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Out-of-hours palliative care by general practitioners

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Out-of-hours palliative care by general practitioners

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door

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geboren te Enschede

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Chapter 1

Introduction

Some years ago I was on call at a post of the GP co-operative, from which general practitioners in the Netherlands provide their out-of-hours care. It was 10.30 in the evening and a man called to announce that his wife had to be hospitalized immediately, as she could no longer sustain. She was in pain and short of breath. When I made my visit I met his sixty-year-old, exhausted wife who was indeed in a lot of pain and with an abdomen filled with fluid. There was no handover form, no patient file present and the husband was clearly panicking. After some time, while unsuccessfully trying to calm him, a daughter arrived who told me that her mother was in a terminal phase of breast cancer and that she had gone downhill in the last two days.

Agreements on how to proceed were never made. How should we continue tonight? Her pain, the ascites and her husband's state of panic was all too much for me; I referred her to a hospital.

Two weeks later I saw a note on the bulletin board of the GP co-operative where I was working that night. It was a letter of thanks from a wife to the doctor, whose name she had forgotten, who had visited her and her husband at night. He was dying and his breath was rasping. She did not have to explain the situation because this doctor was already well-informed. The doctor had said that there was not much he could do, but she wrote: 'He did more than enough by just pulling a chair to the bedside and sitting with me for half an hour.'

During the past decade GP co-operatives in the Netherlands have partly taken over the role of out-of-hours palliative care. There are GPs who are permanently available for their patients, also at night and at weekends, but many GPs leave at least part of this care up to the GP co-operative.

The availability of information on the patient's situation is then crucial and that is the main theme of this thesis.

Palliative care and the changes in out-of-hours primary care

The organisation and delivery of out-of-hours primary health care in the Netherlands have undergone major reforms over the past decade. In the second part of the twentieth century most GPs were organised in small rota groups of five to ten GPs, in which they were on call for each other's patients.(1) This out-of-hours care caused a lot of problems from the GP perspective such as a heavy workload and a lack of a private life, and was the main reason given for GP burn-out.(2) Encouraged by positive experiences in the UK and Denmark, Dutch GPs reorganised their out-of-hours care in around the year 2000 and within a few years shifted from the small on-call rota groups to large-scale GP co-operatives.(3,4,5) Nowadays these co-operatives serve more than 95% of the Dutch population, whereas the remaining 5% are served by small rota groups. Patients can contact the GP co-operative with a single regional telephone number, but visiting them for a consultation is also possible. When patients contact the GP co-operative by phone, a medical secretary performs triage according to which telephone consultations, centre consultations and home visits are provided.

The overall satisfaction with this system, as indicated by patients, is high, showing highest levels for home visits and lowest levels for telephone advice.(6) But although patients in the Netherlands, just as in the UK and Denmark, are generally positive about the care they receive from GP co-operatives, concerns have been raised regarding the care that complex, time-consuming, patients in palliative care receive.(6,7). Criticism with regard to various aspects of care delivery was voiced by GPs themselves, patients, political bodies, and the Dutch Inspectorate of Health Care.(8,9).

A study of the experiences of patients and their carers with out-of-hours palliative care identified barriers in their access to care. Patients were anxious about the legitimacy of their needs and felt uncertain as a result of previous negative experiences. Service responses were sometimes inappropriate, because they are mainly designed for acute medical care and do not meet the palliative care needs. (10)

Continuity of care and house calls are particularly important for this vulnerable group of patients. Due to the recent changes in service organisation, patients are now unlikely to receive care from a doctor who knows them.(10)

The concept of continuity of care, as seen by GPs, is changing. First there is the relation with the patient and as a result a direct personal continuity, an ongoing relationship with the same GP. Sociological trends in general practice in most western countries are considered a threat to the core values of this personal continuity. Due to the changes

in daily practice, such as part-time working, replacement of single-handed practices by multi-handed practices, and the introduction of the GP co-operatives, a shift is taking place towards continuity provided by the professional group of GPs.

Informational continuity, the use of information on past events, personal circumstances and care plans, should fill the gap.(11) This requires an exchange of information between GPs, specialists and care facilities.

Continuity in palliative care must therefore be guaranteed by providing information about patients in palliative care to the GP co-operative.

Palliative care by GPs in the Netherlands

Together with these developments in specialist palliative care, the concept of palliative care took a strong hold in primary care. Many patients with advanced and progressive illnesses spend most of the final year of their lives at home and there is a general consensus that medical care for these patients belongs to the domain of the GP.(14,15,16) For practitioners, this care is not only a rich, intense, experience but also one that demands a lot from them and often evokes uncertainty.(17) They are supported by family and other carers and professionally by their GPs and by district nurses. In 1980 Dutch GPs formulated a new paradigm in which they described their goal of 'integral, continuous and personal care' and they considered delivering care at home for dying patients an important element towards achieving this goal.(18)

Nowadays, GPs in the Netherlands have a pivotal position in palliative care for three key reasons. First, they are the initial point of contact for all patients and frequently gatekeeper to other services. Second, GPs often have a key role in issues of continuity affecting patients and families, especially where other co-morbidities play a role.(19) Finally, GPs are still family doctors; their care includes the care for the patient's family and they (or their locums) make house calls 24 hours a day, seven days a week.

Although palliative care forms only a small portion of the work of GPs, they consider it as an important part of their work. (20)

In the late eighties of the twentieth century, when interest in palliative care in the Netherlands was growing, the role of the GP in terminal home care was criticised for the first time. (21)The lack of cooperation with secondary care and within primary care, poor continuity of care, poor accessibility and lack of knowledge and skills are the subject of this criticism. Although young GPs did get some training in palliative care

History of palliative care

According to the WHO definition, Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.(12)

History reveals that palliative care as a medical specialism, unlike many other specialties, has its roots in primary and community care.(13)The original vision of Dame Cicely Saunders, an English nurse, physician and writer, the 'founding mother' of the hospice movement and of modern palliative care, was primarily to ensure that excellent care relieved patients' suffering as they approached death. She drew attention to a patient's need to feel confident that the professionals are committed to providing care, valuing the individual patient, and above all, not abandoning the patient in their hour of greatest need, whenever that is.(14) Such a personal relationship was seen during the last century in the traditional family doctor role.

It was however the establishment of the hospice movement that brought us the science of palliative care. We have come a long way since the initiation of modern palliative care in 1967 at St Christopher's Hospice in London. An attitude was developed by Saunders and her co-workers that focused not only on pain and symptom control, but also on nursing and psychosocial and spiritual care.(15) The term 'total pain' was coined to express the overwhelming feelings of pain and despair that occur when physical pain is compounded by emotions, social concerns and isolation, and spiritual turmoil.

A landmark in the history of the development of palliative care in the Netherlands was a project in 1975 in the nursing home 'Antonius Ysselmonde' to improve the care for terminally ill patients. Various aspects of terminal care (the adjective 'palliative' was not used at that time) were investigated and researchers spent time in St Christopher's Hospice and in St Luke's Hospice in Sheffield to learn from these new insights.(16)

during their education, because a GP provides palliative care on average for 5 patients per year, it takes time to build up experience in this complicated field.

The solution to these problems within the profession was sought in the improvement of training in the palliative field. A framework for palliative care education was created and a peer group training project started. A major factor in the support of Dutch GPs was the rise of the number of palliative care consultants in many places in the Netherlands. Support also came from the Comprehensive Cancer Centre (IKNL) which provided national guidelines and leaflets.(22)

The development of palliative care in the Netherlands is thus characterised by an emphasis on primary health care. In a recent letter to the Dutch parliament, the Secretary of Health stated that the actual formal approach of the Dutch government is to provide the best quality of life for the patient and his surroundings where palliative care remains as much as possible a part of mainstream care. Therefore palliative care will be predominantly provided by primary health professionals, including GPs, (district) nurses, caregivers, and nursing home doctors.(23)

Out-of-hours palliative care from an international perspective

In a report on out-of-hours palliative care in the community, Thomas stated that a number of trends have contributed to the often inadequate out-of-hours palliative care provided in the UK.(24) They include radical changes in general practice out-of-hours cover, changing demographic profiles and expectations of society, increasing numbers of patients receiving palliative care in the community and uneven developments by area in palliative care services

An important finding in her study, confirmed in other studies, was that communication between those caring for patients during working hours and those working out-of-hours is often inadequate. Worth et al identified the importance of good anticipatory care as a key element both for patients and professionals.(10) Part of good anticipatory care is the provision of information to patients and carers along with regularly updated handover forms sent to out-of-hours services. Burt et al stated that, in spite of recommendations and standards on information transfer, GPs within co-operatives are not routinely alerting out-of-hour doctors to the needs of their vulnerable patients. (25) Diagnosis, prognosis and care preferences of two-thirds of patients with palliative care were not made known to the co-operative.

In a focus group study with bereaved relatives in Denmark, Neergaard found that for carers it is important to know whom to contact during the out-of-hours periods. Furthermore, she found that it was highly appreciated when GPs gave the family their telephone number while others had to use the on-call GPs who were unfamiliar with the patient.(26)

Communication in palliative care

One of the most important aspects of palliative care is the communication between the patient and his doctor. Due to the severity of the situation, involving medical, psychological, social and spiritual issues, GP-patient communication will often be difficult. If communication is not effective, some, if not many, of the problems that patients are facing might not be identified. This is probably even more so in situations where the doctor does not know a patient personally. Some situations in palliative care require a clear communication between patient and GP on aspects of care like medical prognosis, agreement on place of care, wishes concerning the end of life, etc.. Another aspect of communication is the communication between professionals. A GP has to communicate well with a patient and their family but he needs also to transfer the information obtained to the GP co-operation. This is essential for the doctor, working as locum in the out-of-hours period, in order to maintain good communication and to provide quality of care.

Objectives and outline of the thesis

From literature, mainly from the UK and Denmark, we know that, due to many recent changes within the profession, the quality of out-of-hours palliative care is not always adequate. An important problem is the continuity of care, which is suboptimal if information about a patient is not transferred. The organisation of out-of-hours care in the Netherlands was reformed along the same lines, which brought about changes in the provision of out-of-hours palliative care.

We want to contribute to an improvement of out-of-hours palliative care by general practitioners in the Netherlands by mapping the current quality of this care, highlighting the problems in its current provision and making recommendations for improving practice. Our main focus is communication through information transfer and continuity of care. We further wanted to know if an educational intervention,

consisting of the introduction of a handover form, could improve communication between GP and GP co-operative.

In Chapter 2 we report on a focus group study among Dutch GPs. Our aim was to see how they assessed the quality of out-of-hours palliative care provided by GP co-operatives in the Netherlands.

In Chapter 3 we present the analysis of data from a questionnaire sent to all Amsterdam GPs. The aim of this study was to investigate the views of GPs on the transfer of information about their terminally ill patients to the GP co-operative. GPs were asked to give their view from two different perspectives: as a GP in their daily practice and as a locum in the GP co-operative.

Chapter 4 is an exploratory study of all palliative care phone calls made to the Amsterdam GP co-operative during the year 2006. We subsequently assessed the presence or absence of information transferred by the patient's own GP and, if present, its content. We then analysed data on patient characteristics, type of contact with the locum and care provided by the locum.

Communication in palliative care is the main theme in Chapter 5. While effective communication is required for the provision of good palliative care, barriers and facilitators for this communication are largely unknown. We developed a search strategy to identify empirical data on GP-patient communication in palliative care and synthesized our findings in a systematic review on barriers and facilitators for this communication.

In Chapter 6 we report on our trial evaluating the effects of the introduction of a handover form for information exchange on the quality of out-of-hours palliative care, compared to usual GP care. We addressed the research question: does the introduction of a handover form and training GPs to use them improve a) the frequency and b) the quality of information provided for out-of-hours palliative care?

Chapter 7 describes the outcomes of the trial on the level of patients and their carers. We held telephone interviews with patients or their carers and evaluated the effect of a training for GPs in writing information transfers on outcome and process of palliative care, compared to usual GP care.

Chapter 8 is a report on the patients' experiences with information transfer on palliative care by their GPs to the GP co-operative. It is based on the telephone interviews with patients or their carers as described in chapter 7.

In the general discussion, Chapter 9, we summarize the main findings. The results of our research are linked together and put in a wider perspective, discussing the perspectives of the GP, the patient and the GP co-operative. We reflect on some methodological aspects of the studies and discuss implications for clinical practice and future research.

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Out-of-hours palliative care provided by GP co-operatives in the Netherlands: a focus group study

Schweitzer B, Blankenstein N, Deliens L, van der Horst H.
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Introduction

Palliative care for patients who are nearing the end of life involves several elements of the healthcare system. In recent years there has been a strong emphasis on the development of palliative care in Dutch primary care. With the help of governmental finance, efforts were being made to improve expertise and to establish regional networks in which the primary, secondary and tertiary health care settings co-operate. Part of their work was the establishment of Palliative Care Consultation teams in which experienced professional care providers, e.g. hospice staff, specialists in pain treatment and experienced GPs cooperate. These teams give advice and support to GPs and are usually also accessible during the out-of-hours period. Palliative care in the Netherlands is expanding, and the climate for further development is favourable. (1)

A prerequisite for good palliative care is that care does not end after office hours. Reorganisation of the out-of-hours primary care services in the Netherlands, as seen before in the United Kingdom and Denmark, has given rise to concerns about the quality of out-of-hours palliative care. This reorganisation in the Netherlands has been initiated by the GPs themselves, mainly to reduce their workload. As a result, large scale co-operatives providing out-of-hours primary care were established around the year 2000, with the aim to achieve more efficient handling of urgent requests from patients (i.e. requests that cannot wait until the next day). (2, 3) Within a few years a shift took place from small on-call rota groups to large-scale GP co-operatives, now serving over 90% of the population of the Netherlands. On the whole, GPs are positive about this development, although evaluations made by patients and other professionals are more varied. (4-6)

Palliative care is one of the domains of care in which patients express concerns about the quality of the care. (6,7) The challenge is to provide care, which is continuous and responsive in times of need. (8) One of the major problems in palliative care appears to be poor communication about terminally ill patients between the GPs and the GP co-operatives. Out-of-hours providers face substantial difficulties in identifying patients with complex needs, and particularly those with palliative care needs.(9) According to studies carried out in the UK, few GPs report that they routinely transfer information about their palliative care patients to the GP co-operatives. This results in care that is often suboptimal, e.g. resulting in poor symptom control and unnecessary hospital admissions. (10,11) Moreover, it fails to meet the legitimate expectations of patients

and their carers. There are still a number of significant gaps in the provision of out-of-hours care for people receiving palliative care at home. (12)

We therefore aimed to investigate the experiences of GPs in the Netherlands with regard to the quality of the out-of-hours palliative care that is provided by GP co-operatives, and to identify aspects for which recommendations about the organisation of the services could be made. We addressed the following research questions: 1. How do GPs assess the quality of out-of-hours palliative care provided by GP co-operatives in the Netherlands? 2. Which factors contribute to a better or worse quality of out-of-hours palliative care according to the GPs? 3. Which improvements in the quality of out-of-hours palliative care could be made according to the GPs, and how can these be achieved?

Methods

Design

Since research on this subject is scarce, we chose for an explorative design, with the aim to investigate the full array of topics involved. We opted for a qualitative study using focus groups discussions with GPs. (10,11) This method allows the participants to identify and discuss the topics that are important for them. We expected to gain insight into their attitudes, experiences and expectations with regard to out-of-hours palliative care. Our intention was to organise as many focus groups as needed to reach content saturation .

Setting

In the Netherlands the GP is the central professional in the management and coordination of primary health care, including palliative care. District nurses take care of much of the hands-on palliative care and specialist palliative care advice is widely available, also after office hours. The regional palliative care consultation teams provide on call care advice. Most GPs also work as a locum for the local GP co-operatives.

Sampling

We composed three focus groups. We obtained lists of GPs in two different regions from the National Association of GPs, containing approximately 1000 names with addresses and date of start of GP practice. The addresses gave information about gender and

whether a GP was working in a group practice or not. From these lists we selected and invited GPs according to the criteria in Table I. The selected GPs were working for 5 different GP co-operatives in rural and urban areas. We recruited two groups of GPs (N=6; N=7), who differed on relevant aspects: gender, years of experience as a GP, working fulltime or part time, working in a group practice or not, urban or rural practice location, training in palliative care, and working as a GP trainer. A GP trainer is attached to a university and is co-responsible for the GP trainees. (Table I)

Table I Characteristics of GPs participating in the three focus groups

Characteristic	Group 1	Group 2	Group 3, Dutch	Group 3, non-Dutch*
	(N=6) Yes/No	(N=7) Yes/No	(N=7) Yes/No	(N=7) Yes/No
- Male	2/4	5/2	2/5	4/3
- Experience as GP > 5 year	6/0	5/2	4/3	6/1
- Fulltime	3/3	2/5	2/5	3/4
- Group practice	2/4	3/4	5/2	5/2
- City area	4/2	4/3	4/3	5/2
- Palliative care advisor	2/4	1/6	1/6	0/7
- GP trainer	4/2	5/2	4/3	6/1

*Denmark 2, France 3, Italy 2

A third group consisting of 7 GPs from across the Netherlands, and 7 GPs from other European countries (Denmark 2, France 3, Italy 2) was a convenience group of GPs attending a WONCA conference on palliative care. We assumed that the presence of the foreign participants would enliven the discussion. We also wanted to offer them the opportunity to experience a focus group as method of qualitative research.

Data collection and analysis

The participants of the first two focus groups met at the VU University Medical Centre in Amsterdam, in February 2004 and a third focus group discussion was held during the WONCA Conference in Amsterdam in June 2004.

Each group was invited to discuss out-of-hours palliative care provided by GP co-operatives, starting with four open-ended questions (Box 1). The groups were encouraged to raise their own issues with regard to these questions. Each group

discussion was led by an experienced moderator (NB). The focus group meetings lasted for approximately 2 hours.

Box 1 Focus group questions

1. How is, in your experience, the quality of out-of-hours palliative care ?
2. (a) What is contributing to the quality of out-of-hours palliative care ? (b) And what is threatening that quality ?
3. What kind of improvements would you recommend in this field, in regard to your own practice ?
4. And in which way do you suggest we can bring these improvements about ?

The discussions were tape-recorded with the participants' consent, transcribed verbatim and analysed by two researchers (BS and NB, both GPs). We used a qualitative descriptive approach, a method that aims to obtain first-hand knowledge of the participant's experiences with a particular topic. The product of this approach is a description of these experiences in a language similar to the participant's own language. (14-17) Analysis was performed by reading the transcripts repeatedly and making notes manually on the different topics that arose in the discussions. Both researchers identified emerging themes and categories independently, and agreement was reached by discussion. Meaningful text excerpts were grouped according to these categories.

The first two focus groups were conducted in Dutch, the third in English. The Dutch transcripts used in this article were translated in English by an experienced translator. All transcripts were subsequently re-translated into Dutch by another translator to examine if no shift of meaning had occurred, which was not the case. A summary of the transcripts, together with a list of themes and categories, was sent to the participants for a member check.

We started the analysis after we had the results of the first focus group. After the second focus group we analysed the results of this group and compared these with the results from the first group. After analysis of the results from the third focus group we compared these again with the results from the first two groups. At that point we found that no new themes had emerged. Therefore, we assumed that we had reached saturation.

We only analysed the contributions of the Dutch participants. Comments from international GPs were not used in this study. As had been expected, the organisation of out-of-hours palliative care in their countries differed from the situation in the Netherlands.

Results

The characteristics of the GPs participating in the 3 focus groups are presented in Table I. Quotes from Dutch participants were taken from all three focus groups.

The proportion of GPs involved in vocational training was higher in our study (70%) than among GPs in the Netherlands in general (13%).

The participating GPs reported that they relied on the out-of-hours services for palliative care, whereas before the GP co-operatives were established they were accustomed to provide palliative care themselves.

“It is especially the new situation. In the past you did it all by yourself, you had to be on call at home, I can’t manage that anymore. I knew the people then, and their situation, but all that has changed.”

Quality of out-of-hours palliative care

The GPs are concerned about the overall quality of the out-of-hours palliative care that is provided by GP co-operatives, which they describe as meagre.

GP co-operatives mainly focus on acute, biomedical care, and it is difficult to maintain continuity of care for patients with complex needs.

“What we do, while we are on call, is attend to acute problems and wait and see for the rest. This is why I think that the quality of palliative care during the after hours period is meagre.”

Many decisions in out-of-hours palliative care are made ad hoc by a locum without consulting the patient’s own GP or other colleagues. However, sometimes a locum can solve problems that were not adequately addressed during office hours. Continuity of care appears to work both ways: inadequate quality of care from the patients own GP hampers out-of-hours care and vice-versa.

“It strikes me that the situations I’m facing when I’m on call are increasingly different. Sometimes everything is taken care of. Usually the care is meagre. Sometimes situations are distressing, with long overdue maintenance... and in these cases a visit of another doctor is a blessing for the patient.”

The GPs indicated that it is unsatisfactory for patients and their carers that many questions are handled by phone when a home visit is needed.

“What I also see.., if there’s a problem and the own GP is not available... everything is handled by phone. I think that this is awful, making such important decisions about the medication of a terminal patient by telephone. My opinion is that you have to visit the patient personally.”

The GPs also state that palliative care after office hours in care homes for the elderly is especially difficult, mainly due to staffing problems.

“Care homes are another story. In my opinion the staff causes panic, instead of creating an atmosphere in which someone can peacefully die. This is an increasing problem. The level of care is getting lower.”

What contributes to the quality of out-of-hours palliative care?

In Box 2 we present the facilitators and barriers reported by the participating GPs.

GPs should anticipate during office hours palliative care problems that might occur after hours. If this is done properly, most of the palliative care can be arranged during office hours.

“The core aspect of palliative care is anticipating future problems. I know that now, but I didn’t learn that during my training or in the first twenty years of my career. Anticipation is the key.”

