om de palliatieve zorg zoveel mogelijk af te stemmen op de patiënt zal de huisarts diens wensen voor nu en de komende dagen inventariseren en het beleid daarop afstemmen. Dit kunnen persoonlijke wensen zijn: de patiënt wil bijvoorbeeld graag naar het huwelijk van een kleinkind maar vraagt zich af of hij de reis wel aankan en of hij wel zo lang rechtop zal kunnen zitten. Het kunnen ook medische wensen zijn: de patiënt wil misschien niet meer naar het ziekenhuis of stelt prijs op geestelijke bijstand.

Unfinished business, afronding van het leven

Het besef dat het leven over niet al te lange tijd afgelopen zal zijn, leidt bij veel mensen tot reflectie. Zij kijken terug op het leven en maken een balans op. De huisarts kan enerzijds ingaan op deze ‘afronding van het leven’, bijvoorbeeld wanneer oudere patiënten aangeven dat het genoeg is geweest. Anderzijds kan de huisarts ook exploreren of er nog kwesties spelen die ‘onaf’ zijn, zoals slepende ruzies. De tijd die rest om er iets mee te doen, raakt beperkt. De palliatieve fase kan zo een waardevolle periode zijn waarin afronding van het leven, afscheid nemen en loslaten van de naasten elk hun plaats krijgen.

Bespreken van opties inzake behandeling en zorg

Om de helderheid van het gesprek te bevorderen kan de huisarts de tot dan toe besproken problemen nog eens samenvatten, als inleiding op het af te spreken beleid. Daarna is het zaak om samen met de patiënt te bedenken welk beleid (uitleggen, adviseren, een recept uitschrijven, verwijzen naar een geestelijke en dergelijke) in de ogen van de patiënt zinvol is en diens kwaliteit van leven verhoogt.

Anticiperen op diverse scenario’s

Jetje had het vaak moeilijk tijdens de behandelingen van de longkanker. Peter merkte het en vroeg ernaar. Haar grootste vrees was dat de artsen ‘iets zouden doen wat zij niet wilde’. Toen Peter doorvroeg, bleek het te gaan over behandelingen die haar zelfstandigheid zouden kunnen beknotten. Jetje wilde zo lang mogelijk alleen thuis kunnen leven en was bereid om daarvoor ‘te boeten’, zoals ze het zelf uitdrukte, met een kortere levensduur als dat moest. Peter nam haar wens mee tijdens zijn overleggen met de longarts over de behandeling.

De huisarts voert de regie over de palliatieve fase. Daar hoort bij dat hij proactief anticipeert op de toekomst door met de patiënt mogelijke scenario’s te exploreren. We onderscheiden hierbij vijf onderwerpen.

Vervolgafspraken aanbieden

Het is goed om heldere vervolgafspraken aan te bieden, indien de patiënt en diens naasten dat wensen. De meeste patiënten en hun naasten stellen regelmatige visites volgens afspraak op prijs. Zij kunnen dan zelf bepalen of zij een vraag kunnen laten wachten tot het volgende huisbezoek of toch tussentijds contact moeten opnemen.

Mogelijke complicaties

De huisarts kan op grond van zijn kennis over en ervaring met het beloop van ziektes inschatten hoe de conditie van de patiënt zich zal ontwikkelen. Hij kan uitleg geven over complicaties die kunnen ontstaan en adviseren over bijvoorbeeld het aanpassen van de medicatie als de pijn zou verergeren. Soms is het een lastige afweging of uitleg over een mogelijke complicatie (bijvoorbeeld over een mogelijke longbloeding als complicatie van een longcarcinoom) de patiënt en diens naasten iets concreets in handen zal geven of ze juist eerder extra angst zal bezorgen.

Wensen voor de komende weken of maanden

Het streven is de palliatieve fase zoveel mogelijk te laten verlopen volgens de persoonlijke wensen van de patiënt. Daartoe dient de huisarts de wensen en verwachtingen van de patiënt voor de komende weken tot maanden te inventariseren. Dat kunnen persoonlijke wensen zijn, bijvoorbeeld een bepaalde persoon of plaats nog eens willen opzoeken, of voorkeuren inzake medische beslissingen, bijvoorbeeld al dan niet starten met bepaalde medicatie of al dan niet reanimeren.

Het feitelijke stervensproces (laatste uren of dagen)

Reeds geruime tijd voor het overlijden zal de patiënt bezig zijn met gedachten en gevoelens met betrekking tot het feitelijke levenseinde. De meeste huisartsen spreken met hun patiënten meermaals over het naderende sterven, veelal op initiatief van de huisarts. Huisartsen willen graag dat de patiënt het naderende einde onder ogen ziet en accepteert, en de meeste patiënten willen ook dat hun huisarts er met hen over spreekt. Toch stellen niet alle patiënten dit op prijs, met name wanneer de huisarts naar hun beleving te vaak over de naderende dood begint.[11]

De verwachtingen (en de angsten) van patiënten ten aanzien van het sterven worden soms sterk bepaald door eerdere sterfgevallen waarbij zij zelf betrokken waren. De huisarts kan vragen naar deze herinneringen, en ook naar specifieke wensen inzake het sterfbed (bijvoorbeeld de plaats van overlijden, wie aanwezig zullen zijn, rituelen, muziek en dergelijke).