An important contribution to quality is making continuity of care possible by transferring adequate information about the patient to the GP co-operative.

“Hand-over of information is a necessity. I feel more supported if I know beforehand what happened with this patient and his family.”

Involvement of the locums with the patient’s situation is also a prerequisite for delivering good palliative care. Palliative care is not only about providing medical interventions but also about paying attention.

“I really think that involvement with what is happening is crucial. Almost even more so than transferring information. Because information can sometimes be obtained from the family.”

A lot of information can probably be gathered when the locum arrives at the patient’s home, but it is comforting for the patient and his carers if the locum has already been informed.

It would also be an improvement if the patient’s GP provides the GP co-operative with his mobile phone number and can be contacted. Better education in palliative care would also help; it could prevent the locums from getting “cold feet”.

What is threatening the quality of care?

Out-of-hours care has changed with the development of the GP co-operatives and personal continuity of care is no longer the rule.

"In the past I was always on call for terminally ill patients, or I could transfer them easily to a colleague in my rota-group. Now, with the co-operative, it's difficult, mainly because it's more anonymous. And I find it harder to be on call, after five o'clock I'm no longer available."

Transferring information to the GP co-operative is a difficult task. The organisation is anonymous; there is no longer any contact with colleagues about the out-of-hours care.

"If you write, for instance, that a patient does not want any treatment aimed at cure because this is no longer possible, that could result in carelessness. So, just because I transferred information, the locum thought: that patient can wait."

The GP co-operative is primarily biomedical care-orientated. Acute conditions take precedence; there is very little available time to address the needs of palliative care patients.

Palliative care calls, although infrequent, are time-consuming. There is no explicit policy how to handle these calls in the context of a generic out-of-hours service, and there is no additional time for palliative care home visits.

"It is not because the GP co-operation works on a larger scale, but because of the policy. There is no vision, everyone does his own thing, and it is very busy. We do not have time for serious cases because of all the patients with minor complaints."

"It is a problem that most of the time only young, relatively inexperienced, doctors staff the GP co-operatives, especially at night, which reduces the quality of the care that is provided."

The out-of-hours palliative care provided in care homes for the elderly is an area of concern, mainly due to staffing problems.

"Illogical questions without a firm basis come mainly from care homes and much less often from the home situation. Carers in care homes are often not acquainted with the patients. Their protocol tells them to call, and they want to be covered for claims."

Determining whether or not a patient is in a terminal phase is also a problem. The prolongation of the palliative care phase makes it difficult for a GP to decide when he has to arrange extended palliative care. The rationale of a chemotherapeutic treatment is not always clear to a GP in the end stage of life: is there still a palliative benefit or is there not much reason in the continuation of this therapy?

“Patients are treated endlessly. They are more or less in a terminal phase, and are still having chemotherapy. It’s difficult because they don’t get proper palliative care in this way.”

What improvements can be made?

It is helpful if the patient’s own GP has made a care plan anticipating future problems. The GP uses information about past events and personal circumstances to provide care that also extends beyond the hours of his surgery. He is responsible for the continuity of care.

“I think anticipating during office hours is extremely important. It’s one of the most important conditions for good quality out-of-hours palliative care. You have to learn it yourself; it’s more about attitude than about knowledge.”

Provision of information to the GP co-operative and up-to-date information in the patient’s home are viewed as not only important for the delivery of the care, but also for the prevention of uncertainties for the patient and the carers.

“A patient who is terminally ill appreciates it very much if the visiting doctor knows all about him. And as a locum I also want to know what to expect.”

The home visit itself, and not the duration of the visit, is considered to be important because it gives more moral support to a patient than a telephone contact.

“Time is not the most important thing. Being there is important. Often it is okay because you’ve been there, and then they can carry on.”

A major asset, particularly in the after hours period, is a well-arranged support system which involves the family, other carers and district nurses. The possibilities of hospices and palliative care units were mentioned for patients without such help.

“I discuss with patients who are living alone that there are possibilities, such as a hospice. That you don’t have to die at home all alone.”

Suggestions to make these improvements possible

Clear guidelines for the transfer of information would be helpful, and also better use of Information and Communication Technology. Eventually, GP and GP co-operatives will share the electronic files of palliative care patients.

“An online hand-over form would be a great help. In our co-operative, improvements were achieved by the introduction of clinical guidelines on palliative care after office hours.”

Permanent palliative care education is needed: although some doctors receive extensive training in palliative care, the overall level must be raised.

“If palliative care was included in the university training, this problem would have been solved.”

Discussion

Main findings

This study focused on the factors that, according to GPs, influence the quality of out-of-hours palliative care provided by the GP co-operative. GPs considered the quality of out-of-hours palliative care in the Netherlands to be meagre, and regarded out-of-hours service responses to be designed more for acute medical problems rather than for palliative care needs. (Box 2)

Box 2 Facilitators and threats to the quality of out-of-hours palliative care provided by GP co-operatives

Facilitating factors	Threats
- Well arranged support system at home	- Late determination of the palliative phase by GP
- Anticipatory care by GP	- No continuity of care
- Adequate information transfer by GP	- GP co-operatives: focus on acute, biomedical care
- Patient's own GP can be contacted	- Inexperienced doctors staff the GP co-operatives
- Giving attention to palliative care patients	- Staff problems in care homes
- More home visits	
- Better education in palliative care	

Furthermore, there was special concern about the quality of the out-of-hours palliative care that is provided in care homes for the elderly.

Three major issues influencing the quality of care were identified. The most important problem is the lack of adequate information sent to the GP co-operative because there is no adequate method for the transfer of information about patients. Secondly, the quality of out-of-hours palliative care is hampered by insufficient anticipatory care during office hours. Thirdly, because no policy on palliative care has been developed

by the GP co-operatives, calls from palliative care patients are not treated with priority and no additional time is available for home visits. Attitudes to palliative care have to be addressed to prevent careless behaviour 'because there is nothing more to be done'.

The participants indicated that improvements could be made if GPs anticipate problems that could arise after office hours and provide relevant information to the GP co-operatives.

Strengths and limitations

This focus group study was intended as a preparation for further quantitative research among patients and GPs regarding the out-of-hours palliative care system in the Netherlands. We chose for qualitative description because there was no available information on the quality of out-of-hours palliative care in the Netherlands. A strength of the study is that the participating GPs in the three groups differed on relevant aspects, although GP trainers were overrepresented. There was a high level of agreement between the participating GPs with regard to the most important themes, and we reached saturation after three focus groups.

A limitation of the study, due to our restriction to GPs, is that we do not know how patients, family carers or professionals other than GPs assess the quality of out-of-hours palliative care.

Furthermore, there was not much debate in the focus groups on personal continuity of care. This can be caused by the strong impact on out-of-hours care made by the GP co-operatives but it blurs the fact that a number of GPs provide out-of-hours palliative care themselves.

The participants in our study gave their time voluntarily; it is therefore likely that they had more than average motivation and interest in the subject, especially the participants in the third focus group who attended a conference on palliative care.

The participation of GPs from other European countries in the third group livened up the discussion. We had not intended to take their contributions into account in our analyses. Indeed, the organisation of out-of-hours palliative care in their home countries differed widely from the Dutch situation. In retrospect, we might better have organised the third focus group into an inner circle of Dutch participants and an outer circle of foreign listeners.

Comparison with existing literature

Whereas in a study in the UK several areas of concerns were raised about out-of-hours cover for palliative care patients (12), the GPs in our study in the Netherlands assessed the quality of the palliative care provided by the GP co-operatives as meagre, and especially the quality of out-of-hours palliative care that is provided in care homes for the elderly.

Other findings of our study confirm the results from earlier studies. An anticipatory approach to care is most important; it helps to maintain care at home where it enables locums to arrive well-informed at the patient's home. Out-of-hours handover forms are seen as having contributed to better communication between in- and out-of-hours services (19). A high percentage of both nurses and GPs in an Australian study agreed that standardised written patient protocols would improve out-of-hours services. (10) But although these protocols could improve out-of-hours services if on-call staff, including locums, has access to them, GPs do not routinely provide these for the GP co-operatives. (11,12,20) Problems apparently experienced by family carers were associated with poor provision of information and poor access to out-of-hours health care. Information on the provision of care during the out-of-hours period is helpful for patients and their carers. (21) Problems with the administration of the out-of-hours service, as having no access to medical records, have the potential to impact on the place of death. (22) Consistent with other studies is also the problem of lack of time for palliative care patients caused by the constraints of a busy out-of-hours service, where service configuration is based predominantly on acute illness situations and biomedical criteria. (21,23)

In the context of current primary care provision, personal continuity of care is increasingly unlikely to be provided out-of-hours, but data in a UK study suggest that informational and management continuity, supplemented by good communication, may suffice. (21)

Implications

Future research should focus on the assessment of the quality of out-of-hours palliative care by patients and their carers. In the short term much might be accomplished by the development of an effective system of information management and transfer between the GP practices and the GP co-operatives.

Our findings suggest that GPs realise that anticipatory care is essential, and that continuity of care is only possible if information is transferred. GP co-operatives should also develop a policy on the provision of out-of-hours palliative care. The level of care that can be provided must be clear to GPs and patients. If no adequate service can be obtained from the regular out-of-hours service, alternatives, such as a special palliative care service, should be examined. A clear guideline on the transfer of information and more education in palliative care could bring about a further improvement in the quality of out-of-hours palliative care.

A point of concern is the quality of the palliative care that is provided in care homes for the elderly. Education of the nursing staff is needed.

Conclusion

This study explored some aspects of out-of-hours palliative care in the Netherlands. The participating GPs expressed their concerns about the quality of palliative care as provided by the GP co-operatives. They suggested that quality of out-of-hours palliative care in the Netherlands is meagre. Improvements could be made in terms of anticipatory care during office hours, adequate transfer of information, and the development of a policy on palliative care provided by the co-operatives. The results of this study call for a quantitative follow-up study.

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GPs' views on transfer of information about terminally ill patients to the out-of-hours co-operative.

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Introduction

In the Netherlands, 60% of all patients dying with cancer or a terminal chronic disease, dies at home.(1,2) On average, per year, a general practitioner (GP) is responsible for the care of five to six patients with cancer in a terminal phase.(3) Therefore, primary palliative care is regarded as an important task of the GP in the Netherlands. GPs do not only take care of their patients during office hours, but until 1999 most patients also received out-of-hours palliative care from their own GP, including care during the weekends. (1) Until the 1960s, many Dutch GPs personally took care of their own patients out-of-hours. As a consequence, GPs were on call most of the time. Subsequently, more and more GPs formed small rota groups of five to ten GPs, in which they were on call for each other's patients. However, from 1999 on, GPs in the Netherlands have reorganised their out-of-hours care from rota groups to larger scale GP co-operatives with 40-400 GPs taking care of populations ranging from 50.000-700.000 inhabitants (4,5) These co-operatives now provide out-of-hours GP care for more than 90% of the Dutch population. They are organised by and responsible to a board of local GPs.

In general, GPs and patients seem to be positive about these GP co-operatives, (6) but some patients have expressed concerns regarding the care that complex, time consuming, palliative care patients receive.(6,7) In palliative care continuity of the care is considered to be quite important by most patients; when personal continuity is not possible, information must be transferred in order to ensure optimal out-of-hours care. The restructuring of GP care during the out-of-hours period is challenging the continuity of care that is needed in end-of- life care situations. The new out-of-hours arrangements have made informational continuity of crucial importance. (8)

However, one of the major problems in palliative care appears to be the poor communication about terminally ill patients between the GPs and the co-operatives. Several studies in the United Kingdom (UK) have reported that few GPs report that they routinely hand over information about their palliative care patients to their GP co-operatives. This results in care that is often not comprehensive, problems in symptom control and unnecessary hospital admissions. (9) Moreover, it can leave patients and their carers confused, and inadequately supported. (9-14) Although, in general, GPs in the UK are satisfied with current out-of-hours arrangements, there is less satisfaction in the inner-city areas. (15) We did not find any studies focusing on the views of GPs on the transfer of information, specifically about terminally ill patients.

In the process of designing a new out-of-hours protocol for palliative care we wanted to analyse the experiences of GPs with the transfer of information from two perspectives: from their position as a GP caring for their terminally ill patients, and from their perspective as a locum for the GP co-operative

This paper reports on the views of GPs working in a big city on the transfer of information for terminally ill patients from GP practices to GP co-operatives, and vice versa. The research questions were:

1. How many GPs report that they transfer information about their terminally ill patients to the GP co-operative? And, if they do not, what are their reasons?
2. What information do GPs transfer?
3. In their role as locum, what information do GPs want to receive?
4. How satisfied are GPs with the feedback report on their patients from the locum?

The Ethics Board of the Radboud University, Nijmegen was informed about the study, but the study did not undergo formal ethics review.

Methods

A retrospective survey was carried out among all GPs (N=424) in the region of Amsterdam in October 2006, using a web based questionnaire. Names and contact details were obtained from the Amsterdam GP co-operative. This co-operative has been in place since 2000. All GPs participate in 8 out-of-hours GP posts belonging to the Amsterdam GP co-operative. Most of them actually work their shifts as a locum for this co-operative.

In this study, a terminally ill patient is defined as a patient who is in the last phase of life, for whom no further cure is possible and life expectancy is limited, independent of the underlying illness. (16)

Measurement instruments

We used a questionnaire concerning the quality of terminal care provided by the GP co-operative. The questionnaire was based on a review of the literature.

A panel of experts in palliative care assessed a concept questionnaire and amendments were made. The result was commented on by a second panel of experienced GPs and

agreed upon in a meeting with GPs and specialists. It was then piloted with 239 GPs and after minor changes a final version was prepared.

The questionnaire contained open and multiple-choice questions. For the study described in this paper, we used the questions about the transfer of information transfer from GP to GP co-operative and vice versa, and the questions assessing the importance of the information that is transferred. (See Appendix: the survey was conducted in Dutch, the Appendix is an English translation)

Data on GP characteristics were obtained from the annual report of the Amsterdam GP co-operative.

Procedure.

Of all the 424 eligible GPs, 387 received an e-mail inviting them to fill in a questionnaire on a website, and the remaining 37 GPs, who had no e-mail address, received a postal questionnaire. Those who received the e-mail request also received a specific code, which they could only fill in once. In this questionnaire it was not possible to leave questions unanswered. Two reminders were sent, in an attempt to achieve a higher response rate, including a multiple-choice question about the reasons for non-response.

Data analyses

Data were analysed with Microsoft Excel and SPSS 12.0. Answers on a 5-point scale were converted to a 3-point scale. For example answers 1 and 2 (very unimportant and unimportant) were clustered under the denominator "unimportant", answers 4 and 5 (important and very important) were clustered under the denominator "important" and answer 3 remained unchanged under the denominator "neutral".

Chi-square tests were used to analyse differences in GP characteristics between responding GPs versus (1) all GPs in Amsterdam, (2) GPs who stated that they were personally available to provide care for their terminally ill patients during the out-of-hours period (GPs personally available), and (3) GPs who stated that they did not often transfer information.

Results

The response rate for the questionnaire was 42%. The e-mail questionnaire was completed by 175 GPs and the postal version by four GPs, two of whom were excluded from the data analysis due to incomplete answers. Hence, the results are based on the responses of 177 GPs. Of the 249 GPs who did not fill in the questionnaire, 33 (13.3%) answered by e-mail and gave their reasons for non-participation (more than one answer allowed): 25 reported that they were too busy, or forgot to reply, eight stated that they did not like web based questionnaires, and eight indicated that the questionnaire was too long.

None of the GPs reported lack of interest in the subject.

Of the respondents 61% were male, with a mean age of 49.6 years (SD 8.1). 42.3% worked either in a group practice or a community health centre, 32.6% worked in a duo-practice and 25.1% worked in a single-handed practice. The majority (63.4%) was working for three or four days a week and 34.9% were working full-time.

The GPs who responded did not differ significantly from the total population of GPs in the region. (Table 1)

Table 1. GP characteristics

	All GPs in Amsterdam (N=424)	All Responding GPs (N=177)	P values ¹	Responding GPs personally available (N=123)	P Values ²	Responding GPs not frequently transferring information (N=31)	P Values ³
Mean Age		49.6 (range 33-66)		50.8		52.9	
Sex							
Male	246 58%	108 61%	<i>p</i> =0.586	78 65%		28 90% ()	
Female	198 42%	69 39%		45 35%	<i>p</i> =0.104	3 10%	<i>p</i> =0.002
Practice							
Single-handed practice	98 23%	44 25%	<i>p</i> =0.713	32 26%		11 38.7% ()	
Duo practice	144 34%	58 33%		38 32.5%	<i>p</i> =0.908	13 41.9%	<i>p</i> =0.001
Group practice	182 43%	75 42%		53 41.5%		7 19.4%	
Working hours							
3-4 days/week	246 58%	112 63%	<i>p</i> =0.805	77 62.6%		14 45.2%	
4 days or more/week	144 34%	62 35%		45 36.6%	<i>p</i> =0.307	17 54.8%	<i>p</i> =0.002

1= difference between all responding GPs and all GPs

2= difference between GPs personally available and all responding GPs

3= difference between GPs not frequently transferring information and all responding GPs

Of the respondents, 70% stated that they were personally available to provide care for their terminally ill patients during out-of-hours periods, even if they also made use of the GP co-operative. (GPs personally available). In this sub-group male GPs are more often available than female GPs but this difference is not statistically significant ($p=0.104$), neither are the differences in practice form nor working hours.

Transfer of information to the GP cooperative

Of the respondents, 82.3% reported that they transferred information to the GP co-operative about most of their terminal ill patients, 12.6% did this in approximately half of the cases, and 5.1% rarely or never did so. The group of GPs not often transferring information was more often male (90%, $p=0,001$), working in a single-handed practice (38.7%, $p=0,002$) and working four or more days a week (54.8% ($p=0,001$)). The GPs personally available reported in 78.9% that they transferred information usually, 14.6% did this in half of the cases and 6.6% rarely or never. ($p=0,208$)

Table 2 shows the reasons for not transferring information. The most frequently reported reason was a faster than foreseen deterioration of the patient's medical condition (48.6%). In the category "other reasons", four GPs answered that they "did not expect problems with this patient"; two GPs did not transfer information because

Table 2. Reported reasons for not transferring information* (N=177)

* (more than one answer possible)

	Responding GPs (N=177)		Responding GPs personally available (N=123)		P values ¹	Responding GPs not frequently transferring information (N=31)		P values ²
1. Deterioration of patient's medical condition faster than foreseen	86	48.6%	62	50.4%	$p=0.757$	15	48.8%	$p=0.084$
2. Forgotten	66	37.1%	49	39.8%	$p=0.957$	14	45,2%	$p=0.557$
3. I am always personally available	38	21.7%	33	26.8%	$p=0.283$	17	54,8%	$p=0.015$
4. Patient currently dismissed from hospital	35	20.0%	27	22.0%	$p=0.647$	3	9,7%	$p=0.180$
5. Too much administration	12	6.9%	10	8.1%	$p=0.659$	6	19,4%	$p=0.022$
6. Other reasons	8	4.6%	8	6.5%	$p=0.452$	1	3,2%	$p=0.744$

1= difference between GPs personally available and all responding GPs

2= difference between GPs not frequently transferring information and all responding GPs

they were too busy, and one did not do so because he always left the information at the patient's home.

In the group of GPs not often transferring information the most reported reason for not doing so was that they were personally available (54,8%).

The GPs personally available did not differ significantly from the other respondents.

Content of the transferred information

More than 90% of the GPs reported the diagnosis, the terminally ill status of the patient and patient's medication. (Table 3) Information about the treatment wished by the patient and the prognosis was transferred by respectively 87% and 74%. Information about whether or not the patient knows about the diagnosis and prognosis, the psychosocial context, intolerances for medication, and the content of the previous five contacts was transferred by less than 50% of the GPs.

The subgroups did not differ significantly in these aspects.

Table 3. Reported content of information and assessment of information by the locum (N=177)

Information	Information transferred by GP (%)	Assessment of information by locum		
		Unimportant(%)	Neutral(%)	Important(%)
1. Diagnosis	96.6	-	1.1	98.9
2. Terminally ill patient	95.4	-	4.0	96.0
3. Medication	90.9	1.7	2.9	95.4
4. Desired patient treatment (eg. pain treatment)	87.4	0.6	6.9	92.6
5. Prognosis	74.3	5.1	18.3	76.6
6. Relevant changes in disease process	68.0	1.7	10.3	88.0
7. Patients wishes regarding end-of- life care	67.4	3.4	10.9	85.7
8. List of problems	61.1	10.9	29.7	59.4
9. Private telephone number GP	52.0	28.0	35.4	36.6
10. Patient's awareness of prognosis	41.4	8.0	22.3	69.7
11. Psychosocial context	38.9	4.6	30.3	65.1
12. Intolerances for medication	37.1	14.3	30.9	54.9
13. Previous 5 contacts	13.7	42.3	33.7	24.0

Locum assessment of the importance and quality of the information

Information about the diagnosis, the terminally ill status of the patient, and the patient's medication was regarded as important by almost all locums, as was information about the treatment desired by the patient, relevant changes in the illness process, and the patient's wishes regarding end-of-life care. The prognosis, the patient's awareness of the diagnosis and prognosis, and the psychosocial context were considered to be important information by more than 65% of the locums, and 36.6% considered it important that the GP provided his private telephone number.

In their role as locum, 21.2% of the GPs were satisfied with the quality of the information on terminally ill patients that was available on the GP co-operative, 25.7% were dissatisfied, and 53.1% were neutral with regard to the information available. When asked why they were not satisfied with the information (more than one answer possible), 62.9% stated that it was insufficient, 50% stated that it was not up to date, 48% were dissatisfied because of the absence of information about the terminally ill status of the patients and 20% were dissatisfied because the private telephone number of the patient's GP was not available.