Beslissingen rond het levenseinde

Om vervelende situaties ‘aan het eind’ te voorkomen, moet een aantal zaken tijdig met de patiënt worden besproken. Het gaat dan bijvoorbeeld om welke wensen de patiënt heeft ingeval er bepaalde symptomen optreden, of om het machtigen van een vertegenwoordiger voor het geval dat de patiënt zich niet meer kan uiten. Verder zijn patiënten en hun naasten vaak niet goed op de hoogte van de feitelijke procedures rond de uitvoering van palliatieve sedatie, hulp bij zelfdoding en euthanasie. De huisarts kan uitleggen welke hulp kan worden gegeven bij het feitelijke sterven en daarbij ook zijn eigen positie aangeven tegenover eventuele verzoeken om hulp bij het overlijden.

Literatuur

1 **NHG-Standpunt** Palliatieve zorg, *Utrecht: NHG,* 2009.

2 **Thompson TL, Dorsey AM, Miller KI, Parrott R.** Handbook of health communication. *London: Lawrence Erlbaum,* 2003.

3 **Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, et al.** A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage* 2007;34:81-93.

4 **Slort W, Schweitzer BPM, Blankenstein AH, Abarshi EA, Riphagen II, Echteld MA, et al.** Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliat Med* 2011;25:613-29.

5 **Slort W, Blankenstein AH, Deliens L, Van der Horst HE.** Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011;61:167-72.

6 **Farber SJ, Egnew TR, Herman-Bertsch JL.** Defining effective clinician roles in end-of-life care. *J Fam Pract* 2002;51:153-8.

7 **Farber SJ, Egnew TR, Herman-Bertsch JL.** Issues in end-of-life care: Family practice faculty perceptions. *J Fam Pract* 1999;48:525-30.

8 Wet op de geneeskundige behandelingsovereenkomst (WGBO): Burgerlijk Wetboek boek 7, titel 7, afdeling 5. *Staatsblad 1994, 837, laatstelijk gewijzigd bij Wet van 8 februari 2007, Staatsblad* 2007, 92.

9 Wet betreffende de rechten van de patiënt. *Belgisch Staatsblad*, 26 september 2002.

10 WHO definition of palliative care [internet]. *Geneva: World Health Organization,* 2006. *http://www.who.int/cancer/palliative/definition/en.*

11 **Van den Muijsenbergh M.** Palliatieve zorg: De persoonlijke specialiteit van elke huisarts. *Huisarts Wet* 2003;46:80-5.

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Al lang voordat dit onderzoek van start ging, werd mijn interesse in wetenschap gewekt toen ik mijn doctoraalscriptie schreef, begeleid door Marten de Haan en Gerrit Locher in het huisartsinstituut van de VU, toen nog op Uilenstede. Het samenwerken aan dat wetenschappelijke projectje over 'het gezondheidsbeeld' vond ik zeer inspirerend.

Na mijn huisartsopleiding kreeg ik de kans het 'diabetesproject' uit te voeren, weer met Marten en Gerrit. Eén van de vragen was hoe een opleider een effectief leergesprek kan voeren met een huisarts-in-opleiding. Hiervoor hebben we geluidsopnames van consulten en leergesprekken van de opleiders geobserveerd. Achteraf gezien was dat een goede voorbereiding op het werken met de video-opnames voor de studies in dit proefschrift. In die tijd heb ik ook de cursus 'epidemiologisch onderzoek' van onder andere Lex Bouter gevolgd. Ik vond dat geweldig: op een andere wijze dan in de praktijk bezig zijn met mijn lievelingsvak 'huisarts zijn'. Het was voor mij alsof ik regels en doelen van een nieuw en uitdagend spel leerde. Ik dank Marten en Gerrit voor hun inspirerende begeleiding bij de scriptie en het 'diabetesproject'.

Kort na mijn huisartsopleiding ben ik lid geworden van de CWO (Commissie Wetenschappelijk Onderzoek) van het Nederlands Huisartsen Genootschap (NHG). Op de eerste donderdagavond van de maand komen we als in onderzoek geïnteresseerde huisartsen samen om elkaars onderzoek en gerelateerde onderwerpen te bespreken. Ik dank de (ex-) leden van de CWO (inclusief de adviseurs) voor hun inspiratie en steun door het in een plezierige en constructieve sfeer vele malen kritisch bespreken van mijn prille ideeën en later mijn activiteiten en resultaten.

Onderzoek over palliatieve zorg?