When asked if the transfer of information is a bottleneck in end-of-life care provided by the GP co-operative, 53.1% considered the transfer of information from GP to GP co-operative to be the most important bottleneck, 37.7% were neutral and 9.1% of all GPs considered it to be unimportant.

The GPs personally available considered information transfer a bottleneck in 56.9% whereas in the group of GPs not often transferring information this was 42%.

GPs' satisfaction with the feedback report from the locum

In reply to the question about how satisfied they were with the feedback report from the locum at the GP co-operative, 71.5% of the GPs expressed their overall satisfaction. When asked what was missing in the report if they were dissatisfied, 21.7% of the GPs answered that information about "changes in patient treatment" was lacking. Other reasons for dissatisfaction with the locum report were lack of information about:

patients and carer's personal situation (17.1%), treatment/medication (9.7%), physical examination (5.7%), medical history (4.6%) and reason for encounter (2.9%).

The GPs personally available reported an overall satisfaction with the feedback report in 65%, whereas in group of GPs often transferring information this was 58.1%.

The GPs were also asked for suggestions to improve the quality of out-of-hours care for terminally ill patients. More than half of the suggestions concerned improvements in the transfer of information.

Suggestions for improvement of information transfer

- Design a standardised transfer form, to be used as fax form or as e-mail form
- Make direct electronic transfer from GPs electronic file to GP co-operative possible
- Make electronic information available in the locum's car
- Leave a summary of information at the patient's home
- Take down telephone numbers of professionals and carers involved
- Make at least sure that terminally ill patients are known at the GP co-operative
- Update your information regularly

Discussion and Conclusions

Main findings of this study

The majority of the GPs in Amsterdam who responded to our questionnaire reported that they transferred information about most of their terminally ill patients to the GP co-operative. However, in their role as locum, the GPs were not satisfied with the quality of the information that was transferred to the GP co-operative. While both the GP and the locum agreed about the importance of transferring explicit clinical data, the locums seemed to value the transfer of information about the patients' personal situation more than GPs. There is consistency between the percentage of GPs who transferred specific clinical data, and the assessment of the importance of this information by the locums. The largest difference between the information transferred and the assessment of its importance is found in the information about knowledge of the patient's personal situation.

The results of this study suggest a difference in views on the transfer of information between the GP in his daily practice and the GP as locum in the GP co-operative. It is

possible that GPs over-estimate their performance in transferring information about their terminally ill patients. They do not transfer information as often as they think they do, and the content is not as adequate as they would wish it to be. Since 70% of all GPs stated that they were available for their terminally ill patients during out-of-hours periods, this could be a reason for not transferring information. A reason for under-estimating the importance of transferring information about the patient's personal situation could also be that the GPs did not anticipate a possible deterioration or did not ask about the patient's wishes.

The responses from GPs personally available did differ only slightly from the other respondents: they transferred information almost as much as the other respondents. The GPs not often transferring information had other characteristics than the other respondents: more male, more single-handed, working four or more days. It looks like they didn't find information transfer important; they work already almost fulltime and didn't transfer information mainly because they were available themselves.

Both groups, GPs personally available and GPs not often transferring information, use the argument of personal availability as reason for not transferring information.

What is already known on this topic

In the UK, where co-operatives already existed a decade before they were introduced in the Netherlands, the reported problems are similar. GPs are not routinely alerting out-of-hours doctors to the needs of their vulnerable patients. (9,10,11,15) Important information about two thirds of the patients who were in need of palliative care was not transferred to the co-operative. A major reason was reluctance to define patients as palliative, despite their terminal condition. (11)

Limitations and strengths of this study

The response rate of 42% is relatively low. A possible explanation is that during the data collection a major change in the national health care insurance system took place, which absorbed the GPs' time and energy. Furthermore, the retrospective character of the study may have induced recall bias, and some questions might have evoked socially desirable answers. These factors may have contributed to the large number of GPs who reported that they transferred information and to the GPs' satisfaction with the feedback report from the locum.

A strength of this study is the fact that all GPs were asked to give their view from two different perspectives: as a GP in their daily practice and as a locum in the GP co-operative. The disparity between the two views highlights the inner conflict of the

GP who, when busy in daily practice, finds it difficult to write down and transfer the information that he really values when working out-of-hours as a locum. Another strong point is that we approached all GPs in the Amsterdam region, and not only a sample.

Conclusions

The transfer of information about terminally ill patients to GP co-operatives is often inadequate. Although GPs in Amsterdam reported that they often transferred information, when the same GPs were working as a locum in the GP co-operatives they were unsatisfied with the content of the information that was available for the locum. GPs consider that continuity of care for their terminally ill patients is a key aspect of the quality of end-of-life care. (16) The rapid development of large-scale GP co-operatives in the Netherlands can be a threat to the transfer of information and continuity, which is highly valued in end-of-life care

Recommendations

Post-graduate education should focus more on the content of the information that is needed by the locum and train GPs to write adequate (electronic) transfer reports. The use of a standardised transfer form, either as a fax form or e-mail form could be helpful. If an electronic patient file is accessible during the out-of-hours period, this should contain a specific transfer page containing information that is relevant for locums. Details about the personal situation of these vulnerable patients and of their care needs appear to be of value for the locum. Moreover, GP co-operatives could develop a systematic procedure for feedback to the GPs about the quality of the information they transfer.

The authors declare that they have no competing interests.

Authors' contributions

BS participated in the analysis and drafted the manuscript. NB participated in the draft of the manuscript. MW . EL and PG made up the questionnaire and participated in the analysis. LD helped to draft the manuscript. All authors read and approved the final manuscript.

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Out-of-hours palliative care
provided by GP co-operatives:
availability, content and effect of
transferred information.

Schweitzer BP, Blankenstein N, Deliens L, van der Horst H.
BMC Palliat Care. 2009 Nov 28;8:17

Introduction

A great deal of palliative care, especially in the final year of a palliative care patient's life, takes place in the patient's home. In many European countries the development of palliative care has been influenced by a strong emphasis on primary care. (1) Dutch general practitioners (GPs) consider palliative care as an essential part of family medicine. In their opinion, providing care at home for dying patients is an important aspect of achieving their goal of "comprehensive, continuous and personal care" for these patients. Until 2000, most patients received out-of-hours palliative care from their own GP, and availability for home visits and out-of-hours care was identified by both patients and GPs as a core aspect of value in palliative care. (2)

This availability has virtually disappeared after the recent reorganisation of out-of-hours care. In palliative care, continuity of the care is essential, and when this is no longer possible for the patient's own GP, adequate information must be transferred to locums in order to ensure good quality care (3) Palliative care is defined as the active, total care of a patient whose illness is not responsive to curative treatment. Control of pain, other symptoms, and social, psychological and spiritual problems is paramount. (4)

GPs in the Netherlands have reorganised their out-of-hours care from rota groups to larger scale GP co-operatives. (5) Patients are now likely to receive out-of-hours care from a doctor, or even from several different doctors, who do not know them, and night shifts are frequently the responsibility of young doctors who work only as locums in the co-operatives.

This reorganisation in the Netherlands was preceded by reorganizations in out-of-hours primary care in the early 1990s in the United Kingdom (UK) and Denmark. (6,7) Patients in the UK, Denmark, and the Netherlands are generally positive about the care that they receive from GP co-operatives, but some people have expressed concerns regarding the care that complex, time consuming, palliative care patients receive. (8,9) A study of the experiences of patients and their carers identified the barriers in their access to care. These especially concerned patients' uncertainties and the inappropriateness of the service responses, which are mainly designed for acute medical care and do not meet the palliative care needs. (10)

Recent research among Dutch GPs working as locums in a GP co-operative showed that they were unsatisfied with the quality of the information about the patient that was transferred and available to them.

(Schweitzer BPM, Blankenstein AH, Willekens M, Terpstra E, Giesen P, Deliens L. GPs' views on transfer of information about terminally ill patients to the out-of-hours co-operative. Submitted)

Although a study in the UK reported that few GPs routinely handed over information about their palliative care patients to their GP cooperatives, (11) the introduction of a dedicated fax form with which GPs can inform the co-operatives about terminally ill patients resulted in an increase of the transfer of information. (12)

The complex needs of palliative care patients require a well-informed and expert response and inadequate service provision can lead to problems in symptom control and an increase in unnecessary hospital admissions. Moreover, it may leave patients and their carers confused, and inadequately supported. (13)

After introduction of an out-of-hours protocol for community palliative care GPs felt that this protocol had made a positive contribution to palliative care and that the out-of-hours handover form played a key role in improving communication and the co-ordination of services. (14)

In general, GPs in the UK were satisfied with the palliative care provided by their out-of-hours co-operatives, but satisfaction was less for inner-city GPs who had concerns about the continuity of care. (15) District nurses reported less satisfaction, especially with the quality of the advice, the reluctance to visit, and difficulties in obtaining medication. (16)

In a survey among medical directors of GP co-operatives, only 37% believed that they could obtain specialist advice out-of-hours, although 89% of specialists said that they provided such a service. The study confirmed that in the UK there is patchy access to community nursing and palliative care services out-of-hours. (18)

Patients and carers had difficulty in deciding whether or not to call out-of-hours services. Although calls were made predominantly for physical reasons, the decision to call was also strongly influenced by psychosocial factors. Positive experiences of patients were related to effective planning, in particular the transfer of information, and empathic responses from the staff. (9)

The aim of this study was to investigate the transfer of information about palliative care patients to a GP co-operative and the influence of that information on the care provided by the locums in the co-operative.

The following research questions were addressed:

1. In what percentage of palliative care calls was information from the patient's own GP available in the GP co-operative?
2. Which patient characteristics are related to the transfer of information?
3. What is the content of the information transferred by the GP?
4. To what extent is the availability of patient information in the GP co-operative related to the type of contact and actions provided by the locum?

Method

Design: cross-sectional exploratory study.

We performed a retrospective study of all palliative care phone calls made during a one-year period (1/11/05-1/11/06) to the GP co-operative in Amsterdam. All 424 GPs in the region of Amsterdam participate in 8 out-of-hours GP centres belonging to the Amsterdam GP co-operative. Most of the GPs work their shifts as a locum for the GP co-operative and the population served by the Amsterdam GP co-operative is 800.000 inhabitants.

We carried out an electronic search in Callmanager, which is the database of the GP co-operative, containing medical data on all calls with the GP co-operative. It also contains all information transferred by GPs about their patients on a fax form which is sent from the general practice to the co-operative and entered into the database by a medical secretary.

Study populations:

All patient related phone-calls to the Amsterdam GP co-operative between 1/11/05 and 1/11/06; all palliative care calls between 1/11/05 and 1/11/06 and the patients involved.

Measurements:

Numbers of the different types of contact following the phone-calls (telephone consultation, centre consultation, home visit) were obtained from the Annual Reports of the GP co-operative.

The records of all phone-calls in the Callmanager database during the study period were screened electronically.

We identified palliative care calls by means of a search with the text words "palliative", "terminal", "cancer", "carcinoma", "inoperable", "opioid", and "fentanyl". The 2304 identified records were subsequently examined by the researcher, and 1263 non-palliative calls were excluded. The sensitivity of the search was checked by comparing the electronic search results with hand searched data from all calls during a period of one month. This did not produce any new calls regarding palliative care patients, so we decided not to carry out a hand search for the entire study.

To answer the research questions the following data were extracted from each identified record:

Question 1: Presence or absence of information transferred by the patient's own GP.

Question 2: Patient characteristics (age, gender, residence, diagnosis as noted by the locum and terminal status (described as such by the locum).

Question 3: Content of transferred information (information about diagnosis, prognosis, medication, current problems, management plan, patient's awareness of prognosis, patient's wishes, carers and professionals involved, previous contacts, availability of own GP). A previous study showed that locums are satisfied with the quality of the transferred information if these elements are included.

Question 4: Type of contact with the locum (telephone consultation, centre consultation, home visit) and care provided by the locum (prescription or change of medication, advice only, referral for hospital admission)

The data were analyzed with SPSS 15.0. Frequencies were calculated for all variables. To determine whether patients for whom information from the GP was available and patients for whom no information was available differed from each other Chi-square tests were used for the variables gender, residence, underlying disease, terminal status, type of contact and care provided by the locum.

We used logistic regression analysis to analyze determinants for referral to hospital. The dependent variable was referral to hospital versus all other actions by the locum. The independent variables were the continuous variable age-class and the categorical variables residence (home, residential care home), terminal status (yes, no), information transfer (yes, no) and the reasons for encounter (RFE) pain, circulatory and digestive (pain, respiratory, urinary, digestive, fatigue, circulatory, psychological,

other). We calculated the Exp (B) and Wald statistic for each of these parameters. The model's adequacy was determined by calculating Nagelkerke R-square.

Results

The total number of patient calls to the GP co-operative during the one-year study period was 137.828. A total of 1041 palliative care-related calls were made to the GP co-operative during that year, concerning 553 different patients. The mean age of the patients was 74.3, the most frequently mentioned underlying disease was cancer (76.5%) and the disease was unknown in 16.1%. However, in the group of patients over 90 years of age cancer was diagnosed in 33% and the disease was unknown in 52%. According to the locums, 74.5% of all palliative care patients were terminally ill.

Information on 141 patients receiving palliative care was transferred to the GP co-operative (25.5%). (Table 1) The incidence of information transfer did not differ according to the various underlying diseases, gender or age-groups, with the exception of the group of patients over 90 years of age, for 10.5% of whom information was transferred. Information was transferred for 12% of patients in residential care homes and for 28.9% of terminally ill patients.

Table 2 shows the content of information transferred from GP to GP co-operative. Information on diagnosis and current problems was transferred most frequently (>90%). Information about the patient's wishes was transferred in 44.7% of cases, about carers in 41.8%, about previous contacts in 41.8%, about other professionals involved in 39% and about psychosocial aspects in 30.5%. Information about the availability of the patient's own GP (for example: mobile number of the GP) was transferred in 9.9%.

Table 1. Information transfer to the GP co-operative according to patient characteristics

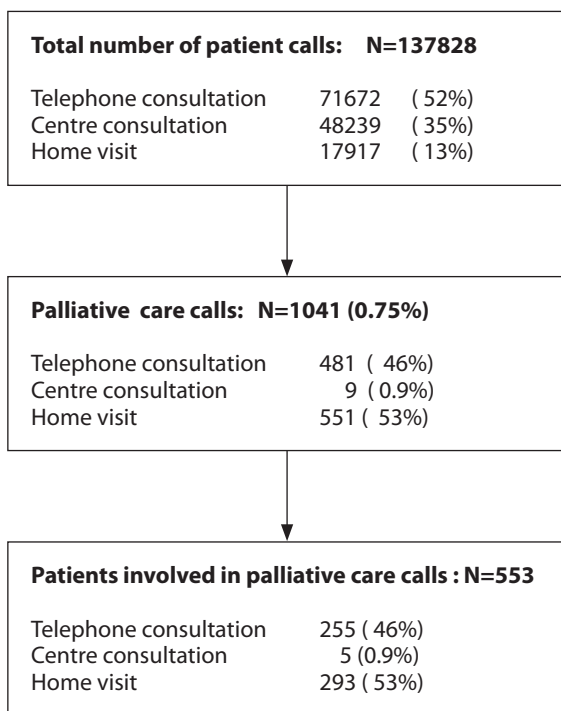
Patient characteristics	No information transferred N= 412 (74.5%)	Information Transferred N =141 (25.5%)	P value
Sex			0.459
Male	216 (73.2%)	79 (26.7%)	
Female	196 (76.0%)	62 (24.0%)	
Age (years)			0.220
<60	79 (72.5%)	30 (27.5%)	
60-70	78 (69.7%)	34 (30.3%)	
71-80	108 (72.8%)	29 (27.2%)	
81-90	96 (69.6%)	42 (30.4%)	
>90	51 (89.5%)	6 (10.5%)	
Mean (SD)			
Residence			0.002
Home	339 (72.1%)	131 (27.9%)	
Care home	73 (87.9%)	10 (12.1%)	
Underlying disease			0.951
Cancer	298 (70.4%)	125 (29.6%)	
Heart failure	16 (76.1%)	5 (23.9%)	
COPD	11 (73.3%)	4 (26.7%)	
Neurological	3 (60.0%)	2 (40.0%)	
Unknown	84 (94.3%)	5 (5.7%)	
Terminal status			0.003
Terminally ill	282 (71.0%)	115 (29.0%)	
Not terminally ill	130 (83.3%)	26 (16.7%)	

Table 2. Content of information transferred from patient's GP to GP co- operative

Content (N=141)	%
Diagnosis	97.2
Current problems	90.1
Medication	84.4
Management plan	72.3
Prognosis	52.5
Patient's wishes	44.7
Information about carers	41.8
Previous contacts	41.8
Patient's knowledge of prognosis	40.4
Other professionals involved	39.0
Psychosocial aspects	30.5
Availability own GP	9.9

Table 3 shows that in 53% of the requests for help regarding palliative care a home visit was made, while the overall percentage of home visits was 13%. It also shows that palliative care-related calls accounted for 0.75% of all calls. These calls resulted more often in a home visit than regular calls, but the presence of information did not make any difference with regard to the handling of the request by telephone or by making a home visit.

Table 3. Palliative care related calls and information transfer to the GP co-operative



When information was transferred, patients were referred to a hospital less often. (Table 4) Information had been transferred for only 8.8% of all patients referred to a hospital. Medication was prescribed by the locum for 57.2% of the palliative care patients.

Table 4. Information transfer to the GP co-operative and action by the locum

	No information transferred	Information Transferred	P value
	N = 412 ((74,5%)	N =141 (25,5%)	
Action by locum			0.009
Advice without medication	120 (73.1%)	44 (26.9%)	
Medication prescribed	227 (71.8%)	89 (28.2%)	
Referral to hospital	62 (91.2%)	6 (8.8%)	

Information transfer and pain as reason for encounter were factors that contributed significantly to hospital referrals. (Table 5) The Nagelkerke R-square for this model was 0,209, so approximately 21% of variance was accounted for in this model.

Table 5 Results of logistic regression for the chance of referral to hospital

	OR	95%CL	Wald	p-value	OR unad-justed	95%CL unadjusted
Residence (home vs carehome)	1,984	0,514-7,659	0,988	0,320	4,204	1,289-13.716
Information transfer (yes vs no)	0,258	0,106-0,628	8,925	0,003	0,252	0107-0,598
Terminal status (yes vs no)	0,621	0,355-1,087	2,783	0,095	0,420	0,250-0,706
Age class (younger vs older)	0,798	0,627-1,016	3,343	0,067	0,683	0,553-0,842
Cancer (yes vs no)	1,290	0,353-4,721	0,148	0,700	1,983	0,590-6,660
Pain as RFE (yes vs no)	0,480	0,235-0,978	4,087	0,043	0,377	0,197-0,772
Circulatory problems as RFE (yes vs no)	6,984	1,168-41,774	4,536	0,033	14,937	2,682-83,195
Digestive problems as RFE (yes vs no)	1,627	0,804-3,294	1,829	0,176	2,646	1,406-4,980

Nagelkerke R²0.209

Discussion

Main findings:

The total number of palliative care phone calls was 0.75 % of all calls to the GP co-operative. Information was transferred in 25%, and when information was transferred the content consisted mainly of clinical data. Less information was transferred about the patient's wishes and the patient's personal situation.

For patients staying in residential care homes, information transfer took place in only 12%. The majority of all palliative care calls concerned terminally ill patients, and for these patients information was relatively more often transferred.

When information was transferred fewer patients were referred to a hospital.

Comparison with the existing literature:

Although GPs are aware of the importance of information transfer, there is no evidence that they routinely alert the out-of-hours doctors to the needs of palliative care patients. (15). Previous studies have suggested that continuity of care is threatened by a lack of information in the GP co-operative. (10)

In answering to a web-based questionnaire, GPs assessed the importance and quality of information transferred. They stated that information about the diagnosis, the terminally ill status of the patient, and the patient's medication was important, as was information about the treatment desired by the patient, relevant changes in the illness process, and the patient's wishes regarding end-of-life care. They also valued the transfer of information about the patient's personal situation. (Schweitzer BPM, Blankenstein AH, Willekens M, Terpstra E, Giesen P, Deliens L. GPs' views on transfer of information about terminally ill patients to the out-of-hours co-operative. Submitted) The adoption of a dedicated fax form for GPs resulted in an increase of information transfer (12)

We found that information was transferred in only 25% of cases, and also that when information was transferred; the content mainly consisted of data on diagnosis and current problems. This reduces the quality of the information transfer.

Although the availability of out-of-hours GP care is highly valued by patients and their carers, little is known about the type of palliative care delivered by a GP co-operative. (2) In this study we found that half of the calls regarding palliative care resulted in a home visit by the locum, and that medication was prescribed in 57% of all palliative care calls.

About the relevance of information transfer : a report from the UK stated that a lack of information can lead to problems in symptom control and an increase in unnecessary hospital admissions (13) We found that when information was transferred less patients were referred to a hospital. Whether these admissions were necessary or not would be an interesting subject for further research.

Our finding that information was transferred less frequently for patients staying in residential care homes might be explained by the GP's opinion that the care

for these patients and the availability of this information is the responsibility of the care home. However, few care home staff members have sufficient training in providing end-of-life care, and it is therefore important that GPs ensure the continuity of their care by providing information to the GP co-operative. (18)

Less information is also transferred for the oldest patients. One reason for this maybe the complexity of conditions and co-morbidities.

Apparently it is more difficult to assess the clinical situation of these patients; in this group no diagnosis was determined for 52% of the patients.

Information was transferred more frequently when patients were terminally ill. The sense of urgency for the transfer of information is apparently greater, and these patients are more likely to be perceived as palliative care patients.

When a call is made for a palliative care patient, this patient is often already terminally ill. This suggests that the need for help, not only for physical reasons, increases in the terminal phase and waiting for care until office hours is no longer an option. It also supports the view that even more home visits should be made.

Strengths and weaknesses of this study:

In order to develop a strategy for the provision of better palliative care by GP co-operatives, we studied the current behavior of GPs with regard to the transfer of information and the consequences of that behavior. A strength of this study is that we included all calls to the GP co-operative regarding palliative care during a period of one year. We studied the availability of information about all patients for whom a call was made. However, a limitation is that we do not know how many times information was transferred for patients for whom no call was made.

From the results of this cross-sectional study we can not determine whether there is a causal relationship between less hospital referrals and the transfer of information.

Conclusions:

Despite the importance of continuity of care in the terminal phase, GPs do not transfer information for the majority of their palliative care patients. If information is transferred to the GP co-operatives, the content is mainly limited to clinical data. Information about the patient's personal situation and wishes is often lacking.

Locums working in the GP co-operative are thus required to provide palliative care in complex situations without receiving adequate information. They might be better

supported if this information is made available and (perhaps unnecessary) hospital admissions could possibly be avoided.

Recommendations:

GP co-operatives need to develop and implement an effective system of patient information management. GPs need to be made aware of the disadvantages of not transferring information about their palliative care patients to the GP co-operative, and should be trained to do this an adequate way. If an electronic patient file is accessible during the out-of-hours period, this should contain a specific transfer section containing information that is relevant for locums. Hence, there are potentials for improvement in the end-of-life care that is provided by the GP co-operatives.

The authors declare that they have no competing interests.

Authors' contributions

BS carried out the search and drafted the manuscript. NB participated in the analysis and draft of the manuscript. LD and HH participated in the design of the study and helped to draft the manuscript. All authors read and approved the final manuscript.

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

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Abstract

Context. While effective GP-patient communication is required for the provision of good palliative care, barriers and facilitators for this communication are largely unknown.

Objectives. We aimed to identify barriers and facilitators for GP-patient communication in palliative care.

Methods. In a systematic review six computerized databases were searched to find empirical studies on GP-patient communication in palliative care.

Results. Fifteen qualitative studies and seven quantitative questionnaire studies were included. 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.

Conclusions. 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, 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.* 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. (10) Clayton *et al.* 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. (11) Rodin *et al.* have noted the problem of variability in patient preferences, but still aim to develop general approaches with regard to communication. (12) 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 communication, 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. First, 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 which 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.* applied 12 criteria. (24) 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’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 which 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

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

	Qualitative studies	Quantitative questionnaire studies
Clarity of reporting		
<i>1. Was the context of the study clearly described?*</i>	X	X
<i>2. Were the goals of the study clearly described?</i>	X	X
3. Was the research question clearly defined?	X	X
4. Was the design adequate for the study goal/question?	X	X
<i>5.a. Was the identification and the recruitment of the sample clearly described and justified?</i>	X	
5.b. Was there an adequate description of the study population (setting, selection criteria, age/gender)?		X
<i>6. Were the data-collection methods clearly described?</i>	X	X
<i>7. Were the data-analysis methods clearly described?</i>	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
<i>10.a. Were methods used to establish the reliability of the data-collection methods?</i>	X	
10.b. Were reliable measurement instruments used?		X
<i>11.a. Were methods used to establish the validity of data-collection?</i>	X	
11.b. Were valid measurement instruments used?		X
<i>12.a. Were methods used to establish the reliability of the data-analysis?</i>	X	
<i>13.a. Were methods used to establish the validity of the data-analysis?</i>	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	
<i>16. Were the findings really rooted in the perspectives of the population studied?</i>	X	
Number of positive criteria	0-16	0-13

* Ten criteria derived from Harden *et al.* (24) are printed in *Italics*.

the effects (of the structural and process factors) of GP-patient communication on palliative care patient outcomes such as quality of life, symptoms, or 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).

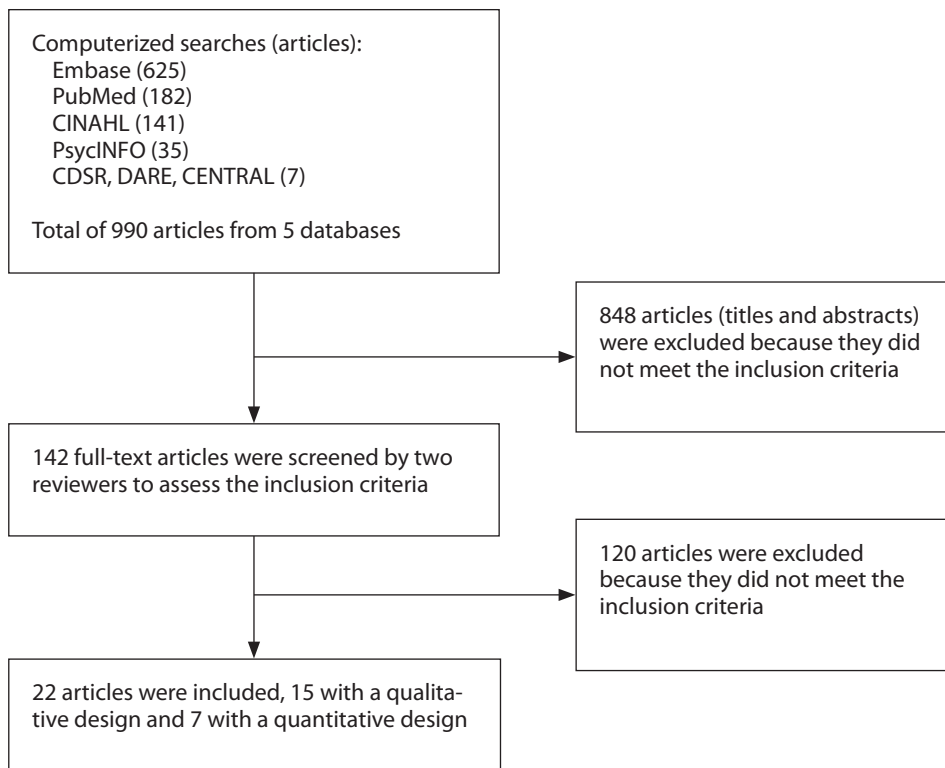
For all studies in our review, both qualitative and quantitative, we examined the possible relationship between the quality of the study (as measured by our quality assessment instruments) and the study characteristics and results. Specifically, we compared the differences in designs (quantitative or 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).

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.

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 sumscore
Qualitative articles							
1. Borgsteede (2007)(30)	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 (2008)(31)	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 (2005)(32)	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 (1999)(33)	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 (2002)(34)	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 (2003)(35)	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)(36)	UK	To study GPs' experiences of caring for dying people.	Open interviews	25 GPs	7	5	12

Study	Country	Research question	Design	Participants	Clarity of reporting	Robustness of the study methods	Quality assessment sumscore
8. Kelly B (2008) (37)	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 (2005) (38)	Netherlands	To identify the GPs' perception of educational needs in palliative care.	Focus groups	39 GPs	7	3	10
10. Michiels (2007) (39)	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) (40)	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 (2001) (41)	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 (2002) (42)	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 (1994) (43)	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

Study	Country	Research question	Design	Participants	Clarity of reporting	Robustness of the study methods	Quality assessment sumscore
15. Steinmetz (1993) (44)	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
Quantitative articles							
					(0-8)	(0-5)	(0-13)
16. Burge (2000) (45)	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 (1985) (46)	USA	To study the physician's attitude toward 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 (2001) (47)	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 (2007) (48)	Netherlands	To identify the obstacles that hinder the delivery of primary palliative care.	Questionnaire	320 GPs	8	5	13
20. Higginson (1990) (49)	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 (2006) (50)	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 (2009) (51)	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

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 (especially making home visits and taking the necessary time), certain GP characteristics (e.g. longstanding 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 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 (especially 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* are 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, or 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.

[Table 3]

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

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	<p><i>Patient characteristics:</i></p> <ul style="list-style-type: none"> - medical condition (throat cancer, aphasia, delirium) [13.PT]* - language [9.GP] and cultural factors [16.GP] <p><i>Characteristics of palliative care:</i></p> <ul style="list-style-type: none"> - cardio-respiratory disease (compared to cancer) [1.GP; 3.PT] - unpredictability of clinical course [6.GP] <p><i>Role of the spouse and family:</i></p> <ul style="list-style-type: none"> - 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] 	<p><i>Patient characteristics:</i></p> <ul style="list-style-type: none"> - older age [17.GP] - longer life-expectancy [17.GP] <p><i>Patients' opinions:</i></p> <ul style="list-style-type: none"> - 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	<p><i>GPs' lack of availability:</i></p> <ul style="list-style-type: none"> - lack of time [2.B; 10.PT; 11.PT] - absence (e.g. holiday) [10.PT] - not making home visits [20.PT] <p><i>GP characteristics:</i></p> <ul style="list-style-type: none"> - lack of knowledge (about palliative care) [10.PT] <p><i>Characteristics of palliative care:</i></p> <ul style="list-style-type: none"> - complexity of medical information [2.GP; 14.PT] - uncertainty of (exact) prognosis [4.GP] - limits of medical knowledge [2.GP] 	<p><i>GPs' availability:</i></p> <ul style="list-style-type: none"> - 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] <p><i>GP characteristics:</i></p> <ul style="list-style-type: none"> - 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] <p><i>GPs' opinions:</i></p> <ul style="list-style-type: none"> - 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]

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]

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'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]

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]
- relabeling 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]

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 which 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]

* 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.

facilitators, and as related to structure, 'how' (the communication should take place) or topics (which 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 GP's availability, were identified in studies based on GP perspective. Probably patients are not really aware of such abstract factors which describe the prerequisites for GP-patient communication that are already present before the actual consultation takes place. Besides, 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 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 like (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, e.g. the Palliative Care Outcome Scale (POS) (52) and the EORTC QLQ-C15-PAL (53). 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 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, (54) it is remarkable that the four studies in our review with the maximal quality assessment scores (41;42;47;48) 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. (55-57) 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 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. (31;51) Additionally, 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;40;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 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. (58) 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 (like heart failure and chronic obstructive pulmonary disease) is 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.* showed that many professionals avoid discussing the actual prognosis.(10) These results are in line with our findings, i.e. 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.* 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. (11) These conclusions are in line with our findings, i.e. 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, 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.(59-70) 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 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 GP's availability and wish to discuss GP's (former) mistakes. GPs should recognise their own and 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.

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Writing information transfers for out-of-hours palliative care: A controlled trial among GPs.

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Submitted

Introduction

The goal of palliative care is to provide the highest possible quality in the last phase of life for patients and their family. Because most patients would prefer to die at home among their family and friends, well organised primary palliative care to ensure this quality is essential. (1,2,3,4) Within primary care, the GP is the key professional, and almost 100% of the inhabitants of the Netherlands have their own GP.(5)

In the Netherlands now, almost 60% of dying patients with non-acute illnesses die at home. (6,7,8) The aging population and the growing number of non-acute deaths are expected to intensify the GPs' involvement in palliative care. (9)

During the past decade, however, important changes have taken place in the primary health care system for out-of-hours service provision that now threaten the continuity of care. GPs in the Netherlands have reorganised their out-of-hours care from rota groups to larger scale GP co-operatives that now serve 90% of the population. (10,11,12) The same shift has taken place in the United Kingdom, Ireland, Sweden and Denmark. (13) Patients are likely to receive out-of-hours care from a doctor they have never seen before, and night shifts are frequently the responsibility of young GPs who work only as locums in the co-operatives.

The out-of-hours period is therefore a potentially problematic time for the delivery of high-quality palliative care. Transfer of information between GPs and their out-of-hours co-operatives is essential to ensure continuity of care. Unfamiliarity with the patients and their problems will have an impact on service provision and may lead to poor symptom control and inappropriate hospital admissions. (14,15,16,17,18,19) This may contribute to the patients' preferred place to die being disregarded. (20)

A main obstacle to the delivery of high-quality palliative care in the out-of-hours period as expressed by GPs in the United Kingdom is inadequate information on patients they are called to see. (15,21) This was confirmed by Dutch GPs in a focus-group study. (22) Some doctors even suggested that passing on notes on palliative patients by their GPs should be compulsory. (23) Information exchange impacted strongly on their experiences of palliative care encounters within the out-of-hours system. They felt that they were often the ones to pick up the pieces when it came to palliative care problems if in-hours GPs failed to transfer information. (21)

Some barriers to writing information transfers are on the operational level: lack of time, technical problems and unclear procedures. Another reason for not transferring information was that the GP had not expected deterioration of the patient's condition. (23)

We wanted to know if the introduction of structured handover forms could improve communication between GPs and the out-of-hours service.

Research questions:

Does the introduction of structured handover forms improve a) the frequency and b) the adequacy of information provided for out-of-hours palliative care, compared to usual care?

In this study, patients receiving palliative care included cancer and non-cancer patients. Palliative care was defined according to the European Association for Palliative Care: Palliative care is the active, total care of a patient whose illness is not responsive to curative treatment. Control of pain, other symptoms, and social, psychological and spiritual problems is paramount. (25)

Method

Study design

We conducted a controlled trial. The GP co-operation in Amsterdam provides out-of-hours services from two clinics at night and six clinics during the evenings and weekends. Two groups of GPs were formed according to the boundaries of the GP clinics in which they co-operate: 1) all GPs working in the western half of Amsterdam (N=240) and 2) all GPs working in the eastern half of the city (N=186). By flipping a coin we randomly assigned group 1 to the experimental condition and group 2 to the control condition.

Study population

We studied all out-of-hours contacts with the GP co-operative of Amsterdam concerning patients in palliative care from December 1st 2005 to September 30th 2007. In the case of patients who had had several contacts with the GP co-operative, only the first contact was included.

Sample size and power calculation

We planned to include 500 contacts in order to detect an absolute increase of information transfers of 10% after intervention with an α of 5% and a power of 90%.

Procedure

The pre-measurement period for the experimental- and the control group started on December 1st 2005 and ended on February 28th 2007. The intervention was performed from January 2006 to February 28th 2007. (Figure 1 and Figure 2) On several dates during this period we organised training sessions for GPs in the experimental group to introduce the handover form. Contacts with patients from GPs who had attended the training sessions were registered as post-measurement contacts after the date of the training. The intervention was concluded on February 28th 2007 through a final letter to all GPs in the experimental group – those who had attended the training as well as those who had not – containing the handover form and the procedure to be followed. From that moment on, all contacts with patients from the remaining GPs in the experimental group, as well as all contacts with GPs in the control group, were registered as post-measurement contacts. Data were collected until September 30th 2007.

Figure 1 Overview of palliative contacts (Total N=772)

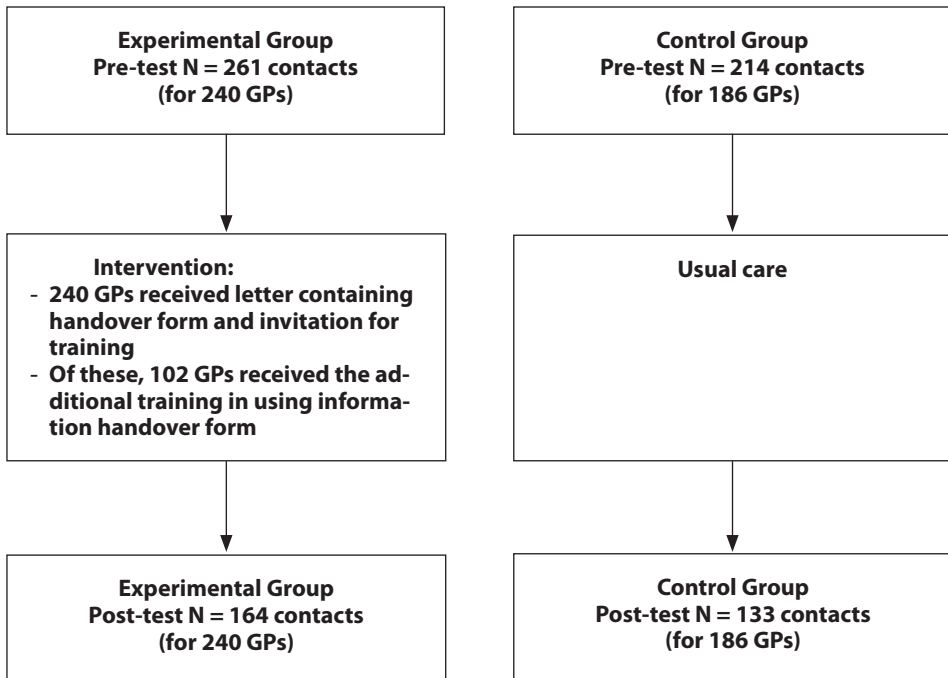
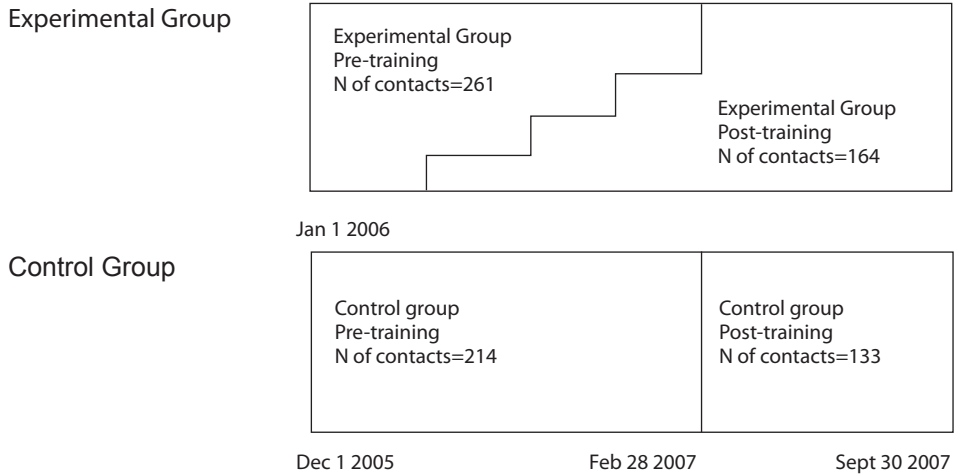


Figure 2. Study design



5. Intervention

Our intervention was based on a prior needs assessment by GP focus group meetings. (22) We drafted a handover form that, when filled in, contains all essential information about a patient in palliative care. The handover form has to be sent by fax to the GP co-operative, where a secretary enters the data into the database-system on the same day, creating a new record for this patient if no prior information is available. These data are made available for a locum when a patient receiving palliative care contacts the GP co-operative. An educational intervention was designed to practise working with this tool. (Box 1) All GPs in the experimental group received a letter to inform them about the project and to invite them for a single one-hour training session.

Box 1 Process and content of the intervention

Process of intervention:

- Written invitation to participate in training
- Groups of 6-10 GPs
- Training by GP experts in palliative care (90 mins)

Content of intervention:

- Importance of proactive planning and anticipatory care
- Structured case discussion: role of GPs in continuity of care at the end of life
- Discussion of the barriers on information exchange between in-hours GPs and out-of-hours GPs
- Introduction of a structured handover form
- Exercise: writing an information transfer using a case study

A newsletter on the project was sent to all GPs in the intervention group three times as a reminder of the project in order to boost the writing of information transfers. The intervention ended with a final letter containing the information on the handover form to all GPs in the intervention group.

Control group

The control group did not receive any structured handover form or training.

Measurement procedures

To identify palliative care contacts, we carried out an electronic search in the out-of-office data management system of the GP co-operative in Amsterdam 'Callmanager'. This database contains medical data on all calls with the GP co-operative. It also contains all information transferred by GPs about their patients. The records of all phone calls during the study period were searched electronically. We identified palliative care contacts by means of a search with the text words "palliative", "terminal", "cancer", "carcinoma", "inoperable", "opioid", and "fentanyl". This search yielded palliative care contacts regarding cancer and non-cancer patients but also other contacts, for example when a patient used an opioid for acute low back pain. A GP with extensive experience in palliative care (BS) subsequently examined the identified records and identified palliative contacts according to the definition on palliative care stated above. The context of the complete Callmanager record found in this way with the anamnesis, the description of the symptoms and the actions undertaken by the locum made this

possible. All non-palliative contacts were excluded. A sample of the identified records was examined by a second experienced GP (NB) but no differences in judgement were found. The sensitivity of the search was checked by comparing the electronic search results with hand-searched data (BS) from all contacts during a period of a month. Since this did not produce any new contacts regarding palliative care patients, we decided not to carry out a hand search for the entire study.

Outcome measures

The outcome measure for the first research question was the number of contacts in which information was present at the GP co-operative.

For the second research question, the outcome measure was the adequacy of this information. We therefore noted the presence or absence of the following items: diagnosis, prognosis, medication, current problems, management plan, patient's knowledge of prognosis, patient's wishes, carers and professionals involved, previous contacts, availability of own GP. We also noted the time interval between the entrance of the transferred information in Callmanager and the first out-of-hours contact. We defined an information transfer as adequate if:

1. Transferred information was present at the GP cooperative AND
2. The information was not older than a month AND
3. The information contained the following three elements:
 - diagnosis
 - medication
 - current problems

We based our definition of adequacy on a previous study (24) that showed that locums consider the quality of the transferred information sufficient if it contains the elements specified above, and up-to-date.

GP and patient characteristics and type of contact

We registered the GPs' gender, age and type of practice. These data were found in medical year books.

The patient's gender, age group and place of residence were registered for all contacts. The reason for the encounter, the diagnosis and whether a patient was terminally ill or not were registered if the locum had noted this in their records. The type of contact: telephone consultation, home visit or consultation in the GP clinic was extracted from the record.

Data analysis

Descriptive frequency distributions were carried out for patient and content characteristics. Patient characteristics and type of contact in intervention- versus control condition were compared using Chi-square tests.

Question 1. We defined the effect of the intervention as the difference in the presence of information transferred between the experimental group versus control group in pre- and post-measurement, i.e. the time (pre/post)*intervention effect.