Meedoen binnen de CWO betekende voor mij het levend houden van mijn wens me ooit te willen wagen aan een onderzoek, over een onderwerp dat zich nog moest aandienen. Eind vorige eeuw begon de palliatieve zorg in Nederland meer in de aandacht te komen. In de praktijk merkte ik hoe belangrijk het was om te proberen zo goed mogelijk te zorgen voor mensen in de laatste fase van hun leven. Ik vroeg me af wat ik als huisarts zinvol zou kunnen onderzoeken aan palliatieve zorg. Om me verder te oriënteren heb ik twee weken meegelopen met internist-oncoloog Paul van der Velden in zijn hospice en oncologische praktijk in Dirksland. Zijn bijzondere wijze van omgaan met patiënten maakte dat ik nog meer wilde weten over de communicatie tussen huisartsen en hun patiënten in de palliatieve zorg.

Tijdens een NHG-Wetenschapsdag sprak ik Sander Borgsteede, een apotheker die onderzoek deed naar palliatieve zorg door huisartsen. Sander, dank voor de zetjes in mijn rug bij het ontwikkelen van mijn prilste onderzoeksideeën. Op advies van Sander legde ik mijn plannen voor aan Wim Stalman, ook aanwezig op die Wetenschapsdag. Wim nodigde me uit om mijn ideeën op een A4'tje te noteren en daarover een afspraak met hem te maken. In een serie maandelijkse gesprekken werden de plannen concreter en serieuzer. Wim betrok Gerrit van der Wal en Nettie Blankenstein erbij. En Gerrit vroeg Neil Aaronson mee te denken. Zo ontstond mijn projectgroep en we ontwierpen een schets voor onderzoek naar de huisarts-patiënt communicatie in de palliatieve zorg. Graag wil ik hier de leden van mijn initiële projectgroep heel erg bedanken:

Beste Nettie, heel veel dank en mijn grote waardering voor je geweldige en nooit aflatende begeleiding bij dit langdurige project! Ik was al een bewonderaar van je geworden toen je voorzitter van de CWO was. Je hebt een feilloos gevoel voor wat de kern van iets is en zorgde daarmee binnen de CWO al voor efficiënte en zinvolle besprekingen. Daarnaast gaf je ons soms even ruimte om te 'steggelen'. Jouw talenten om 'to-the-point' te denken en knopen door te hakken hielpen mij extra vanwege mijn neiging tot verbreden en over punten blijven nadenken. Jouw nuchterheid hielp om mijn missiedrang (zoveel mogelijk) te beteugelen. Je inzet bij het denken over en het schrijven van het onderzoeksplan, en later bij de vele documenten tot en met het proefschrift vond ik indrukwekkend. Tussendoor was er ook vaak gelegenheid tot reflectie en uitwisseling over andere zaken dan onderzoek. Nettie, enorm bedankt dat je zoveel in mij en in dit project hebt willen investeren.

Beste Wim, je hebt mij enorm gestimuleerd en geholpen bij het uitwerken van mijn eerste ideeën tot een concreet onderzoeksplan. Je gaf me het weldadige gevoel dat je mijn plannen belangrijk vond en dat je mijn pogingen waardeerde. Dat hielp me enorm. Ik bewonder je vermogen ergens creatief en krachtig vorm aan te geven. Zo was je in mijn herinnering gangmaker toen we (jij, Nettie en ik) de vele verzamelde factoren probeerden samen te vatten in een handzaam model: het AAA-model werd geboren. En je was de bedenker van de projectnaam COMPACT. Wim, heel erg bedankt!

Beste Gerrit, jij hebt door je brede kennis van onderzoek over palliatieve zorg gezorgd voor het maken van realistische plannen. Je gaf aan dat het na enkele beschrijvende onderzoeken over palliatieve zorg door huisartsen tijd werd voor een interventiestudie. Zie hier het resultaat. Gerrit, dank voor je grote aandeel in het ontwerpen en schrijven van het onderzoeksplan voor COMPACT.

Beste Neil, ik beschouw het als een voorrecht dat jij op essentiële momenten hebt meegedaan aan het project. Ik ben onder de indruk geraakt van je grote wetenschappelijke kennis over interventiestudies. Ik denk dan terug aan de gesprekken in het begin over de opzet van het project, aan de discussie over de beste uitkomstmaten voor de interventiestudies en aan de gesprekken over de ‘general discussion’. Daarnaast bewonder ik je talent om helder en krachtig te formuleren. De artikelen waaraan je hebt meegeschreven zijn mede door jouw inbreng sterk verbeterd. Daarbij is de toon van je commentaar altijd positief en constructief. Neil, dank voor je waardevolle inbreng!

Wie gaat dat betalen?

In de eerst fase ging het niet alleen over de inhoud, maar ook over de financiering van het project. Ons mooie onderzoeksplan werd helaas niet door het KWF gehonoreerd. Toen moesten we op zoek naar andere financiers. In die tijd leerde ik, als lid van het Netwerk Palliatieve Zorg Moerdijk/Drimmelen, Theo Koks kennen. Hij was coördinator palliatieve zorg van het IKZ (Integraal Kankercentrum Zuid). Hij reageerde enthousiast op mijn plannen en zocht binnen het IKZ naar mogelijkheden om een deel te financieren. Het IKZ heeft meebetaald aan het project en de eerste onderzoeksgroep huisartsen waren de Peergroup-huisartsen ‘van het IKZ’. Theo, voor je enthousiasme en actieve steun voor mijn plannen wil ik je nog eens bedanken.

Toch was het rond krijgen van de financiering heel lastig. In feite was het lang onzeker of het wel zou lukken. In die fase liet ik op een dag onze hond uit. Op straat kwam ik Becker Awad tegen, de directeur van het lokale verzorg- en verpleeghuis. Hij vroeg hoe het met mijn onderzoek ging. Ik legde uit dat het maar de vraag was of het kon doorgaan. Hij stelde krachtig dat ik nooit moest opgeven, en hij nodigde me uit samen met hem naar de regionale zorgverzekeraar te gaan om daar financiële ondersteuning te vragen. Voor mijn doen extra netjes aangekleed gingen we bij Joël Gijzen en enkele collega’s van de verzekeraar OZ op bezoek en ik vertelde ze over mijn onderzoeksplannen. Ik was verrast dat ze enthousiast raakten over het feit dat een huisarts met zulke plannen rondliep, en dan ook nog over zo’n onderwerp. Na enige tijd kreeg ik het positieve bericht dat ze aan het project wilden meebetalen. Dat betekende voor mij een enorme stimulans. Dat mensen die niet direct met het onderzoek te maken hadden er niet alleen enthousiast over waren, maar er zelfs geld voor wilden geven! Heel erg bedankt, Becker Awad en Joël Gijzen plus collega’s! (En onze hond Goldie natuurlijk.)

Samen met Wim Stalman, Nettie Blankenstein en de andere leden van de projectgroep lukte het uiteindelijk het benodigde bedrag bijeen te krijgen zodat we echt van start konden. Wim en Nettie, ook voor jullie enorme inzet bij het geld verzamelen mijn grote dank! En natuurlijk aan de sponsoren: IKZ (o.a. Theo Koks), IKA (o.a. Marianne Klinkenberg), CZ zorgverzekering, Pfizer bv, de Janivo Stichting (dankzij een tip van Clara) en de Stichting Beroeps Opleiding Huisartsen (SBOH).

Gerrit en Wim gingen, Luc en Henriëtte kwamen

Eind 2006/begin 2007 vertrokken Gerrit en Wim uit de projectgroep omdat ze elders gingen werken. De lege plekken werden op voortreffelijke wijze opgevuld door Luc Deliens en Henriëtte van der Horst.

Beste Luc, ik dank je heel erg voor je belangrijke inbreng bij het uitvoeren van COMPACT. Door je grote kennis en ervaring op het gebied van onderzoek over palliatieve zorg hielp je me door je kritische vragen en richtinggevende suggesties. Door je enthousiaste inzet heb ik me steeds zeer gesteund gevoeld door je. Heel veel dank daarvoor!

Beste Henriëtte, dank dat je zo'n voorbeeldige promotor voor me was. Het lijkt zo simpel, maar het is heerlijk dat je altijd je afspraken nakomt. Vaak kwamen je commentaren al ruim voor de afgesproken deadline. Door je sterke kritisch vermogen heb je op vele momenten en op vele plaatsen de kwaliteit van het project en van de artikelen flink verhoogd. Tot de 'laatste zinnen' aan toe. Daarbij trof ik alle keren een luisterend oor en had je steeds een constructieve inbreng. Henriëtte, heel veel dank daarvoor!

Het exploratieve deel

In de aanloop naar de officiële start van COMPACT hadden we al een literatuuronderzoek en een kwalitatief onderzoek uitgevoerd. Voor die kwalitatieve studie vulden palliatief consulenten en SCEN-artsen (Steun en Consultatie bij Euthanasie in Nederland) een vragenformulier in, namen twee groepen van tien huisartsen deel aan een focusgroep-gesprek onder leiding van moderator Peter Lucassen en waren een aantal patiënten bereid zich te laten interviewen. Ik wil al deze patiënten (en hun naasten), huisartsen en consulenten nog eens erg danken voor hun belangrijke inbreng (zie hoofdstuk 3). Ik bedank Pauline voor het op prima wijze uittypen van de opnames van de focusgroep-gesprekken en de interviews met de patiënten.