To analyze the effect of the intervention on the transfer of information, we performed a logistic regression. In this analysis we had to deal with the exceptional situation that contacts from different patients from a GP in post- versus pre-measurement groups were studied. We therefore used the method of Generalized Estimating Equations that allows the inclusion of all contacts in the analysis and allows for dependency of patients from the same GP in the pre- and post-measurement. We used the same method to analyze determinants for information transfer. The outcome variable was the dichotomous variable presence versus absence of information transfer. Because we studied contacts from different patients in pre- versus post-measurement groups, covariates could vary in pre- versus post-measurement. We therefore analyzed possible differences for the dichotomous variables gender, residence (home, residential care home), terminal status, cancer, and the continuous variable age-class for the four groups separately (experimental pre- and post-measurement group and control pre- and post-measurement group).

Question 2: The effect of the intervention on the dichotomous variable 'adequate information transfer available' was analyzed using the same method.

Results

We retrieved 3,665 records during the trial period of 22 months, of which 1993 non-palliative records were excluded. From the 1662 identified palliative care contacts, we excluded the contacts where the GP belonged to another region, or was unknown, and all follow-up contacts. We included a total of 772 first palliative contacts, 261 pre-measurement contacts and 164 post-measurement contacts in the experimental group, and 214 pre-measurement and 133 post-measurement contacts in the control group. (Figure 2) Data from these contacts are included in the analyses.

The experimental group consisted of 240 GPs: 102 of them attended the training and all 240 received the final letter with the handover form. The control group consisted of 186 GPs.

GP characteristics

Table 1 shows GP characteristics. We found contacts with patients from 320 GPs, 181 from the experimental group and 139 from the control group. The mean number of included contacts for a GP was 2.4. The mean age of the GPs was 50.6 years, range 28 to 66 years. At pre-measurement, there were significantly more male GPs in the experimental group, and in the control group there were significantly more GPs working in a group practice.

Table 1. GP characteristics

GP characteristics	Total	Exp. Pre-measurement group	Control Pre-measurement group	Exp. Post-measurement group	Control Post-measurement group	Exp. Group pre versus post	Control group pre versus post	Pre-measurement Exp. versus Control P value	Post measurement Exp. versus Control P value
Gender	N=320	N=100	N=81	N=78	N=61	P value	P value	0.309	0.146
Male	541 (67%)	78%	55%	71%	59%		0.674	0.002	
Missing	13								
Age Group						0.581	0.242	0.752	0.966
<30	5 (1.8%)	1.2%	0	4.3%	2.0%				
30-40	30 (10.8%)	9.4%	12.3%	10.0%	12.2%				
40-50	81 (29.2%)	30.6%	39.7%	21.4%	22.4%				
50-60	109 (39.3%)	38.8%	32.9%	42.8%	44.8%				
>60	52 (18.8%)	20.0%	15.0%	21.4%	18.4%				
Missing	43								
Type of practice						0.064	0.394	0.000	0.380
Single-handed	103 (33.5%)	35.3%	23.7%	40.8%	33.9%				
Duo	119 (38.8%)	51.5%	31.6%	35.5%	30.4%				
Group	85 (27.7%)	13.1%	44.7%	23.7%	35.7%				
Missing	13								

Patient characteristics

Table 2 shows characteristics of patients and the type of consultation. The mean age was 71.9 years and 84.5% of patients resided at home.

Pain, respiratory problems and digestive problems were the most frequently reported reasons for encounter. Cancer was the most frequent underlying disease (76.4%), and according to the locums 57.5% were terminally ill.

Place of residence of the patient differed significantly between the experimental and the control group at pre-measurement, and underlying disease at post-measurement. Within the control group there were significant differences between pre- and post-measurement: patients were older, more patients stayed in a nursing home and fewer patients had cancer as underlying disease at pre-measurement.

Pre-measurement patients in the control group more often resided in a nursing home, compared to pre-measurement patients in the experimental group.

Post-measurement patients in the control group more often had cancer as underlying disease compared to post-measurement patients in the experimental group.

In 62.2 % of the contacts, a home visit was made, a telephone consultation took place in 36.4% of the contacts and a consultation in the GP clinic in 1.4%.

Table 2. Patient characteristics and type of contact

Patient characteristics	Total	Exp. Pre-measurement group	Control Pre-measurement group	Exp. Post-measurement group	Control Post-measurement group	Exp. Group pre versus post	Control group pre versus post	Pre-measurement Exp. versus Control P value	Post-measurement Exp. versus Control P value		
Gender	N=772	N=261	N=214	N=164	N=133	P value	P value	0.427	0.441	0.645	0.727
Male	51%	54%	52%	50%	47%						
Age											
Mean age in years (SD)	71.9 (14.1)	72.4	75.2	70.7	68.2	0.899	0.002*	0.616	0.242		
Residence											
Home	652 (84.5%)	86.5%	77.0%	86.0%	90.1%	0.885	0.002*	0.011*	0.289		
Care home	120 (155%)	13.5%	23.0%	14.0%	9.9%						
Reason for encounter											
Pain	285 (36.9%)	38.7%	35.0%	35.4%	38.3%	0.872	0.109	0.357	0.722		
Respiratory problems	150 (19.4%)	16.2%	19.2%	23.2%	21.9%						
Urinary problems	15 (2.1%)	1.9%	1.9%	1.2%	3.0%						
Digestive problems	94 (12.2%)	13.5%	10.7%	12.8%	11.3%						
Fatigue	1 (0.1%)	0.4%	0	0	0						
Circulatory problems	14 (2.0%)	1.9%	1.4%	1.2%	3.0%						
Psychological problems	54 (7.0%)	6.9%	7.5%	7.9%	5.3%						
Other problems	149 (19.3%)	18.1%	23.4%	15.9%	15.0%						

Information transfer (Table 3)

Information transferred by the patient's GP was available for the locum in 179 of the 772 first palliative contacts (23.2%).

In the experimental group at pre-measurement, information on the patient was available in 21% of the cases and at post-measurement in 30% of the cases. In the control group at pre-measurement, information on the patient was available in 23% and in 19% at post-measurement.

Table 3 shows that the proportion of contacts in which an information handover form was present increased more in the intervention group compared to the control group. In this analysis we controlled for pre-post differences in gender and age group of the GP, type of practice, gender, age and residence of the patient, terminal status and cancer,

(OR = 2.7 (1.2-5.9) p 0.014) from the control group.

Table 3. Effects of introducing a handover form on the presence of transferred information. Generalised Estimating Equations. N of contacts: 772

	Wald Chi-squared (df=1)	p-value	Odds ratio	95% CI Lower - Upper
Exp/Contr pre/post	8.751	.003	.270	.114 - .643
Gender GP (male)	.057	.811	.944	.588 – 1.515
Age class GP <30	.615	.433	1.496	.547 – 4.094
30-40	10.544	.001	3.440	1.632 – 7.251
40-50	.738	.390	1.323	.699 – 2.505
50-60	3.139	.076	1.719	.944 – 3.131
>60				
Single-handed Practice	.005	.944	.980	.563 – 1.708
Duo	.810	.368	1.255	.765 – 2.060
Group	.		1	
Gender Patient (male)	.252	.616	1.110	.739 – 1.668
Age class <60	.003	.960	1.022	.442 – 2.364
Age class 60-70	.021	.884	.940	.407 – 2.170
Age class 70-80	4.407	.036	2.381	1.059 – 5.351
Age class 80-90	.063	.802	1.101	.520 – 2.331
Age class >90	.		1	
Residence (at home)	.275	.600	1.274	.515 – 3.156
Terminal status (yes)	.231	.631	1.140	.669 – 1.943
Cancer (yes)	1.177	.278	1.362	.779 – 2.381

Adequacy of the information transferred.

For the 179 contacts in which information was transferred, this information was adequate in 110 contacts (61.5%), not adequate in 57 contacts (31.8%), missing data in 12 contacts (6.7%). When the information was not adequate, this was in 31 contacts (17.3%) because the information was older than one month and in 26 contacts (14.5%) because the content was insufficient.

In Table 4 we present the odds of the presence of adequate information. The experimental group and the control group did not differ significantly regarding the presence of adequate information.

Table 4. Effects of introducing a handover form on quality of transferred information. Generalised Estimating Equations. N of contacts with information transferred = 167.

	Wald Chi-squared (df=1)	p-value	Odds ratio	95% CI Lower - Upper
Exp/Contr pre/post	.081	.777	1.342	.176 – 10.213
Gender GP (male)	.169	.681	1.222	.470 – 3.179
Age class GP <30	.001	.972	1.047	.081 – 13.601
30-40	3.545	.060	.269	.069 – 1.055
40-50	.442	.506	.663	.198 – 2.224
50-60	.429	.512	.687	.223 – 2.113
>60	.	.	1	
Single-handed Practice	.006	.940	1.053	.273 – 4.068
Duo	3.657	.056	3.179	.972 – 10.400
Group	.	.	1	
Gender Patient (male)	.004	.953	.968	.330 – 2.839
Age class <60	1.586	.208	7.495	.326 – 172.267
Age class 60-70	2.566	.109	12.880	.565 – 293.637
Age class 70-80	1.580	.209	7.656	.320 – 183.038
Age class 80-90	1.119	.290	4.902	.258 – 93.199
Age class >90	.	.	1	
Residence (at home)	2.515	.113	.101	.006 – 1.719
Terminal status (yes)	3.456	.063	.294	.081 – 1.069
Cancer (yes)	.767	.381	.577	.168 – 1.976

Adherence to Intervention

We performed a subgroup analysis for the experimental group to look for differences between GPs who attended the training (102) and GPs who only received the final letter with the handover form.

Post-intervention, we found 164 contacts from patients whose GPs belonged to the experimental group. Although there were more contacts with information available provided by GPs who attended the training (N=89, information available 32), the difference with the subgroup of GPs who only received the final letter (N=75, information available 19) was not significant. Regarding the second research question, in the subgroup of GPs who attended the training, information was adequate in 19 out of 32 contacts with handover form, versus 13 out of 19 in the subgroup of GPs who only received the final letter. (n.s.)

Discussion

The main finding from this controlled trial is that the introduction of an information handover form combined with the training of GPs in transferring information on their palliative patients to the out-of-hours GP co-operative had a positive, statistically significant, influence on the number of contacts in which information on the palliative patient was available in the co-operative. However, despite the absolute increase of 9%, the percentage of contacts in which information was available remained low (30%) in the experimental group. The majority of GPs did not attend the training and received only the introduction letter and the handover form. There is no proof that the one-hour training session contributes to the effect. No significant further benefit from our intervention was identified in terms of the adequacy of the information available.

Comparison with existing literature

Previous studies showed that, similar to our results, GPs do not routinely write information transfers (15,26) Where in the UK Burt *et al.* found that a transfer of information was available in 1.2-13%, Munday *et al.* found that transferred information was present in 21% of the patients who contacted the out-of-hours co-operative. In the Netherlands, De Bock *et al.* found that a transfer of information was available in 20%. (26,1,27) In comparison to these studies, our improvement towards 30% can be qualified as a positive result.

To our knowledge there are no studies on initiatives to improve the writing of information transfers, although in Scotland a palliative care handover form is being piloted that is transmitted electronically. (28) Working with handover forms sent from in-hours practices to out-of-hours providers is recommended in the literature to address the problem of an isolated working doctor in the night. (4,16,18,21)

A reason for not transferring information could be that GPs are available themselves for their terminally ill patients during out-of-hours periods. Burt *et al* stated that GPs are often reluctant to define patients as 'palliative', in spite of their terminal condition, and therefore are unlikely to recognise the need for information handover. (26) Another reason for under-estimating the importance of transferring information could be that the GPs did not expect a rapid deterioration. (24)

Many GPs complete special notes only when they think an out-of-hours call is likely, rather than 'not unexpected'. This is often at the very end of life. (15) Our intervention made an appeal to GPs to overcome the barriers in writing an information transfer to the out-of-hours co-operative by convincing GPs of the importance of good anticipatory care and by giving them a standardised handover form. This minimised time constraints by offering a pre-printed form with all necessary headings.

A factor that might have contributed to our positive result may be that the intervention was based on our prior needs assessment by means of focus-group discussions. It made clear that GPs felt that there was a need for better communication. They were therefore susceptible for a change in behaviour.

The effect of the intervention, however, remained moderate. Our intervention focused mainly on the improvement of knowledge and skills. This is perhaps not enough to bring about a change in behaviour of the GPs.

In spite of the standardised form, lack of time and 'forgetting' caused by the constraints of a busy GP practice remain a problem. Where GPs in Scotland found that special notes to inform the out-of-hours service about patients were not specific enough for patients receiving palliative care (15), we found that the quality of the information noted and sent when GPs used our dedicated form was adequate. Perhaps the main obstacle in writing information transfers has been overcome when a GP starts writing them.

Strengths and limitations of the study

A strength of the study is that we included all contacts with the GP co-operative with patients receiving palliative care from a full population of GPs in Amsterdam. We studied the availability of information about all patients for whom a call was made.

A further strength is that this study builds on prior studies (focus group and database study).

A limitation is that we do not know how many times information was transferred for patients for whom no call was made, nor did we register whether regular updates were sent.

Because of the small number of contacts per GP, it was not possible to examine to what degree the same GPs write information transfers.

Although studying the complete text of the contacts with the GP co-operative made it possible to identify palliative care contacts, it is possible that not all palliative care contacts were recognized as such.

Recommendations

Further improvement could be made by a change of attitude of GPs, which could be brought about by giving them feedback on their information transfer. When one of their patients receiving palliative care has had contact with the GP co-operative, they could be contacted the next morning by an assistant of the GP co-operative to inform them whether adequate information on this patient had been available to the locum. Better logistics through the use of an electronic information system would be helpful. It is then possible to flag patients in the system of the GP co-operative and to ask the GP electronically for a regular update on an automatically generated review date. These suggestions could be included in quality standards for GP co-operatives.

Conclusion

The introduction of a handover form combined with a training of GPs in writing information transfers resulted in a moderate increase of information transfers to the GP co-operative. However, the total percentage of contacts in which this information was present remained rather low. GP co-operatives should develop additional policies to improve information transfer.

Ethics Board

The Ethics Board of the VU University Medical Center, Amsterdam, was informed about the study, and they decided that the study did not require a formal ethical review.

Funding

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Writing information transfers for
out-of-hours palliative care by GPs:
effects on the quality of care as
experienced by patients and carers.
A controlled trial

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Submitted

Introduction

Most patients requiring palliative care in the terminal phase of their disease prefer to stay and die at home. In the Netherlands almost one-third of the people dying from cancer or other chronic diseases die at home. (1) Patients with cancer receiving palliative care spend about 90% of the last year of life at home.(1,5)

It has been suggested that poor delivery of care in the primary sector may be a major reason why the majority of cancer patients die in hospitals despite their preference for a home-death. (2,3,4)

GPs' understanding of the experiences of patients in palliative care and their carers is a prerequisite to ensure that the quality of out-of-hours care is optimal. Continuity of care, especially for this vulnerable group of patients, is important.(8)

This continuity of care is challenged by recent changes in the organisation of out-of-hours care.

Since unexpected problems are inherent to palliative care even with adequate advanced care planning, palliative care takes place also in the out-of-hours period. The out-of-hours period in the Netherlands is defined as evenings, nights, weekends from Friday evening to Monday morning and public holidays. During the last decade out-of-hours primary care services in the Netherlands have been re-organised from small rota groups to large GP co-operations in which 40 to 250 GPs take care of populations ranging from 100,000 to 500,000 inhabitants. Most GPs working for the GP co-operation do have a day-time job as a GP, but there is also a group of GPs working only in the out-of-hours setting. There is small chance that patients receive care out-of-hours from a doctor who knows them.(6)

The severance of the link between the GPs' daily care and the out-of-hours service has brought concerns about how patients with complex needs can be managed appropriately. A recent Australian study showed that lack of after hours care was an important barrier to optimal care of the dying in the community.(7)

In a study by Worth et al., many patients said that they preferred to wait until the morning so they could speak to their own GP, and some described low expectations of out-of-hours services. A factor that helped patients and their carers when seeking help out-of-hours is being known to the out-of-hours service.(9)

The provision of information to patients and carers along with regularly updated handover forms sent to out-of-hours services, was identified as key by both patients and professionals (9). Information about the patients situation is also important to avoid unnecessary hospital admissions. Now locum GPs are less likely to access a

patient's medical information prior to a home visit; as such they are reviewing the patient 'in the dark'.(10)

The process of contacting the out-of-hours service is now sometimes cumbersome and protracted at a time of strain.(11)

This can partly be helped by good anticipatory care by the patients own GP which includes exchanging information with the GP co-operative.

We evaluated the effect of the introduction of an information handover form for out-of-hours palliative care. In an earlier publication we describe the effects of this training on the frequency and the quality of information provided for out-of-hours palliative care. In this article we examine the effects on outcome and process of palliative care according to patients and their carers. We addressed the following research questions:

1. Regarding the outcome: does the number of contacts increase in which the locum addresses the reason for encounter (RFE) and in which the patient's problem improves?
2. Regarding the process: does the number of contacts increase in which:
(a) the locum is informed about the patient's situation, (b) the patients get a home visit when they ask for it and (c) patients and their carers have trust in after hours primary palliative care?

In this study patients receiving palliative care included cancer and non-cancer patients. Palliative care was defined according to the European association for Palliative Care : Palliative care is the active, total care of a patient whose illness is not responsive to curative treatment. Control of pain, other symptoms, and social, psychological and spiritual problems is paramount.(12)

Method

Study design

We conducted a controlled trial. The GP co-operation in Amsterdam provides out-of-hour services from two clinics during nighttimes and six clinics during evenings and weekends. Two groups of GPs were formed according to the boundaries of the GP clinics in which they co-operate, 1: all GPs working in the western half of Amsterdam (N=240) and 2: all GPs working in the eastern half of the city (N=186). By flipping a

coin we randomly assigned group 1 to the experimental condition and group 2 to the control condition.

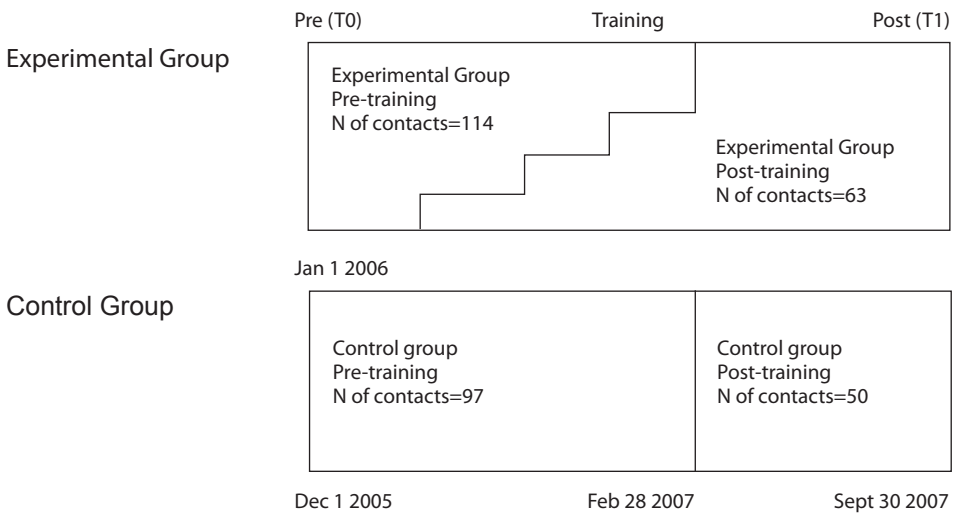
Study population

Patients needing palliative care who contacted the GP co-operative during the study period. Patients were only interviewed once, so different patients were interviewed before and after the intervention.

Procedure

We held telephone interviews with patients in palliative care or with their carers. The focus of our study was on effect on patient level. We assumed, however, that most patients would be too ill to be interviewed, in which case we planned to interview the carer (family or professional). Interviews were held within three days after a contact regarding the patient with the GP co-operative. A contact was defined as a call with the GP co-operative followed by either a telephone consultation, a home visit or a consultation at the GP co-operative. Consent was gained from all participants directly before the start of the interview.

Figure 1 Study design



The pre-measurement period for the experimental and the control group started December 1st 2005 and ended February 28th 2007. After all first out-of-hours contacts with the GP co-operative from patients in palliative care a trained research assistant tried to reach the patient or his carer by telephone and held, after given consent, a telephone interview. From January 2006 to February 28th 2007 the intervention (box 1) was performed. On several dates during this period we organised training sessions for GPs in the experimental group to introduce the handover form. Interviews with patients from GPs in the experimental group who attended the training were after this moment registered as post-measurement interviews. The intervention was concluded February 28th 2007 with a final letter to all GPs in the experimental group, those who had attended the training as well as those who had not, containing the handover form on information transfer and the procedure to be followed. From that moment all interviews with patients from GPs from the experimental group as well as from the control group were registered as post-measurement interviews. Interviews were held till September 30th 2007.

Intervention

Our intervention was based on a prior needs assessment by GP focus group meetings. (13) We drafted a handover form that, when filled in, contains all essential information about a patient in palliative care. The handover form has to be sent by fax to the GP co-operative where a secretary brings it the same day into the database-system, making a new record for this patient if there is no prior information. These data are the available for a locum when a patient receiving palliative care contacts the GP co-operative. An educational intervention was designed to exercise working with this tool. (Box 1) All GPs in the experimental group received a letter to inform them about the project and to invite them for one single training session.

Control condition

In the control group no handover form was provided and no training.