Het literatuuronderzoek dat we in de beginjaren uitvoerden, hebben we later nog een keer systematisch herhaald en netjes opgeschreven (zie hoofdstuk 2). Ik dank Ingrid Riphagen voor haar enthousiasme en zorgvuldigheid bij het systematisch zoeken naar relevante artikelen over mijn onderwerp in de diverse databases. Ik dank Ebun Abarshi voor het samen beoordelen van de vele 'hits' en het selecteren van de artikelen die voldeden aan de inclusiecriteria. En ik dank Bart Schweitzer voor het samen lezen van de geselecteerde artikelen op zoek naar factoren die de huisarts-patiënt communicatie in de palliatieve zorg bevorderen of juist hinderen. Daarnaast bedank ik Bart voor het jarenlang solidair meedoen in elkaars projectgroep. En zeker ook voor de gesprekjes tussendoor, waarbij we onze ervaringen als 'oudere' promovendi uitwisselden. Dan bedank ik ook Liesbeth van Vliet nog voor haar deskundige commentaar op een concept voor het review-artikel zoals dat werd besproken bij het NIVEL (Nederlands instituut voor onderzoek van de gezondheidszorg) in Utrecht tijdens een bijeenkomst van de PPI (the Patient

Provider Interaction study group); je commentaar hielp om het artikel op enkele punten nog aanzienlijk te verbeteren.

Het AAA-onderwijsprogramma

De volgende uitdaging was om de kennis uit de literatuur en de kwalitatieve studie om te zetten in een onderwijsprogramma. De creativiteit binnen de projectgroep leidde tot het ontwikkelen van de zogenaamde AAA-checklist (zie hoofdstuk 4).

Om rond die checklist een onderwijsprogramma te bouwen hebben Nettie en ik intensief samengewerkt met Bernardina Wanrooij, in Nederland 'de moeder van de palliatieve zorg', en dan zeker ook van het onderwijs over palliatieve zorg. Zij werkte actief mee aan het ontwerpen van het AAA-onderwijsprogramma en aan het schrijven aan het AAA-oefenboekje. Zij gaf ons programma een plek in enkele edities van de Peergroup-cursussen voor huisartsen over palliatieve zorg. Bernardina, ik wil je heel erg bedanken voor je zeer deskundige en onmisbare bijdrage aan ons project! Dank ook aan alle docenten van de Peergroup-cursussen van IKZ, IKA en IKR (Integraal Kankercentrum Zuid, Amsterdam en Rotterdam) die praktisch meewerkten aan het uitvoeren van het AAA-programma.

Een aantal stafleden van de huisartsopleidingsinstituten van het UMCU en het VUmc werkten eraan mee dat het AAA-onderwijs in een serie aios-groepen gegeven werd. Van de opleiding van het UMCU wil ik daarvoor speciaal Marga Bogaards-Godschalk, Ron Pieters, Aad van Leeuwen en Raf Hirsch bedanken; en van de opleiding van het VUmc Willem Feijen, Joost Smitskamp en Piet Schoonheim. En natuurlijk dank aan alle groepsdocenten die het onderwijsprogramma aan de aios praktisch verzorgden.

In het AAA-onderwijsprogramma namen de gesprekken tussen de huisartsen en huisartsen-in-opleiding met zogenaamde simulatie patiënten een zeer voorname plaats in. Een groep enthousiaste en trouwe acteurs en actrices waren heel belangrijk voor het project door soms vele malen per dag de rol van een ongeneeslijk zieke patiënt te vertolken. Door de aard van het onderwerp waren dat zware gesprekken. Het ging in totaal om ruim 400 gesprekken die werden opgenomen. De opnames werden ten eerste gebruikt om feedback te geven aan de huisartsen en huisartsen-in-opleiding over hoe ze communiceerden. En ze werden ten tweede gebruikt voor het evalueren van het effect van het AAA-programma (de experimentele studies). Ik bedank Marianne Oldenbeuving, Jeroen van Veenendaal, Mark de Ridder, Lâle Freie, Dorien Straatsma, Vincent van den Akker, Mieke Klomp en Nico van Spanje heel erg voor hun belangrijke acteer-bijdrages aan het project!

Verder dank ik Tom Bottelier die zijn wetenschappelijke stage in het kader van zijn geneeskundestudie besteedde aan het evalueren van de implementatie van het AAA-onderwijsprogramma bij de huisartsopleidingen van UMCU en VUmc. En Ellen Golbach dank ik voor het op prima wijze verrichten van de grote klus om alle huisartsen van de controle groepen feedback te geven op hun opname van een gesprek met een simulatie patiënt; ze deed die klus in het kader van de wetenschappelijk stage van haar huisartsopleiding.

Het experimentele deel

Voor de interventiestudies verzamelden we veel gegevens (zie de tabellen in de hoofdstukken 5-7). Bij het uitvoeren en controleren van die inzamelingsacties was Marianne Koridon de onmisbare spin in het web. Nadat we de namen van de Peergroup-huisartsen ontvingen van de IKC's, gingen er brieven uit met informatie over ons project en het verzoek om eraan deel te nemen. Vervolgens vroegen we de huisartsen om aan patienten die palliatieve zorg nodig hadden in hun praktijk te vragen of ze een vragenlijst wilden invullen. Daarna stuurden we brieven aan die patiënten. We controleerden of de huisartsen wel antwoordden en of patiënten wel reageerden. Anders belden of schreven we ze opnieuw. Nota's van acteurs en actrices moesten worden betaald. Antwoorden op ingevulde papieren vragenlijsten werden ingevoerd in elektronische databestanden. Enzovoorts, enzovoorts. Marianne zorgde er met overzicht en nauwgezetheid voor dat al deze zaken in goede banen werden geleid. Daarnaast hebben we vaak gezellig informatie uitgewisseld over lekkere restaurants en leuke hotelletjes in Italië. Marianne, ik wil je heel erg bedanken voor je belangrijke en grote aandeel in COMPACT!

Voor het project hebben we ongeveer 450 gesprekken tussen een huisarts of een huisarts-in-opleiding en een simulatie patiënt opgenomen. Ik wil hier ook graag al die huisartsen en huisartsen-in-opleiding heel erg bedanken. Verder dank ik Bernardina Wanrooij, de docenten van de Peergroup cursussen, Annemarie Stoffer-Brink van het IKA en Irene van Tetering-van Slobbe (onze voortreffelijke POH-Somatiek) voor alle praktische hulp bij het uitvoeren van deze grote klus. Alle gesprekken werden opgenomen op 'ouderwetse' minivideocassettes, twee gesprekken per bandje. Later werd elke opname gekopieerd naar een apart dvd-schijfje met een code, zodat de gesprekken later 'blind' beoordeeld konden worden. Voor die kopieerklus dank ik Thijs van Tetering.

Alle opnames moesten worden beoordeeld voor de interventiestudie. We hadden gekozen om dat met het 'RIAS'-instrument te doen. Het bleek nog een hele uitdaging om het instrument geschikt te maken voor gebruik voor COMPACT. Ik wil Barbara Hendriksen en Rosaida Broeren danken voor hun systematische en creatieve werk om dit voor elkaar te krijgen. Ook het team 'jonge psychologen' dat alle banden heeft gescoord, dank ik zeer. Naima Abouri, Doutzen Koopmans, Tesse van Veldhuyzen en Lenneke Hoeksema deden dat met veel enthousiasme, nauwgezetheid en deskundigheid. Geregeld werd gezamenlijk overlegd om de gesprekken betrouwbaar te kunnen scoren. Jullie deden een grote klus op voortreffelijke wijze!

Met de projectgroep hebben we vaak besproken hoe we de uitkomsten van het programma het best konden meten. Tijdens een aparte discussiebijeenkomst kregen we daarover deskundige adviezen van Myriam Deveugele, Bregje Onwuteaka-Philipsen, Marianne Klinkenberg (IKA) and Akke Albada (NIVEL).

Na het scoren van de vele banden verkregen we veel data die vervolgens geanalyseerd moesten worden. Voor zijn onmisbare adviezen en praktische hulp bij het analyseren van onze data dank ik Dirk Knol.

De leescommissie

Ik wil graag Myriam Deveugele, Hanneke de Haes, Francois Schellevis, Bregje Onwuteaka-Philipsen, Cees Hertogh en Marjolein Berger bedanken dat ze bereid waren zitting te nemen in de manuscriptcommissie. Vervolgens was ik natuurlijk erg blij te horen dat zij mijn manuscript positief hadden beoordeeld.

Last but not least

Het werken aan COMPACT gedurende vele jaren kostte tijd en energie. Dat betekent dat ik vaak weg was en mijn taken elders moesten worden waargenomen. Daarbij denk ik dan voornamelijk aan onze huisartsenpraktijk en aan thuis. Ik bedank onze praktijkondersteuners Irene van Tetering-van Slobbe en Sandra Schoonen-Stokman, onze (ex-)praktijkassistentes Friedje Kock, Margriet Smits, Nina Eikenbroek-Boekhoudt, Lida Ishanzada, Nancy van Hulten-Kwaaitaal en Bernadette Nobel-Timmerman heel erg voor hun jarenlange enthousiaste belangstelling voor mijn onderzoek en het verdragen van periodes dat ik best moe was door het werken aan het onderzoek naast de praktijk. Daarnaast dank ik de vaste (ex-)waarnemers voor het meewerken in onze praktijk waardoor ik aan mijn onderzoek kon werken. Dat waren in chronologische volgorde: Stefaan Blondelle, Monique Cramer, Bart Dahler en nu Carolina van Moolenbroek. Daarnaast dank aan de ‘losse’ waarnemers die op indicatie kwamen invallen, René Disseldorp, Ton Vermeulen en Eef Rosbak.

Aan het eind van een lang traject, bleek het nog een hele uitdaging om van een aantal Word- en PDF-documenten een mooi proefschrift te maken. Ik dank Bart Herber voor zijn creativiteit, enthousiasme, inzet en zorgvuldigheid bij het vormgeven van ‘mijn boekje’. Zowel de cover als de lay-out vind ik heel mooi geworden.

Ik dank de paranimfen Eric van den Bergh (vriend en ex-huisarts) en Pauline Struijs-Slort (dochter en huisarts-in-opleiding) dat ze deze huisarts-onderzoeker willen bijstaan tijdens de promotie. Ik dank onze zoon Janwillem voor het redigeren van de Nederlandstalige teksten. Jullie jarenlange belangstelling voor mij en mijn onderzoek heb ik steeds als een warm bad ervaren. Ook bedank ik onze familieleden en vrienden voor hun belangstelling en voor het leuker maken van mijn leven. Helaas mag ik slechts twee paranimfen vragen.