Measurement procedures

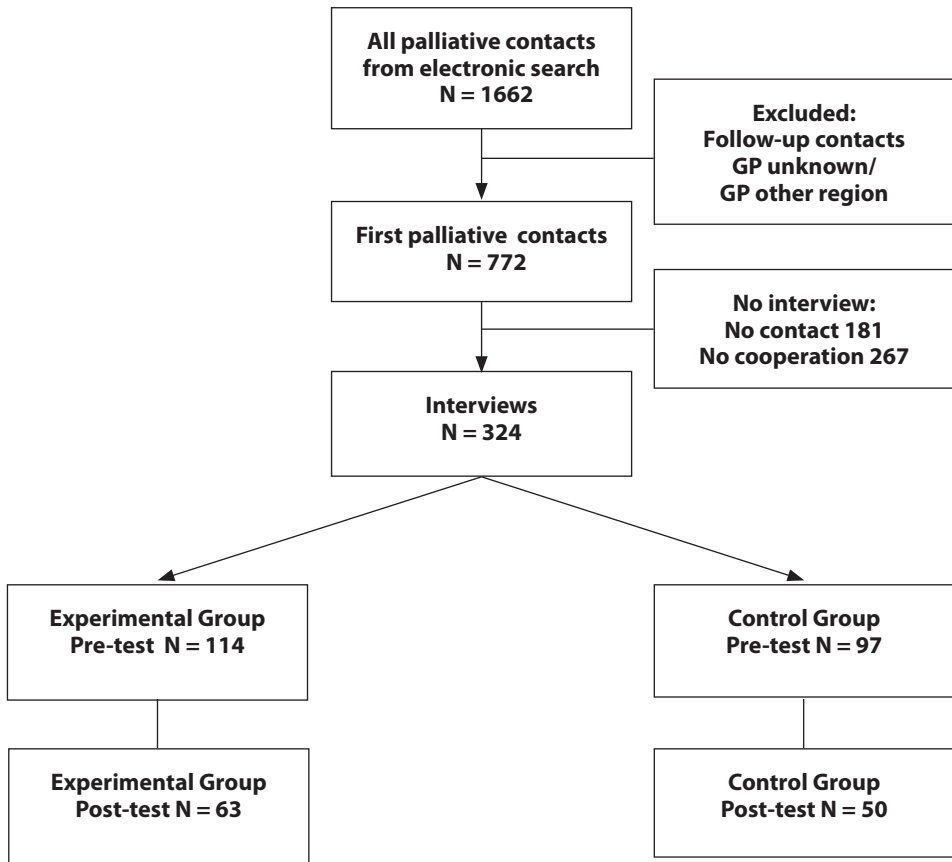
To identify palliative care contacts we carried out an electronic search in the out-of-office data management system of the GP co-operative in Amsterdam 'Call manager'. This database contains medical data on all calls with the GP co-operative. It also contains all information transferred by GPs about their patients. The records of all

phone-calls during the study period were searched electronically. We identified palliative care contacts by means of a search with the text words "palliative," "terminal", "cancer", "carcinoma", "inoperable", "opioid", and "fentanyl". This search yielded palliative care contacts regarding cancer and non-cancer patients but also other contacts, for example when a patient used an opioid for acute low back pain. A GP with extensive experience in palliative care (BS) subsequently examined the identified records and identified palliative contacts according to the definition on palliative care stated above. He included only those contacts in which, apart from a possible fatal diagnosis, any mention was made of palliative care needs, palliative medication, remarks about terminally illness, etc. The context of the complete call manager record found in this way with the anamnesis, the description of the symptoms and the actions undertaken by the locum made this possible. All non-palliative contacts were excluded. A sample of the identified records was examined by a second experienced GP (NB) but no differences in judgment were found. The sensitivity of the search was checked by comparing the electronic search results with hand-searched data (BS) from all contacts during a period of one month. This did not produce any new contacts regarding palliative care patients; hence we decided not to carry out a hand search for the entire study. From all identified palliative care contacts we used only the first contact regarding a specific patient with the GP co-operative for data extraction. In the study period we identified 772 first palliative care contacts. The patient or his carer were contacted by telephone in the first three days after this contact with the GP co-operative by an experienced researcher (MK). An interview guide was used. Interviews lasted a maximum of fifteen minutes.

Beside the interviews the following data were extracted from the included records:

Presence or absence of information transferred by the patient's own GP. A home visit a telephone consultation or a consultation at the GP-clinic as a result of the call. The action performed by the locum. Patient characteristics: gender, age-class, residence, terminal status, diagnosis.

We did a planned sub-group analysis to look for differences in interviews between patients who were interviewed themselves (N=37) and interviews with family (N=190) and other carers (N= 97)



Outcome measures

The outcome on our first research question was an increase of the number of contacts in which the locum addressed the RFE properly and in which the patient's problem as defined by the patient improved, in answer to open interview questions.

For the second research question was this an increase of the number of contacts in which the locum was informed about the patient's situation, the patient got a home visit when they asked for it, and in which patients and their carers had trust in after hours primary palliative care.

Data analysis

Descriptive frequency distributions were carried out for patient and content characteristics. Patient and contact characteristics in intervention versus control condition were compared using Chi-square tests.

To analyze the effect of the intervention on patient outcomes we performed a logistic regression. In this analysis we had to deal with the exceptional situation that we studied contacts from different patients in post- versus pre-measurement groups. We therefore used the method of Generalized Estimating Equations that allows to include all contacts in the analysis and allows for dependency of patients from the same GP in the pre- and post-measurement. Because we studied contacts from different patients in pre- versus post measurement groups, covariates could vary in pre- versus post measurement. We therefore analyzed possible differences for the dichotomous variables gender, residence (home, residential care home), terminal status, cancer, and the continuous variable age-class for the four groups separately (experimental pre- and post measurement group and control pre- and post measurement group).

We made a sub-group analysis to look for differences in interviews between patients who were interviewed themselves and interviews with family and home care professionals

Results

We tried to contact all patients with whom a first palliative care contact in the out-of-hours period was registered (N=772).

In total we held 324 telephonic interviews (42% of all first palliative care contacts) after given consent, from which 37 with the patient, 190 with a member of the family or a friend, and 97 with a professional carer who was at the patient's home at the moment of the interview call. No interview was held in 181 cases because no patient or carer could be contacted and because of non co-operation in 267 cases. Co-operation was refused mostly for emotional reasons, for example when a patient had died in the meantime. Another reason for non co-operation was a carer who had not been present when the GP co-operative had been contacted.

With patients who's GP belonged to the experimental group we held 177 interviews, 114 pre-measurement and 63 post-measurement, with patients who's GP belonged to the control group 147 interviews, 97 pre-measurement and 50 post-measurement.

Interviews were held with patients from 217 GPs in total, 121 from the experimental group and 96 from the control group: from 149 GPs one patient was interviewed, from 48 GPs 2, and from 20 GPs 3 to 6 patients were interviewed.

Patient characteristics

Table 1 shows characteristics of patients and the type of consultation. The mean age was 72.1 years and 83% of patients resided at home.

Pain, respiratory problems and digestive problems were the most frequently reported reasons for encounter. Cancer was the most frequent underlying disease (78%), and according to the locums 48% of patients was terminally ill.

Within the control group place of residence differed significantly between pre- and post-measurement.

In 60% of the contacts a home visit was made, a telephone consultation took place in 38% and a consultation in the GP clinic in 2%. Information on the patient was transferred in 19% of the contacts.

Table 1. Patient and contact characteristics

	Total	Exp. Pre-measurement group	Control Pre-measurement group	Exp. Post-measurement group	Control Post-measurement group	P Exp. Group ^a	P Control group ^a
Gender	N=324	N=114	N=97	N=63	N=50		
Male	49%	53%	54%	40%	46%		
Age							
Mean age in years (SD)	72.1 (13.1)	71.1	74.1	73.5	71.4		
Residence							
Home	269 (83%)	86%	76%	82%	90%		P 0.007
Care home	55 (17%)	14%	24%	18%	10%		
Reason for encounter							
Pain	134 (41%)	48%	36%	35%	44%		
Respiratory problems	62 (19%)	14%	20%	24%	24%		
Urinary problems	9 (3%)	3%	2%	3%	4%		
Digestive problems	36 (11%)	11%	10%	13%	10%		
Circulatory problems	4 (1%)	2%	1%	1%	0%		
Psychological problems	20 (6%)	7%	7%	3%	6%		
Other problems	59 (18%)	16%	24%	21%	12%		
Terminal status							
Terminally ill	157 (48%)	44%	51%	54%	48%		
Not terminally ill	166 (51%)	56%	49%	46%	52%		
Missing	1 (0.3%)						
Underlying disease							
Cancer	253 (78%)	83%	74%	76%	76%		
Heart failure	13 (4%)	2%	3%	10%	4%		
COPD	8 (2%)	1%	5%	0%	4%		
neurological	3 (1%)	0%	1%	2%	2%		
Unknown	41 (13%)	14%	17%	11%	13%		

Type of contact						
Telephone consultation	124 (38%)	41%	41%	36%	29%	P 0.06
Home visit	196 (60%)	57%	58%	64%	68%	
Consultation in GP clinic	4 (1%)	2%	1%	0%	2%	
Information Transfer						
Information available	62 (19%)	15%	22%	25%	16%	P 0.06

^a = pre-versus post measurement

Effects of introducing a handover form (Table 2)

In the experimental group, according to the patient or his carer, more locums were adequately informed about the patient's situation after the intervention.

Controlling for the pre-post differences in gender, age class, residence, terminal status and underlying disease, the change in percentage of well-informed locums differs however statistically not significantly between experimental and control group.

Regarding the other research questions there were also no significant differences between the experimental and control group.

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Table 2. Quality of out-of-hours palliative care according to patients and their carers: effects of introducing a handover form
N of interviews = 324

	Experimental Group pre	Control Group Pre	Experimental Group post	Control Group Post	Wald*	p-value*	Exp(B)*	95% CI* For Exp(B)	95% CI* For Exp(B)
NN	N=114 35%	N=97 30%	N=63 19%	N=50 15%				Lower	Upper
Did the locum address the RFE? (N=320, missing N=4)	89%	86%	90%	90%	.469	.493	1.757	.350	8.812
Was there improvement regarding the problem? (N=320, missing N=4)	85%	84%	90%	86%	.004	.950	1.049	.239	4.598
Was the locum well informed? (N=309, missing N=15)	29%	37%	43%	30%	1.621	.203	2.004	.687	5.842
Did patients get a home visit when they asked for it? (N=204)	88%	94%	97%	97%	.240	.625	.441	.017	11.707
Do patients/carers have trust in out-of-hours palliative care? (N=278, missing N=46)	88%	83%	87%	90%	1.348	.246	2.498	.533	11.717

* differences in pre-post changes between Experimental and Control group

Sub-group analysis

We did a planned sub-group analysis to look for differences in interviews between patients who were interviewed themselves (N=37) and interviews with family (N=190) and home care professionals (N= 97). In the experimental group, according to the family, more locums were adequately informed about the patient's situation after the intervention. This was, after controlling for pre- post differences in other variables, statistically significant. There were no significant differences regarding the other research questions.

Discussion

Principal findings

We found few differences in the effects on palliative care as experienced by patients and their carers after introducing a handover form for information transfers. In the experimental and control group, both pre- and post-measurement, a vast majority of patients and their carers stated that the locum addressed the reason for encounter and that there was improvement regarding the problem they called for. As far as the process is concerned: according to family of patients locums were significantly better informed about the patients situation after the training. In both groups a majority of patients got a visit if they asked for it and patients and carers expressed their trust in out-of-hours palliative care.

The reason that we found few differences on patient outcomes is related to the fact that there was only a small increase in information transfers in the experimental group, statistically not significant compared to the control group.

Comparison with existing literature

Deficits in communication and information transfer to out-of-hour services in primary care are common and may adversely affect patient care. In recent studies was found that a transfer of information was available in about 20% of the patients who contacted the out-of-hours service, which is comparable with 19% in our study. (14,15). But even when an information transfer was present, they were often not specific enough for palliative care patients, sent too late and generally under-utilized. (15)

Table 3. Locum well informed? Sub-group analysis. N of interviews:324

	Experimental Group pre	Control Group Pre	Experimental Group post	Control Group Post	Wald	p-value	Exp(B)	95% CI For Exp(B) Lower	95% CI For Exp(B) Upper
Was the locum well informed according to the family of patients? (N=184)	N=63 30%	N=53 45%	N=35 43%	N=33 21%	5.608	.018	5.667	.348	23.817
Was the locum well informed according to patients (N=13, 41%)	N=6 37%	N=1 33%	N=3 50%	N=3 43%					
Was the locum well informed according to home care professionals (N=28 30%)	N=6 21%	N=9 25%	N=8 42%	N=5 50%					

In an earlier study we found that according to locums 74,5% of patients was terminally ill at the time of the first palliative care contact.(16) Now we found, in the group of interviewed patients, that according to the locums 48% was terminally ill. This can be explained by the fact that interviews were held some days after the palliative contact and in the group of terminally ill patients more patients died before an interview could be held.

In a Scottish study non of the patients or carers interviewed expressed any concern about privacy aspects when medical details should be made available in advance to an out-of-hours service. (17)

King et al. stated that when out-of-hours providers have up-to-date information about palliative care patients this makes it easier for professionals to quickly build rapport with carers. They found cases with significant weaknesses in quality of care and support, in most of which a hand-over form had not been in place.(18)

In this study we found that, according to the family, more locums were adequately informed about the patient's situation after the intervention, but the percentage of contacts in which information was available remained low.

Strenghts and limitations

A strength of this study is that we held 324 telephone interviews within a controlled trial design. Interviews with terminally ill patients are rare, due to ethical and practical difficulties. We choose for a short telephone interview. A limitation is that we could only interview a minority of the patients themselves. Most interviews were held with family or home care professionals. This is however inherent on the situation of patients in end-of-life care.

There is a chance that responders answered too much in a positive way due to the social pressure to give the 'desired answer'. They also would possibly not like to 'disappoint' an organisation they probably needed again in the future. This bias would however be the same for all groups.

Conclusions

Locums are better informed, according to the family of patients, after the training of GPs in writing information transfers. In both experimental and control group patients and their carers are positive about the aspects of quality of care examined. They have trust in the quality of out-of-hours palliative care. Because there was only a small

increase in information transfer in the experimental group no big differences between the two groups could be expected.

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We thank our research assistant Marianne Koridon, who performed the challenging task of calling and interviewing patients and their carers.

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Short Report

Patients' and carers' experiences
with out-of-hours palliative care:
does information transfer from the
GP to the locum make a difference?

Bart Schweitzer, Nettie Blankenstein, Luc Deliens, Henriette van der Horst

Submitted

Introduction

Due to the changes in the primary health care system, out-of-hours service provision is now delivered by large scale GP co-operatives in the Netherlands . (1) The same shift took place in the United Kingdom, Ireland, Sweden and Denmark. To ensure good quality of care for vulnerable patients, continuity of care is essential. Palliative care patients are extremely vulnerable, and unfamiliarity with the patient and his problems may lead to poor symptom control and inappropriate hospital admissions. (2,3,4)

The information of a patient's own GP is not automatically available for the GP co-operative.(5,6) According to GPs working out-of-hours, information exchange impacts strongly on their palliative care encounters.(7) If the locum is well informed because information has been transferred from the GP to the locum, the patient and his carer get the feeling that they are known to the out-of-hours service which helps them in seeking help out-of-hours. (3) When a negative experience of the present service may cause some patients to delay calling for help, the mere presence of information is a reassuring factor.(5,8) Most participants in a recent study of patients seeking palliative health care in out-of-hours expected the doctor to be able to access a summary of their complex medical history. (9) In a qualitative study by King et al in nine cases described, there were five with some significant shortfalls in quality of care due to lack of information.(8)

There is only limited information whether information transfer from the GP to the locum has an impact on the quality of care as experienced by patients or their carers. In this study we explored whether patients' experiences were related to the absence or presence of information during out-of-hours care.

Methods

In 2006 we held structured telephone interviews with palliative patients or their carers. After all first out-of-hours contacts with the GP co-operative from patients in palliative care a trained research assistant tried to reach the patient or his carer by telephone and held, after given consent, a telephone interview. If patients were too ill to be interviewed, we interviewed a family care giver. When no family care giver was present we interviewed a professional care giver.

Our aim was to get more insight from the patients' point of view.

Interviews took place within three days after a contact regarding the patient with the GP co-operative of Amsterdam.

In this paper we compare cases in which information transfer from the GP to the co-operative took place or not. Chi-square tests were used to analyse differences between these two groups.

Results

In total we held 324 telephonic interviews after given consent, from which 37 with the patient, 190 with a member of the family or a friend, and 97 with a professional carer. No interview was held in 181 cases because no patient or carer could be contacted and because of non co-operation in 267 cases. Co-operation was refused mostly for emotional reasons, for example when a patient had died in the meantime. For 63 patients the patient information was transferred to the locum, and for 261 it was not (Table 1).

Patients or their carers deemed the locum significantly more often to be well informed if information was transferred. When asked if the problem had improved after the action of the locum, 86% said that it did improve. In the group where information was available this percentage was 95%, which is a significant difference.

The locum addressed the reason for encounter also more often in this group, but this result is not significant. No significant difference between the groups was found when asked about the trust in out-of-hours primary care. The total result of the groups, with and without information transfer, regarding trust in out-of-hours primary care was 87%.

A subgroup analysis to look for differences in answers given by patients or caregivers did not reveal significant differences.

Table 1 Patients' and carers' experiences with the out-of-hours locum, by information transfer.

As judged by the patient or carer:	Total N=324	Information transfer available N=63	Information transfer not available N=261	p-value*
Locum well informed	106 (34%)	32 (52%)	74 (30%)	.005
Locum addressed the Reason for Encounter	N=274 (86%)	57 (93%)	227 (88%)	.142
There was improvement regarding the problem	N=275 (86%)	N=58 (95%)	N=217 (84%)	.013
There is trust in out-of-hours primary care	N=250 (87%)	N=46 (84%)	N=204 (88%)	.233
The own GP is personally available in out-of-hours	N=51 (16%)	N=10 (17%)	N=41 (16%)	.471

* Difference between information transfer available and information transfer not available

Discussion

Main findings

Palliative patients or their carers find the locum more often well informed when information was transferred to the out-of-hours co-operative and hence available to the locum.

They also state more often that there was improvement regarding the problem they called for. No difference was found when asked if the locum addressed the reason for encounter properly and in their trust regarding out-of-hours primary care.

Comparison with literature

The availability of information on the patients' situation has impact on patient and carer outcomes in out-of-hours palliative care in the community. We found no other

studies on availability of information and patient outcomes. Pain and symptom management are important aspects of good quality end-of-life care.(8,9) We found that the problem patients called for improved in a vast majority of the contacts, and that there was a significant positive difference when information was available. It is possible that a locum with information on the patients' situation is more able to handle a difficult situation. This confirms the opinion of professionals who stated that improved communication between in-hours and the out-of-hours service was crucial in improving triage, decision making and continuity of care (3)

Strengths and limitations

A strength of this study is that we held 324 telephone interviews within a controlled trial design. Interviews with terminally ill patients are rare, due to ethical and practical difficulties. We choose for a short telephone interview. A limitation is that we could only interview a minority of the patients themselves. Most interviews were held with family or home care professionals. This is however inherent on the situation of patients in end-of-life care.

Conclusion

Communication has often been mentioned as the key factor in good out-of-hours palliative care. In this study we examined the impact of information transfer according to patients and their carers and found a positive relationship with some patient outcomes.

These outcomes underline the importance of initiatives to enhance the flow of information regarding patients with palliative care from GP to out-of-hours service providers.

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Out-of-hours palliative care by general practitioners

General discussion

Introduction

In this chapter we describe the objective of this thesis, the studies we performed, the main findings and the conclusions. The results of our research are linked together and discussed from different perspectives, taking the viewpoint of the GP, the patient and the GP co-operative. We will discuss methodological issues of the studies and present recommendations for clinical practice and future research.

Objective of this thesis

Our objective was to contribute to an improvement of out-of-hours palliative care by general practitioners in the Netherlands by analysing this care and tackling bottlenecks in information transfer.

We investigated the experiences of GPs with regard to the quality of out-of-hours palliative care that is provided by GP co-operatives. By performing a qualitative study using focus group discussions with GPs, we aimed to identify aspects for which recommendations about the organisation of the services could be made.

One of the major problems in palliative care highlighted by the focus groups appeared to be poor communication between GPs and GP co-operatives. This confirmed findings in several earlier studies in the UK, where continuity of care was identified as a major problem and the transfer of information to out-of-hours providers remained a key challenge.(1-9)

We further studied GPs' views on transfer of information about terminally ill patients to the GP co-operative by means of a web-based questionnaire.

To identify possible gaps in service provision and quality, we investigated the palliative care provided by GP co-operatives, in particular the availability, content and effect of transferred information. We did this by means of a survey of phone calls made to the GP co-operative.

We performed a trial to evaluate the effects of an intervention to enhance the percentage of out-of-hours palliative care contacts in which transferred information was available. A handover form for information transfer was provided and a training in using this form was offered to all GPs in the western half of Amsterdam with the eastern part as control group. Using patient interviews, we studied the effects of this trial on patient outcomes.

Finally we conducted a systematic literature review in order to identify barriers and facilitators for GP-patient communication in palliative care.

In the next sections we present a summary of the main findings and discuss the meaning of these findings in their context.

Main findings of this thesis

Quality of out-of-hours palliative care

According to the GPs, the quality of out-of-hours palliative care is meagre. They state that quality is hampered by the lack of adequate information sent to the GP co-operative and insufficient anticipatory care during office hours. Further, because no policy on palliative care has been developed by GP co-operatives, calls from patients receiving palliative care are not treated with priority and no additional time is available for home visits. (focus groups)

Information transfer

Eighty-two percent of the responding GPs in Amsterdam report that they transfer information about most of their terminally ill patients to the GP co-operative. However, we found information transfers for patients receiving palliative care in only 25%. The most frequently reported reason for not transferring information was a faster than foreseen deterioration of the patient's medical condition (questionnaire and survey)

The introduction of a handover form for the transfer of information resulted in a moderate increase of information transfers to the GP co-operative in the experimental group compared to the control group. The total percentage of contacts in which this information was present nevertheless remained rather low (30%). Half the GPs in the experimental group received a training in using the handover form, although this had no additional effect on the increase of information transfers.