‘Maar de artikelen en dit proefschrift zouden levenloze dingen zijn, zonder jou’ (vrij naar ‘Avond’ van Boudewijn de Groot). Lieve Gerry, dank dat je me de ruimte gaf voor dit project, dat je vaak hebt verdragen dat ik minder aanwezig was. Dank dat je dingen voor me opving in huis en praktijk. Dank voor je relativeringsvermogen, nodig om mij met de voeten op aarde te houden. Dank voor je humor, voor je adviezen en aansporingen. Dank voor het organiseren van onze vakanties om heerlijk te wandelen of te reizen; met deze ontspannende onderbrekingen voorkwam je diverse keren dat ik overbelast raakte. Tijdens sommige wandelingen werden we geholpen door steenmannetjes om het juiste pad te vinden. We zagen de symboliek dat wij als huisartsen vaak als steenmannetjes proberen patiënten te gidsen, ook op het voor hen onbekende pad van hun laatste levensfase. Ik hoop op nog vele jaren samen met jou, met vanaf nu weer meer wandelen, tuin, lezen, film, vleugel, enzovoorts.

Over de auteur

Willemjan Slort (1958) studeerde Geneeskunde aan de Vrije Universiteit (VU) in Amsterdam en behaalde in 1985 zijn artsexamen.

Daarna werkte hij een jaar als arts-assistent chirurgie in Zaandam en een jaar als arts-assistent gynaecologie-verloskunde in IJmuiden, in het kader van de opleiding tot tropenarts. Vervolgens werkten hij en zijn vrouw drie jaar als tropenartsen in Sengerema in Tanzania.

Teruggekomen in Nederland volgde hij van 1991 tot 1993 de Huisartsopleiding aan de VU. In zijn eerste jaren als huisarts werkte hij deels als waarnemend huisarts in Andijk en deels als onderzoeker bij de huisartsopleiding van de VU. Als onderzoeker voerde hij het ‘diabetesproject’ uit, dat inging op de rol van de opleider als leermeester voor de huisarts-in-opleiding. Dit project leverde onder andere een model op voor het voeren van leergesprekken.

In 1996 vestigden hij en zijn vrouw zich in een duo-praktijk in Zevenbergen. Tegelijkertijd begon hij als groepsbegeleider bij de huisartsopleiding in Utrecht en werkte daar tot 2002.

Vanuit zijn interesse in onderzoek is Willemjan vanaf 1994 lid van de Commissie Wetenschappelijk Onderzoek (CWO) van het Nederlands Huisartsen Genootschap (NHG). Rond 2000 kreeg hij het idee om onderzoek te doen naar de communicatie tussen huisarts en patiënt in de palliatieve zorg. Samen met Wim Stalman, Nettie Blankenstein, Gerrit van der Wal en Neil Aaronson werd een concreet plan ontwikkeld. In 2007 werden Gerrit van der Wal en Wim Stalman opgevolgd door Luc Deliens en Henriëtte van der Horst. Het uiteindelijke resultaat hiervan is dit proefschrift.

Zijn nevenactiviteiten op het gebied van de palliatieve zorg waren: voorzitter van het subregionale Netwerk Palliatieve Zorg Moerdijk/Drimmelen, initiatiefnemer van het Advance Care Planning-project in de regio Breda, deelname aan het nationaal Platform Palliatieve Zorg namens het NHG, initiatiefnemer (met anderen) van de NHG-expertgroep PalHAG. Verder is hij sinds 2001 opleider voor de huisartsopleiding in Rotterdam.

Willemjan Slort is sinds 1979 getrouwd met Gerry Tan. Samen kregen ze een zoon (Janwillem, 1980) en een dochter (Pauline, 1986).

List of publications

Slort W, Blankenstein AH, Schweitzer BPM, Knol DL, Van der Horst HE, Aaronson NK, Deliens L. Effectiveness of the palliative care 'Availability, Current issues and Anticipation' (ACA) communication training programme for general practitioners on patient outcomes: A controlled trial. *Palliative Medicine* 2014, June 20, doi: 10.1177/0269216314538302.

Slort W, Blankenstein AH, Schweitzer BPM, Deliens L, Van der Horst HE. Effectiveness of the 'availability, current issues and anticipation' (ACA) training programme for general practice trainees on communication with palliative care patients: A controlled trial. *Patient Educ Couns* 2014; 95: 83-90. Doi: 10.1016/j.pec.2013.12.012. Epub 2013 Dec 26.

Kortekaas MF, van de Pol AC, van der Horst HE, Burgers JS, Slort W, de Wit NJ. Towards efficient use of research resources: a nationwide database of ongoing primary care research projects in the Netherlands. *Fam Pract* 2014; 31: 229-235. Doi: 10.1093/fampra/cmt067. Epub 2013 Nov 25.

Slort W, Blankenstein AH, Schweitzer BPM, Knol DL, Deliens L, Aaronson NK, Van der Horst HE. Effectiveness of the ACA (Availability, Current issues and Anticipation) training programme on GP-patient communication in palliative care; a controlled trial. *BMC Fam Pract* 2013; 14: 93.

Slort W. Palliatieve chemo en hoop op curatie. *Huisarts Wet* 2013; 56: 300 (Import).

Pype P, Slort W, Van den Eynden B, Deveugele M. Huisarts-patiënt communicatie aan het einde van het leven. Aanbevelingen op basis van de literatuur. *Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg* 2013; 13: 12-27.

Slort W, Vilrokx C, Belderbos H, Loosveld O, Thijssen F, Frankenhuis R, Bennink C. Specialisten en huisartsen spreken met ongeneeslijk zieke oncologische patiënten over de laatste levensfase. Een regionale pilot met 'Advance Care Planning'. *Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg* 2012; 12: 28-39.

Slort W, Blankenstein AH, Wanrooij BS, Van der Horst HE, Deliens L. The ACA training programme to improve communication between general practitioners and their palliative care patients: development and applicability. *BMC Palliat Care* 2012; 11: 9. Doi:10.1186/1472-684X-11-9.

Slort W, Pype P, Deveugele M. Communiceren met palliatieve patiënten. *Huisarts Wet* 2011; 54: 614-617.

Slort W, Blankenstein AH, Deliens L, Van der Horst HE. Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011; 61: 167-172.

Slort W, Schweitzer BPM, Blankenstein AH, Abarshi EA, Riphagen II, Echteld MA, Aaronson NK, Van der Horst HE, Deliens L. Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliat Med* 2011; 25: 613-629.

Tilstra J, Slort W. Geen plaats voor ergometrine bij de behandeling van endometritis puerperalis. *Huisarts Wet* 2001; 44: 315 (ingezonden).

Slort W, De Haan M, Van Staveren G, Schoonheim PL. Improving the quality of tutorials in general practice by means of instruction and quality assessment. *In: Scherpbier AJJA, Van der Vleuten CPM, Rethans JJ, Van der Steeg AFW, editors. Advances in Medical Education. Dordrecht: Kluwer Academic Publishers,* 1997: 295-298.

Slort W, Van Staveren G, De Haan M, Schoonheim PL. Verhoogt ervaring de kwaliteit van huisartsopleiders? *Bulletin Medisch Onderwijs* 1996; 15: 88-93.

Slort W, Van Staveren G, De Haan M. Dragen instructie en toetsing bij aan de kwaliteit van huisartsopleiders? *Bulletin Medisch Onderwijs* 1996; 15: 8-16.

Slort W, Van Staveren G, De Haan M. De ontwikkeling van een beoordelingsinstrument voor leergesprekken. *In: Pols J, Ten Cate ThJ, Houtkoop E, Pollemans MC, Smal JA, redactie. Gezond Onderwijs - 4. Houten/Zaventem*: *Bohn Stafleu Van Loghum,* 1995: 253-256.

De Groot ANJA, Slort W, Van Roosmalen J. Assessment of the risk approach to maternity care in a district hospital in rural Tanzania. *International Journal of Gynecology and Obstetrics,* 1993, 40: 33-37.

Van Staveren G, De Haan M, Slort W. Het gezondheidsbeeld: een bruikbaar instrument voor de huisarts? *Huisarts Wet* 1985; 28: 338-340.

Slort W. Het gezondheidsbeeld: het beeld dat de huisarts van de patiënt heeft. *(doctoraalscriptie) A’dam: H.I.V.U.*, 1984.

Willemjan Slort (1958) is huisarts in Zevenbergen en heeft bij de afdeling Huisartsgeneeskunde van het VU medisch centrum in Amsterdam onderzoek gedaan naar de huisarts-patiënt communicatie in de palliatieve zorg.

Hij heeft gezocht naar factoren die een rol spelen bij de communicatie tussen huisarts en patiënt in de palliatieve zorg. Met de resultaten heeft hij een nieuw onderwijsprogramma ontwikkeld voor huisartsen en huisartsen-in-opleiding. Centraal in dit programma staan de ***A****anwezigheid* van de huisarts voor de patiënt, de ***A****ctuele onderwerpen* die de huisarts aan de orde moet stellen en het ***A****nticiperen* op diverse scenario's. Vervolgens heeft hij onderzocht of dit AAA-programma de communicatie van huisartsen en huisartsen-in-opleiding verbetert. In dit onderzoek werd geen effect van de training gevonden, maar er werd wel aangetoond dat sommige onderwerpen veel minder vaak werden besproken dan andere. Uitgebreid wordt gereflecteerd op de factoren die het aantonen van effectiviteit bemoeilijkt hebben. Deze reflectie levert aanbevelingen op voor de praktijk, het onderwijs en toekomstig onderzoek op het gebied van huisarts-patiënt communicatie in de palliatieve zorg.