The quality of the information transferred was adequate at baseline and did not improve after the intervention.

When information was transferred, this information consisted mainly of clinical data.

For the oldest group of patients and for patients in residential care homes, information is transferred less often (10.5% and 12%). (trial)

When information was transferred, patients find the locum more often well-informed.

When asked if they found this important, 92.5% stated that they did so.

Improvement occurs more often regarding the problem they called for and fewer patients were transferred to a hospital. (patient interviews, survey)

Palliative care provided by the GP co-operative

In our study, 0.75% of all phone calls to the GP co-operative were from a patient who needed palliative care. According to the locums, 74.5% of these patients were terminally ill.

Pain was the most frequent reason for encounter for these patients (41%), followed by respiratory problems (19%) and digestive problems (11%),

A phone call to the GP co-operative about a palliative care problem was followed by a home visit in 53% of the cases.

The most common action by the locums was prescribing medication (57.1%), followed by giving advice without prescribing medication (27.7%), and being referred to a hospital (12.3%). (survey)

Communication in palliative care

The most important barriers for GP-patient communication are: the GP's lack of time, the patient's ambivalence to knowing about the prognosis and the GP not communicating honestly about diagnosis and prognosis.

The most important facilitators for GP-patient communication are the availability of the GP and GPs who anticipate various scenarios and discuss these with the patient, followed by longstanding GP-patient relationships, GPs showing commitment, GPs being open and allowing any topic to be discussed. (systematic review)

Regarding this availability during the out-of-hours period, 70% of the GPs state that they were personally available to provide care for their terminally ill patients.

(questionnaire). According to patients or their carers who called the GP co-operative, however, only 16% of GPs were personally available out-of-hours. (patient interviews)

Overall, the results presented here confirm several existing insights abroad for the situation in the Netherlands, both on the quality of out-of hours palliative care (e.g., quality is meagre, no policy on palliative care has been developed by the GP co-operatives) and on communication regarding the out-of-hours period (e.g., communication is often inadequate).

Additionally, our results provide new information. Firstly, regarding information transfers (e.g., the difference between the opinion of GPs that they transfer information and the information found, the quality of the information transferred, the small effect of the introduction of a handover form, and the effects of an existing information

transfer on patient outcomes), secondly regarding patients receiving palliative care from a GP co-operative (e.g., patient characteristics, actions of the locum), and thirdly regarding GP-patient communication (e.g., barriers and facilitators).

The GP's perspective

We studied the perspective of GPs from different angles.

Our research showed that a majority of GPs in Amsterdam feel that they are responsible for the provision of out-of-hours palliative care: 70% stated that they were personally available to provide care out-of-hours for their terminally ill patients (even if they also made use of the GP co-operative). In the vision of the Dutch College of General Practitioners (NHG) on the future of palliative care as articulated in 'Standpunt Palliatieve Zorg' all GPs should be capable of providing palliative care for their patients. (10) They will have education in this field during their GP vocational training and post-graduate education and will not hesitate to consult palliative care specialists when needed. A core aspect regarded as most valued in end-of-life care was availability of the GP for home visits and after office-hours.(11) Personal availability and commitment are keystones of good quality of palliative care. An important goal therefore is that a patient's own GP is the provider of care, especially in the terminal phase of life. As constant personal availability is not possible, care can be transferred in the second instance to a direct colleague or, in the third instance, to a GP co-operative.(10)

The answers of GPs in this study to questions regarding their availability support the opinion of the Dutch College of General Practitioners.

According to patients and their carers, upon calling the GP co-operative, however, only 16% of GPs is personally available for out-of-hours palliative care. We do not know how many patients do not have to call the GP co-operative because their GP is always available, but there is probably quite a difference between the opinion of the GPs about their personal availability and their actual behaviour.

Part of this difference may be caused by the definitions of 'terminally ill' versus 'palliative care'. The palliative phase is sometimes hard to define, due to the wide scope of possible treatments nowadays, and it is not always easy for a GP to recognise a patient in need of his palliative care.(12,13) But in out-of-hours palliative care, 74.5% of the patients for whom the GP-co-operation is contacted is already terminally ill, according to the locums.

Another reason for this difference may be that doctors have set personal availability for out-of-hours palliative care of old as a benchmark for quality of care, in accordance with the vision of the NHG, but that this is no longer a realistic goal since the reforms regarding out-of-hours primary care were implemented.

Approximately 0.75 percent of all calls to the GP co-operative are made for a patient in palliative care. This means that palliative care out-of-hours is frequently left up to the GP co-operative. Although, as stated above, we do not know how many GPs provide all palliative care themselves, it seems that personal continuity by the patient's own GP is no longer the rule.

So what are the guarantees for continuity of care if the GP does not personally provide care during the out-of-hours period? Different models exist: Some of the GPs still provide palliative care on a regular basis, including during the out-of-hours period, or choose to share this care with a close colleague; some are available for consultation by telephone directly by the patient or by the GP co-operative, and others hand all out-of-hours care over to the GP co-operative. In all these models a patient care plan, introduced by the GP and developed as much as possible with the patient and their carers, should be taken over by a locum when needed. It is therefore important that information about the patient's situation and this care plan is available.

Transfer of information, however, is often inadequate – information was transferred in only 25.5% of palliative care patient calls to the GP co-operative.

There are many reasons why GPs do not transfer information about their patients receiving palliative care. Apart from the barriers caused by time constraints (writing an information transfer is time-consuming) and technical problems (no standardised form available, no internet connection) there are problems inherent to the relation between the doctor and the patient receiving palliative care. First of all a major problem is the timely recognition of the palliative phase by the GP. One of the perceived barriers in the communication between GP and patient is the unpredictability of the clinical course and the uncertainty of an exact prognosis in palliative care. This means that it is difficult for a doctor to address items concerning diagnosis and prognosis with his patient in time.

When asked why no information transfer was written, the most frequently reported reason was a faster than foreseen deterioration of the patient's medical condition. If a GP states that "the situation of this patient started deteriorating suddenly and much faster than I expected", this can absolutely be true. GPs will often delay steering a

palliative course until a sudden deterioration of the patient's condition forces them to do so. But if there is the early realisation that this concerns a patient in a palliative phase, it is easier to anticipate these sudden deteriorations which are common among patients in palliative care.

Recognition of the palliative phase is therefore an important issue. This is often especially difficult for patients with non-cancer related diseases like heart failure or COPD.

Although our intervention leads to an increase in information available compared to usual care, this increase is small. Our intervention does apparently not provide a sufficient solution to all the barriers in writing information transfers. Although the intervention teaches GPs to write an information transfer by means of a handover form, they do not learn to anticipate palliative care in this way. For anticipation it is necessary to acquire information on the patient which can then easily be transferred. Another factor may be the fact that GPs have only a few patients receiving palliative care and that they are not focused on the need of anticipation in time.

When GPs state that the quality of out-of-hours palliative care is meagre, this could be because they compare this care with the palliative care they provide themselves during office hours. Out-of-hours palliative care is meagre in their perception because it is temporary care without regard for continuity. There is less symptom control and there are unnecessary hospital admissions. But part of this may be due to insufficient anticipatory care during office hours. If a GP wants to support the patient through the illness, it might be good to set up a patient care plan and to communicate this with other carers. This includes writing an information transfer to the GP co-operative in an early stage.

The perspective of the patient

Although the introduction of a handover form did not lead to a large increase in information transfer, the results from the patient interviews when information transfer was available or not showed relevant differences. Patients noted significantly more often that the locum was well-informed when information transfer had taken place, and when asked if they found this important, 92.5% stated that they did so.

In the group where information was transferred, more improvement regarding the problem for which patients called was observed.

The fact that fewer patients were transferred to a hospital when information was transferred is likely due to the locum being able to handle the situation at the patient's home more easily with this information in hand.

These results indicate that information transfer does have a direct effect on patient outcomes.

Patients and their carers stated in the interviews that they had trust in out-of-hours primary care (87%) and this was independent of whether information was transferred or not. It is however possible that these answers in a telephone interview, given by people still in need of help, are biased towards socially desirable answers.

We found that GPs transferred information for palliative care patients in 25.5% of the cases, but for palliative care patients in residential care homes in only 12%. There were also remarks in the focus group study referring to a lower level of care in residential care homes due to staffing problems. This finding is in line with current research where it is argued that people in residential care homes have unequal access to both generalist and specialist palliative care. Understaffing and inadequate training to provide palliative care are mentioned as a problem. There is also concern about how to introduce palliative care methods with untrained carers.(14,15,16)

The lack of information transfer therefore means double jeopardy: not only is there the difficulty of understaffing and untrained staff, there is also no adequate information on the patients for them to work with. GPs may have the opinion that they are transferring part of their responsibility for a patient to a care home, but when it comes to palliative care they fall short of the mark if they do not provide this information.

We found that pain was the most frequent reason for encounter in our survey, followed by respiratory and digestive problems. Borgsteede et al found digestive symptoms as the most prevalent under patients who died at home, followed by pain and psychosocial problems.(17) The difference may be due to the fact that he studied existing symptoms during a longer period of time while we studied acute reasons for encounter. Getting relief from pain is perhaps a more powerful reason to contact a doctor out-of-hours than digestive or psychosocial problems.

As the review made clear, the availability of GPs is a prerequisite for good GP-patient communication. Being there is important, also during nights and weekends. This is one of the reasons that a visit is almost always necessary in palliative care situations

out-of-hours. These visits are highly appreciated and seen as evidence of genuine concern for the patient and carer.(18).

The perspective of the GP co-operative

The percentage of patients with palliative care problems who contact the GP co-operative was 0.75% of all contacts in our study. In another Dutch study, 2% of all contacts were with patients in palliative care.(19) Burt found 2.1% of all calls to co-operatives palliative care-related.(7) These differences possibly reflect demographic differences, since our study was performed in an inner city area where the number of contacts (both palliative and non-palliative) with the GP co-operative is high, while the other studies took place in mixed rural/urban areas.

Information about these patients was transferred in 25% of cases in our study. In another Dutch study, 20% transfer of information was found, in the UK Burt et al found transfer of information in 1.2 - 13% and Munday et al found that a handover was present in 21%.(19,7,3) This means that in most cases GPs working for the GP co-operative are not informed about patients receiving palliative care and perceive a lack of communication with the regular GP.(8) No continuity of care can be provided if the policy of the regular GP cannot be followed because it has not been made clear to the doctor working at the GP co-operative. Patients and their carers may be able to inform the visiting GP but if they are not able to do so, doctors have to make difficult decisions practically in the blind.

Recently, Taubert stated in an article with the ominous title "‘Oh God not a Palliative’: out-of-hours general practitioners within the domain of palliative care" that GPs in the UK working out-of-hours did so mainly from a financial motivation and that they experienced many problems in palliative care situations. There was clear concern about the lack of information and therefore of continuity.(9)

We found a positive relation between information transfer and symptom control and between information transfer and fewer hospital referrals. It is therefore important that a more effective transfer of patient information takes place if patients receiving palliative care are to receive the care they need.

This may also be true for other vulnerable groups with difficult symptom management, like psychiatric patients or patients receiving chronic care.

In our study, a home visit was made after a palliative care call in 53% of cases, while the overall percentage of home visits was 13%. In a recent, as yet unpublished study that we performed in Rotterdam, a home visit after a palliative care call was made in 65% of cases. When one realises that phone calls to the GP co-operative concerning palliative care are made for terminally ill patients in the last days of life, a visit is almost always needed. When it is not absolutely necessary for medical reasons, it might be beneficial in terms of bringing comfort and support. It is possible that either phone calls to the GP co-operative are not always recognised as being made for palliative care, or these calls are not treated with the urgency they deserve.

It is probably hard for patients and their carers to express feelings of uncertainty and discomfort in a telephone conversation focusing on triage. Requests for help can be interpreted as a 'demand' where an urgent 'need' is the real reason.

Important aspects of generalist care for terminally ill people include accessibility, availability, technical skills and doctors who are willing to listen in an unhurried manner, as we found in our review.(11,20,21). A home visit from a GP who takes their time at the bedside is particularly appreciated, maybe even more so in the out-of-hours period.

That no policy on palliative care has been developed by GP co-operatives, as stated in the focus groups, is understandable, but regrettable. The main focus of the GP co-operatives in the early years of their existence was acute biomedical care, with less attention for patients with chronic problems and palliative care patients. The service seems designed more for acute interventions and for triage rather than for the complex physical and psychosocial needs of the terminally ill.(22)

Methodological aspects

This thesis is based on data from different sources. We used a mixed methods design to collect, analyse and interpret our data. We sent a questionnaire to GPs to provide an overview of their opinions and attitude and we held focus groups with GPs to determine the important factors in out-of-hours palliative care. In this way, we obtained detailed qualitative information on the opinion of these groups concerning out-of-hours palliative care. Quantitative information on palliative care by the GP co-operation was collected by means of a survey of phone calls to the GP co-operative.

Furthermore we studied the possibility to improve palliative care by evaluating a trial in information transfer. Telephone interviews in the context of the trial were held with patients and their carers.

We chose this triangulated design because we wanted to combine qualitative data with quantitative data, collected at the same time, to enhance the validity of the interpretation of our data. This applies for instance to the importance of information transfer, highlighted in focus groups and answers to the questionnaire, but also confirmed by data from survey and patient interviews.

Qualitative research

We investigated the viewpoints of GPs in a focus group study and with a questionnaire. The strength of this design was that we included both GPs with and without special interest in palliative care and that almost all GPs were working both in daily practice and as a locum at the GP co-operative. It would however also be interesting to interview GPs who work exclusively out-of-hours, because their number is growing and because they are mostly young GPs with relatively little experience in palliative care. It is therefore possible that they have a different attitude to palliative care.

A limitation is that we have no means of evaluating how many contacts GPs themselves have had with their patients receiving palliative care out-of-hours. It is therefore difficult to estimate how much palliative care is provided by GPs themselves in this period.

Quantitative research

Quantitative results were obtained by studying the data from the database of the GP co-operative in Amsterdam. First, we analysed all telephone calls regarding palliative care and the subsequent actions during one year and later we studied telephone calls before and after our intervention. We used an electronic search method, the validity of this search being enhanced by a manual examination of the data found electronically. The database of the GP co-operative was not designed specifically for research purposes and contains only data registered during the out-of hours period. Relevant data on a patient's situation, normally registered by their own GP, regarding (co)morbidity, therapies and hospital admissions were therefore not available.

During the analysis of the data from the trial, we had to deal with the situation that we were training GPs who mostly have only a few patients in palliative care. We studied outcome (the presence of an information transfer) on the basis of patient contacts with the GP co-operation. It was not possible to collect a large number of contacts with patients of each GP in pre- and post-measurement due to the limited presence of patients in palliative care. The number of contacts with patients from the same GP in the pre- and post-measurement group was small and variable. To take this into account, we used the method of Generalized Estimating Equation, which makes it possible to estimate the parameters of a generalized linear model with a possible unknown correlation between outcomes.

We were able to hold 324 telephone interviews with patients or their carers immediately after their contact with the GP co-operative. In a palliative care study this is a large population. A limitation is that, due to the terminal status of most patients, most interviews were held with carers. We asked them to focus on perceived needs and experiences of the patient, but inevitably their answers will be coloured by their own perspective.

Generalisability

The study was conducted in Amsterdam, a city with 750,000 inhabitants and the capital of the Netherlands, and may therefore not be representative for the whole country. The population differs from the Dutch population as a whole: there are more singles and one-parent families. On 1 January 2011, the ethnic makeup of Amsterdam was 49.7% Dutch and 50.3% ethnic groups.(23)

It is possible that because of the structure of the population, with fewer possibilities for voluntary assistance by the family members, more patients in palliative care call on help by professionals like their GP, as a result of which GPs are more inclined to share responsibilities with the GP co-operative. It is, on the other hand, possible that more people in Amsterdam die in hospitals, nursing homes and hospices, and that GPs are less involved in the palliative care process than their colleagues in rural areas.

Palliative care for large parts of other ethnic groups in Amsterdam may also be different. In a Dutch study on palliative care for Turkish and Moroccan immigrants, the analysis reveals that a barrier in decision-making is partly related to differences in ethnic-cultural views on 'good care' at the end of life: Dutch palliative care providers prefer to focus on quality of life rather than on prolonging life, while Turkish and Moroccan

families tend to insist on cure. It is possible that writing an information transfer, and thus labelling a patient as being in the palliative phase, is not always accepted. A barrier in communication is caused by the fact that Dutch care providers see the patient as their primary discussion partner, while in Turkish and Moroccan families, relatives play a major part in the communication and decision-making.(24)

However, regarding the structure of the organisation, the most GP co-operatives are organised in a similar way to the GP co-operative of Amsterdam.

Implications of the results

The primary aim of his thesis was to learn more about the state of affairs of out-of-hours palliative care in the Netherlands. The results have implications for the improvement of practice and the development of a policy on palliative care by the GP co-operatives. Also, the results raise new questions that demand further research.

Practice implications

A key finding in this thesis is that the quality of palliative care in the out-of-hours period benefits from information transfer between GPs caring for their patients during working hours and those working out-of-hours. A doctor, working out-of-hours, should be able to use information regarding the patients and especially regarding patients with palliative care. We conclude that the transferring of information by the GP to the GP co-operative needs to be encouraged. Training and the use of a protocol can be useful but that is not enough.

We recommend the introduction of a palliative care form, preferably to be filled in electronically, which should include: information about the patient's illness, treatment and management considerations, medication, information about the carers, the understanding of the patient about the state of affairs, the psychological and spiritual condition of the patient, preferred place of care, and wishes about end of life care. This form could be completed and transmitted electronically to the GP co-operative.

These forms should be completed for all palliative care patients as early as possible and they should be updated after relevant changes.

Our research experiences lead us to believe that these recommendations will not easily be achieved. It would be helpful if the boards of GP co-operatives make an effort by stimulating their staff to provide feedback to GPs when information on a palliative care patient is missing. Furthermore it is vital that the software evolves to allow audit

and possible targeting and monitoring of vulnerable groups in order to improve the access of palliative care patients to out-of-hours services.(25)

As we know from the systematic literature review, anticipation and availability are important issues in palliative care. GPs should be encouraged to take an anticipatory approach to the provision of out-of-hours palliative care (5), which includes the transfer of information. They should also be explicit about their own availability out-of-hours and inform their patients about an eventual transfer of care to the GP co-operative.

New incentives including the identification of patients suitable for inclusion on a palliative care register, and regular multidisciplinary meetings to review such patients, provide an ideal mechanism to facilitate greater use of special alerts to out-of-hours services.(25)

Some doctors consider the availability of an electronic medical record as a transfer of information. However, terminal care plans are hardly ever recorded in these electronic records.(19) Even if an electronic patient record is in common use, this only provides a solution when concise, up-to-date information, is available. Therefore a specific form, like the one we used for the transfer of information in our trial, should be included in this record

It would be very helpful if a standardised way of electronic registration was adopted by GPs. A recent advice from the College of Dutch General Practitioners is to opt for a special 'episode' in the electronic patient record with specific information on the palliative care provided.

Another recommendation is the expansion of patient-held nursing notes to be completed by all visiting professionals (medical and nursing, regular and out-of-hours). These notes are not available in every palliative care situation, mostly because no district nurse is involved, but they can be very informative. However, they provide no solution for the decisions that have to be made at the GP cooperative, for instance whether or not a patient in palliative care is concerned and whether or not a visit has to be made.

When a GP's patient in palliative care is living in a residential care home, this does not relieve the GP of the duty to write an information transfer. On the contrary, a possibly inexperienced member of staff will welcome remarks and advice.

We advise that GP co-operatives develop a quality standard in which these recommendations are included. Until now, working in a generic setting with limited staff and time means that acute medical conditions take precedence.(1) We recommend

paying a visit as standard after a call regarding a patient in palliative care, because we know from our research that almost all patients are in the terminal phase of their disease. It is therefore probably one of the last chances of enhancing the quality of care. This, however, demands an organisation that recognises palliative care calls in time and gives them the priority they need.

Future research

The need to improve the transfer of information to out-of-hours providers is a key target for both GPs and GP co-operatives. We studied the effect of the introduction of a handover form and a training but the number of palliative contacts in which transferred information was available remained low. Further research is needed for other tools which might enhance this number, like giving feedback from the GP co-operative to GPs on excellent information transfer versus a lack of it.

From our findings, it would appear that out-of-hours palliative care in other parts of the Netherlands may be different due to demographic factors, which need to be examined.

What has been left unexplored in this dissertation is out-of-hours palliative care provided by GPs themselves for their own patients. Where a majority stated that they were personally available to provide care out-of-hours for their terminally ill patients, how much care is actually provided by GPs, and how much is transferred to the GP co-operative? Is the role of the GP co-operative in palliative care getting more important and are the arrangements for providing this care satisfactory?

We have summarised barriers and facilitators for GP-patient communication in palliative care. Empirical studies are needed to investigate the effects of these perceived barriers and facilitators, for example regarding the availability of GPs out-of-hours, on the outcomes of palliative care.

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Summary

Chapter 1. General introduction

Palliative care, although only a small portion of the work of GPs, is considered by them as an important part of their work. Many patients with advanced and progressive illnesses spend most of the final year of their lives at home and medical care for these patients belongs to the domain of the GP. Traditionally, GPs in the Netherlands are family doctors; their care includes the care for the patient and his family and they (or their locums) are used to make house calls 24 hours a day, seven days a week.

The delivery of out-of-hours primary care, however, has changed radically over the past ten years. The use of GP co-operatives in which 40 to 250 GPs take care of populations up to 500.000 inhabitants, is now widespread which has had a negative impact on continuity of patient care. There are GPs who are permanently available for their patients in palliative care, also at night and at weekends, but many GPs leave at least part of this care up to the GP co-operative.

Concerns have been raised regarding the quality of care that complex, time-consuming, patients in palliative care receive during the out-of-hours period.

This thesis aims to contribute to an improvement of out-of-hours palliative care by GPs in the Netherlands by mapping the current quality of this care, highlighting problems in its current provision and making recommendations for improving practice.

Chapter 2. A focus group study on out-of-hours palliative care provided by GP co-operatives.

Our aim was to investigate the experiences of Dutch GPs with regard to the quality of out-of-hours palliative care provided by GP co-operatives and to identify elements of care that might need to be improved.

A main finding was that GPs considered the quality of out-of-hours palliative care in the Netherlands to be meagre. They regarded the services rendered by the GP-co-operatives to be designed more for acute medical problems rather than for palliative care needs. Three major issues influencing the quality of care were identified. The most important problem is the lack of adequate information sent by GPs to the GP co-operative. Secondly, the quality of out-of-hours palliative care is hampered by insufficient anticipatory care during office hours. Thirdly, because no policy on

palliative care has been developed by the GP co-operatives, calls from palliative care patients are not treated with priority and no additional time is available for home visits. Improvements could be made in particular if GPs anticipate problems that could arise after office hours and provide relevant information to the GP co-operatives.

Chapter 3. GPs' views on the transfer of information about terminally ill patients.

This study focused on the views of GPs working in a big city on the transfer of information for terminally ill patients from GP practices to GP co-operatives, and vice versa. It describes a retrospective survey carried out among all GPs in the region of Amsterdam using a web based questionnaire. We wanted to analyse the experiences of GPs with the transfer of information from two perspectives: from their position as a GP caring for their terminally ill patients, and from their perspective as a locum for the GP co-operative.

The majority of the GPs in Amsterdam who responded to our questionnaire reported that they transferred information about most of their terminally ill patients to the GP co-operative. However, in their role as locum, the GPs were not satisfied with the quality of the information that was transferred to the GP co-operative.

Both the GP and the locum agreed about the importance of transferring explicit clinical data. The locums valued the transfer of information about the patients' personal situation more than GPs.

The results suggest a difference in views on information transfer between the GP in his daily practice and the GP as locum in the GP co-operative. GPs apparently do not transfer information as often as they think they do, and the content is not as adequate as they would wish it to be.

Since 70% of all GPs stated that they were available for their terminally ill patients during the out-of-hours periods, this could be a reason for not transferring information.

Chapter 4. The out-of-hours palliative care provided by GP co-operatives and the role of transferred information.

We describe in this chapter the results of a retrospective study of all palliative care phone calls made during a one-year period to the GP co-operative in Amsterdam.

The aim of this study was to investigate the transfer of information about palliative care patients to a GP co-operative and the influence of that information on the care provided by the locums in the co-operative. We carried out an electronic search in the database of the GP co-operative, containing medical data on all calls and also all information transferred by GPs about their patients.

We found that the total number of palliative care phone calls was 0.75 % of all calls to the GP co-operative. Information was transferred by GPs in 25%, and when information was transferred the content consisted mainly of clinical data. Less information was transferred about the patient's wishes and the patient's personal situation.

For patients staying in residential care homes, information transfer took place in only 12%. The majority of all palliative care calls concerned terminally ill patients, and for 29% of these patients information was transferred.

When information was transferred fewer patients were referred to a hospital.

A conclusion is that despite the importance of continuity of care, GPs do not transfer information for the majority of their patients in palliative care.

Chapter 5. Systematic review on barriers and facilitators for GP-patient communication in palliative care.

The objective of this review was to identify barriers and facilitators for GP-patient communication in palliative care. Computerized searches to find empirical studies yielded 990 articles from seven databases. Finally twenty-two articles were included in our study, fifteen with a qualitative design and seven with a quantitative design. The main perceived barriers in communication were GPs' lack of availability, and patients' and GPs' ambivalence to discuss a 'bad prognosis'. The main perceived facilitators were GPs being available, initiating discussion about several end-of-life issues and anticipating various scenarios. The results of our review 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, and they should be more forthcoming to initiate honest discussions about the many relevant end-of-life issues. Empirical studies are needed to investigate the effects of these perceived barriers and facilitators on the outcomes of palliative care.

Chapter 6. A controlled trial to assess the effectiveness of introducing a handover form on palliative care.

In this chapter we describe a controlled trial among GPs. Its objective was to evaluate the effects of the introduction of an information handover form on the presence and the quality of information transferred in contacts with the GP co-operative for patients in palliative care. Two groups of GPs were formed, the experimental group received a structured handover form and an invitation for a training, the control group did not receive a handover form or training.

The main finding from this controlled trial is that the introduction of an information handover form combined with the training of GPs in transferring information on their patients in palliative care to the out-of-hours GP co-operative had a positive, statistically significant, influence on the number of contacts in which information on the palliative patient was available in the co-operative. However, despite the absolute increase of 9%, the percentage of contacts in which information was available remained low (30%) in the experimental group. The majority of GPs in the experimental group did not attend the training and received only the introduction letter and the handover form. There is no proof that the one-hour training session contributes to the effect.

Our intervention did an appeal on GPs to overcome the barriers in writing information transfers by convincing GPs of the importance of good anticipatory care and by giving them a standardised handover form. A factor that might have contributed to our positive result may be that the intervention was based on our prior needs assessment by means of focus group discussions.

The effect of the intervention, however, remained moderate. Our intervention focused mainly on the improvement of knowledge and skills. This is perhaps not enough to bring about a change in behaviour of the GPs.

Chapter 7. The evaluation of the introduction of an information handover form on patient outcomes in palliative care.

This study is the second part of the controlled trial, described above. We measured aspects of quality of care by telephone interviews with the involved patients in palliative care or with their family carers after their first contact with the GP co-operative of Amsterdam. We held 324 telephone interviews (42% of all first palliative

care contacts), from which 10% with patients, 60% with family and 30% with home care professionals.

No significant difference was found between the experimental and the control group when asked if locums were adequately informed about the patient's situation. Nevertheless, in a subgroup analysis according to family of patients, locums were significantly better informed after the intervention. There were also no significant differences between the experimental and the control group of GPs on other aspects of quality of care.

In both experimental and control group of GPs the patients and their carers are positive about the aspects of quality of care examined.

The reason that we found few differences on patient outcomes is related to the fact that there was only a small increase in information transfers in the experimental group compared to the control group.

Chapter 8. Information transfers for out-of-hours palliative care and effects on quality of care.

This study builds further on the evidence found in the trial. We compared contacts in which information transfer from the GP to the GP co-operative took place or not.

We analyzed 324 telephonic interviews, for 63 patients in palliative care the patient information was transferred, for 261 patients no information was transferred.

When information was transferred the patients or their carers find the locum more often well informed. They also state more often that there was improvement regarding the problem they called for. It is possible that a locum with information on the patients' situation is more able to handle a difficult situation properly. No difference was found when asked if the locum addressed the reason for encounter and in their trust regarding out-of-hours primary care.

These outcomes underline the importance of information transfer regarding patients with palliative care from GP to out-of-hours service providers.

Chapter 9. General discussion.

In this chapter the results of our research are linked together and discussed from different perspectives, taking the viewpoint of the GP, the patient and the GP co-

operative. Our results have implications for the improvement of practice and for the policy of GP co-operatives. A key finding is that the quality of out-of-hours palliative care benefits from information transfer. This needs to be encouraged, and the introduction of a handover form is useful but not enough. GPs should take an anticipatory approach to the provision of (out-of-hours) palliative care, which includes the transfer of information.

Samenvatting

Hoofdstuk 1. Inleiding.

Huisartsen beschouwen palliatieve zorg, hoewel het maar een klein deel van hun werk is, als een belangrijke taak. Veel ongeneeslijk zieke patiënten zijn het grootste deel van hun laatste levensjaar thuis en de medische zorg voor deze patiënten behoort tot het domein van de huisarts. Huisartsen in Nederland zijn van oudsher gezinsartsen, hun zorg strekt zich uit tot het hele gezin en zij, of hun waarnemers, maken thuisvisites zo nodig 24 uur per dag, zeven dagen per week.

De huisartsenzorg buiten kantooruren is echter in de laatste tien jaar sterk veranderd. Huisartsenposten, waarin 40 tot 250 huisartsen participeren die de zorg buiten kantooruren voor een populatie tot 500.000 inwoners verzorgen, zijn nu gemeengoed, en dit heeft een negatieve invloed gehad op de continuïteit van zorg.

Er zijn huisartsen die permanent beschikbaar zijn voor hun patiënten in palliatieve zorg, ook in de nacht en de weekenden, maar veel huisartsen laten ten minste een deel van deze zorg aan de huisartsenpost over.

Het is de vraag of de kwaliteit van zorg buiten kantooruren die patiënten met complexe, tijdrovende, palliatieve problemen krijgen voldoende is.

Dit proefschrift probeert een bijdrage te leveren aan een verbetering van de palliatieve zorg buiten kantooruren door de huidige kwaliteit van zorg in kaart te brengen, problemen binnen die zorg te belichten, en aanbevelingen te doen voor de praktijk.

Hoofdstuk 2. Een focusgroep onderzoek naar de palliatieve zorg buiten kantooruren door de huisartsenposten.

Ons doel was de ervaringen van Nederlandse huisartsen met betrekking tot de palliatieve zorg buiten kantooruren door de huisartsenposten te onderzoeken en te achterhalen wat er aan die zorg verbeterd kan worden.

Een belangrijke bevinding was dat huisartsen de kwaliteit van de palliatieve zorg buiten kantooruren 'mager' vinden. Ze vinden dat de zorg die door de huisartsenposten wordt verleend meer is toegesneden op acute medische problemen dan op palliatieve zorg. Drie grote problemen beïnvloeden de kwaliteit van zorg. Het belangrijkste probleem is het gebrek aan adequate informatie verstrekt door de huisarts aan de huisartsenpost. Op de tweede plaats wordt de kwaliteit van zorg buiten kantooruren negatief beïnvloed door het ontbreken van anticiperende zorg overdag. En op de

derde plaats is er geen beleid op het gebied van palliatieve zorg ontwikkeld door de huisartsenposten waardoor telefoontjes betreffende palliatieve zorg niet met voorrang behandeld worden en er geen extra tijd beschikbaar is voor visites. Verbeteringen kunnen met name bereikt worden als huisartsen leren om te anticiperen op problemen die buiten kantooruren kunnen ontstaan en relevante informatie naar de huisartsenposten sturen.

Hoofdstuk 3. De visie van huisartsen op de informatieoverdracht over terminaal zieke patiënt.

Deze studie betreft een onderzoek naar de visie van huisartsen uit een grote stad op de informatieoverdracht betreffende terminaal zieke patiënten van de huisartsenpraktijk naar de huisartsenpost en andersom. Het is een retrospectief onderzoek gehouden onder alle huisartsen in de regio Amsterdam met behulp van een webenquête. We analyseerden de ervaringen van huisartsen met informatieoverdracht vanuit twee perspectieven: vanuit hun positie als huisarts die zorgt voor zijn terminaal zieke patiënten, en vanuit hun positie als waarnemer voor de huisartsenpost.

De meerderheid van de Amsterdamse huisartsen die de enquête beantwoordde gaf aan dat ze voor het grootste deel van hun terminaal zieke patiënten informatie overdroegen aan de huisartsenpost. Maar in hun rol als waarnemer waren de huisartsen niet tevreden met de kwaliteit van de overgedragen informatie.

Zowel huisarts als waarnemer waren het eens over het belang van de overdracht van duidelijk klinische gegevens. De waarnemers stelden de overdracht van informatie over de persoonlijke situatie van de patiënt meer op prijs dan de huisartsen.

De resultaten suggereren een verschil in de visie op informatieoverdracht tussen de huisarts in zijn dagelijkse praktijken de huisarts werkend als waarnemer op de huisartsenpost. Huisartsen dragen kennelijk niet zo vaak informatie over als ze denken dat ze doen, en de inhoud is niet zo adequaat als ze zouden willen.

Een belangrijke reden waarom huisartsen geen informatie overdragen zou kunnen zijn dat 70% van de huisartsen stelt zelf beschikbaar te zijn voor terminaal zieke patiënten buiten kantooruren.

Hoofdstuk 4. De palliatieve zorg buiten kantooruren door de huisartsenpost en de rol van overgedragen informatie.

In dit hoofdstuk beschrijven we de resultaten van een retrospectieve studie van alle telefoontjes met betrekking tot palliatieve zorg gedurende een jaar met de huisartsenpost van Amsterdam. Het doel van de studie was de informatieoverdracht over patiënten met palliatieve zorg naar een huisartsenpost te onderzoeken en de invloed van die informatie op de door de waarnemers van de post geleverde zorg.

We screenen elektronisch de database van de huisartsenpost die alle medische gegevens over alle telefoontjes bevat en ook de informatie die door huisartsen over hun patiënten wordt overgedragen.

Het totale aantal telefoontjes betreffende palliatieve zorg bedroeg 0,75% van alle telefoontjes met de huisartsenpost. Informatie werd door huisartsen overgedragen in 25%, en als er informatie werd overgedragen betrof de inhoud vooral klinische gegevens. Minder informatie werd overgedragen over de wensen van de patiënt en zijn persoonlijke situatie.

Voor patiënten die in een verzorgingshuis verbleven werd maar in 12% informatie overgedragen. De meerderheid van alle telefoontjes betreffende palliatieve zorg betrof terminaal zieke patiënten, en voor 29% van deze patiënten werd informatie overgedragen.

Als er informatie was overgedragen werden er minder patiënten naar een ziekenhuis verwezen.

Een conclusie is dat ondanks het belang van continuïteit van zorg, huisartsen voor de meerderheid van hun patiënten in palliatieve zorg geen informatie overdragen.

Hoofdstuk 5. Systematische review betreffende huisarts-patiënt communicatie in de palliatieve zorg.

Het doel van deze review was het identificeren van belemmerende en bevorderende factoren voor de huisarts-patiënt communicatie in de palliatieve zorg. Een elektronische zoektocht naar empirische studies leverde 990 artikelen op uit zeven databases. Uiteindelijk werden tweeëntwintig artikelen geïncludeerd in onze studie, vijftien met een kwalitatief design en zeven met een kwantitatief design.

De belangrijkste belemmerende factoren in de communicatie waren een gebrek aan beschikbaarheid van de huisarts, en de ambivalentie bij zowel patiënt als huisarts om

te praten over een 'slechte prognose'. De belangrijkste bevorderende factoren waren de beschikbaarheid van de huisarts, zijn initiatief om diverse levenseinde vragen aan te kaarten en zijn anticiperen op verschillende scenario's. De resultaten van onze review suggereren dat, wanneer huisartsen effectief willen communiceren in de palliatieve zorg, ze beschikbaar moeten zijn voor hun patiënten, ze een open houding en een grote betrokkenheid moeten tonen, en dat ze meer initiatief moeten tonen om eerlijke discussies aan te gaan over de vele relevante levenseinde vragen. Empirische studie is nodig om de effecten van deze belemmerende en bevorderende communicatie factoren op de kwaliteit van palliatieve zorg na te gaan.

Hoofdstuk 6. Een gecontroleerde trial om het effect van de introductie van een overdrachtsformulier voor palliatieve zorg te onderzoeken.

In dit hoofdstuk beschrijven we een gecontroleerde trial onder huisartsen. Het doel was de evaluatie van het effect van de introductie van een overdrachtsformulier op de aanwezigheid en de kwaliteit van overgedragen informatie als patiënten met palliatieve zorg naar de huisartsenpost belden. Er werden twee groepen huisartsen gevormd, de experimentele groep kreeg een gestructureerd overdrachtsformulier en een uitnodiging voor een training, de controle groep kreeg geen formulier en geen training.

De belangrijkste bevinding van deze trial is dat de introductie van het overdrachtsformulier, in combinatie met de training van huisartsen in het overdragen van informatie over hun palliatieve patiënten naar de huisartsenpost, een positieve, statisch significante, invloed had op het aantal contacten waarin informatie over de patiënt in palliatieve zorg op de huisartsenpost aanwezig was.

Echter, ondanks de absolute toename van 9%, bleef het totale percentage van contacten in de experimentele groep waarin informatie aanwezig was laag (30%).

De meerderheid van de huisartsen in de experimentele groep maakte geen gebruik van de training en ontving alleen de introductiebrief en het overdrachtsformulier. Er is geen bewijs dat de een uur durende trainingssessie aan het effect bijdroeg.

Onze interventie deed een beroep op huisartsen om de obstakels om een overdracht te schrijven te negeren door ze te overtuigen van het belang van anticiperende zorg en door ze een gestandaardiseerd overdrachtsformulier aan te bieden. Een factor

die kan hebben bijgedragen aan het positieve resultaat is dat deze interventie was gebaseerd op ons eerdere behoefte onderzoek met focusgroepen.

Het effect van de interventie blijft echter matig. De interventie was vooral gebaseerd op een verbetering van kennis en bekwaamheid. Dat is misschien niet genoeg om een gedragsverandering bij huisartsen te bewerkstelligen.

Hoofdstuk 7. De evaluatie van de introductie van een overdrachtsformulier op het effect bij patiënten in palliatieve zorg.

Dit onderzoek is het tweede deel van de gecontroleerde trial, zoals hierboven beschreven. We maten aspecten van de kwaliteit van zorg door telefonische interviews met de betrokken patiënten in palliatieve zorg of met hun verzorgers na hun eerste contact met de huisartsenpost in Amsterdam. We hielden 324 telefonische interviews (42% van alle eerste palliatieve contacten), waarvan 10% met patiënten, 60% met familie en 30% met zorgprofessionals.

Er werd geen significant verschil tussen de experimentele en de controle groep gevonden als er gevraagd werd of de waarnemers adequaat geïnformeerd waren over de situatie van de patiënt. Overigens vonden we in een subgroep analyse dat volgens de familie van de patiënten de waarnemers wel significant beter geïnformeerd waren. Er waren ook geen significante verschillen betreffende andere kwaliteits aspecten.

Zowel in de experimentele als in de controle groep van huisartsen waren de patiënten en hun verzorgers positief over de onderzochte aspecten van kwaliteit van zorg.

De reden dat we weinig effect vonden op patiënt niveau is gerelateerd aan het feit dat er maar een kleine toename was in de informatieoverdracht in de experimentele groep vergeleken met de controlegroep.

Hoofdstuk 8. Informatieoverdracht voor palliatieve zorg buiten kantooruren en effecten op kwaliteit van zorg.

De laatste studie beschreven in dit proefschrift bouwt voort op de gegevens gevonden in ons trial onderzoek. We vergeleken contacten waarin informatie van de huisarts naar de huisartsenpost was overgedragen met contacten waarin dat niet was gebeurd. We

analyseerden 324 telefonische interviews. Bij 63 patiënten met palliatieve zorg was informatie overgedragen bij 261 patiënten niet.

Als er informatie was overgedragen vonden de patiënten of hun verzorgers de waarnemer vaker goed geïnformeerd. Ze vinden dan ook vaker dat er verbetering is opgetreden betreffende het probleem waar ze voor belden.

Het is mogelijk dat een waarnemer met informatie over de situatie van de patiënt beter in staat is om in een moeilijke situatie adequaat te handelen.

Er werd geen verschil gevonden op de vraag of de waarnemer de reden voor het bezoek goed besprak en wat betreft het vertrouwen in de palliatieve zorg buiten kantooruren.

Deze uitkomsten onderstrepen het belang van informatieoverdracht voor patiënten met palliatieve zorg van de huisarts naar de huisartsenpost.

Hoofdstuk 9. Algemene discussie.

In dit hoofdstuk worden de resultaten van ons onderzoek samengevat en bekeken vanuit verschillende perspectieven: vanuit het standpunt van de huisarts, de patiënt en de huisartsenpost. Onze resultaten hebben implicaties voor het verbeteren van de dagelijkse praktijk van de huisarts en voor het beleid van de huisartsenposten. Een belangrijke bevinding is dat de kwaliteit van de palliatieve zorg buiten kantooruren verbetert door informatie overdracht. Dit moet aangemoedigd worden, en de introductie van een overdrachtsformulier is nuttig maar niet genoeg. Een anticiperende houding in de palliatieve zorg is van belang voor huisartsen, en daarbij hoort het tijdig schrijven van een overdracht.

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De inspiratie voor dit proefschrift komt voort uit mijn jarenlange werk als huisarts met patiënten die in de laatste fase van hun leven thuis waren en mede door mij verzorgd werden. Deze zorg is, zoals ergens in dit proefschrift staat, een rijke intensieve ervaring en al wordt er dan veel van de huisarts gevraagd, hij krijgt ook veel. Veel patiënten en hun familie staan me scherp voor de geest en ik ben hun zeer dankbaar dat ze hun emoties en gedachten met me hebben gedeeld.

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About the author

Bart Schweitzer was born on May 29, 1947 in Enschede, the Netherlands. He graduated from secondary school (Aartsbischoppelijk Klein Seminarie, Apeldoorn) in 1965. In 1974 he graduated from the School of Medicine, Radboud University, Nijmegen. Together with friends and colleagues he founded a health centre in Diemen where he worked as a general practitioner for 37 years.

He was involved in the vocational training for general practice at the University of Amsterdam. From 1990-2001 he was President of the Amsterdam Association of General Practitioners, and from 2001-2008 President of the Amsterdam Department of the Royal Dutch Medical Association. He is a member of the Central Disciplinary Board for Professions in Individual Health Care and member of the Board of SWG Arts en Werk, an employment agency for the medical profession. Since 2001 he is Chairman of the Board of Hospice Veerhuis in Amsterdam.

He started a research project on information transfer in palliative care in 2005, which was acknowledged as a PhD project and financially supported by Agis Health Insurances.

He is recently involved in promoting the PaTz project (Palliative Homecare) among general practitioners and districtnurses in the Netherlands.