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Transfer of information on palliative home care during the out-of-hours period

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Background. Continuity of end-of-life care for patients receiving palliative care is an important challenge for out-of-hours services in general practice.

Aim. To investigate how frequent information is transferred on patients receiving palliative care from GPs to the out-of-hours services, to explore the perceptions of GP's on this information transfer and to study the relation between information transfer and the used GP information systems.

Methods. This is a mixed-method design study. The frequency of information transfer to the out-of-hours services was investigated by analyzing a regional out-of-hours database. Barriers and promoting factors for this transfer of information were investigated by using semi-structured interviews among a purposive sample of GPs from the same region. The relation between information transfer and the GP information system was investigated by a postal questionnaire in a national random selection of GPs.

Results. When a palliative patient contacted the out-of-hours service, for 20% of these patients, a transfer of information was available and only half of these transfers included an anticipating end-of-life plan. All interviewed GPs considered continuity of care for these patients as important. However, some doubted whether a transfer of information is relevant for the quality of care. There was no relation between the information transfer and the used GP information systems.

Conclusion. For only a minority of patients receiving palliative care, a transfer of information including an anticipating management plan was present. There is a large variation in the opinions of GPs on how to organize continuity of end-of-life care.

Keywords. Family physicians, GP information system, out-of-hours care, palliative care, patient care planning.

Background

About a quarter of patients with end stage disease die at home in most Western countries.^{1,2} Terminal home care is of great importance to the majority of these patients and their families.^{3,4} GPs play a critical role in providing care for these end-of-life patients; patients who died at home not only use more homecare but also have frequent GP home visits.⁵ In a Dutch registration study, the mean number of GP visits in the last week of life was 5.1 for home visits and 4.4 for care home visits.⁶

Patient's accessibility to GPs and the continuity of care are considered to be good indicators for the quality of end-of-life care.^{7,8} In the past, continuity of care was often guaranteed by a small group of GPs and information about care for patients receiving palliative care was transferred by direct personal

contact. Nowadays, in The Netherlands, since 1998, out-of-hours services are organized in regional health-care organizations, providing care during two-thirds of the time (on weekdays from 5 p.m. till 8 a.m. and during the weekends).⁹ This system does not guarantee the continuity of care by personal contact between GPs. Lack of personal contact between professional caregivers might influence the continuity of end-of-life care for the vulnerable group of patients receiving palliative care.^{10,11} A UK study showed that where three-quarters of urban GPs were willing to make themselves available during out-of-hours for palliative care patients as death approached, a quarter relied on local after-hours GP cooperative.¹² In this context, an accurate transfer of information between GPs and their out-of-hours service seems essential to ensure continuity of care.¹³ In The Netherlands, most GPs use a GP information

system and an electronic medical record in their daily practice.^{14,15} There are several GP information systems to support the use of electronic medical records, and all systems have their own strength to support transfer of information.¹⁶

In a retrospective web-based questionnaire sent to all 424 GPs in the Amsterdam region, it was found that though most GPs reported that they transferred information about their terminally ill patients to the GP cooperative, only 21% of the GPs were satisfied with the quality of the information transferred.¹⁷ As the results of this study were based on a self-reported questionnaire, the aim of the present study was to investigate the current degree of transfer and the content of the information that was transferred on patients receiving palliative care from GPs to the out-of-hours services on actual behaviour and to explore the experiences and perceptions of the transfer of information in a purposive sample of GP's from the same region. In addition, the relation between the transfer of information and used GP information system was assessed in a random national selection of Dutch GPs.

Methods

This is a mixed-method design study. To assess whether the information on patients receiving palliative care was transferred from the own GP to the out-of-hours service, the frequency of transfer and the content of the information from the GPs to the local out-of-hours service was studied, using the database of an out-of-hours service. All contacts during a period of 3 months were analysed. To explore the experiences and perceptions of the transfer of information, a random selection of 19 GPs participating in this regional out-of-hours service was interviewed by the use of semi-structured interviews by IMVK. By using a postal structured questionnaire, the relation between the degree of information transfer and several handover systems throughout The Netherlands was assessed.

Palliative care

In this study, palliative care was defined according to the World Health Organization.¹⁸ Palliative care is a care that improves the quality of life of patients and their families facing life-threatening illness. With palliative care, particular attention is given to the prevention, assessment and treatment of pain and other symptoms and to the provision of psychological, spiritual and emotional support.

Local setting

In The Netherlands, there are a total of 52 GP out-of-hours services (http://www.vhned.nl/site/uw_huisartsenpost/linkshaps.html). These services are performed

by regular GPs. Each GP is supposed to work on the average 220 hours annually in such an out-of-hours service. This study was performed in the area of Groningen, where one out-of-hours service exists, offering out-of-hours medical care for patients living in the province of Groningen and the North of Drenthe (605 000 inhabitants). Approximately, 300 GPs are connected to this GP service Groningen. All contacts with this GP service are registered in a database by doctors and nurses. In this database, for each contact, the following is registered: name of patient, sex, date of birth, postal code, own GP, date and time of contact, type of contact (advice give by nurse, contact with GP by telephone, visit at out-of-hours service or GP home-visit) and notes on content of each type of contact. If a patient is transferred to the out-of-hours service, the information is entered electronically by the GP or the GP sends a fax to the out-of-hours service and a nurse enters the information to the database.

Transfer of information on patients receiving palliative care for the out-of-hours services

To assess whether the information on patients receiving palliative care was transferred during out-of-hours services from the own GP to the GP cooperative, all contacts ($n = 34\ 685$) in the study period January through March 2006 were analysed. A contact was supposed to concern a palliative patient if one of the search terms as presented in Table 1 was present in the registration of that contact. Firstly, we decided to include visits and telephone consultations but not consultations in the doctors' surgery since we assumed that GP contacts with patients receiving palliative care mostly consist of home visits. The annotations of the visits and GPs' telephonic advices by phone were examined manually. In a second step, the same search was done electronically. In the third step, the electronic search was repeated on all contacts. In this way, the probability to find all contacts with patients receiving palliative care was enhanced as well as the validity of our search. All the selected contacts between patients receiving palliative care and the GP cooperative were read for the presence of a handover. If there was any transfer of information, the presence of one of the following aspects was noted: diagnosis, prognosis, patient's history, medication use, proposed management and accessibility to the own GP. If

TABLE 1 *Terms that were used to search for the presence of a contact with a palliative patient*

▶ Abstinence policy	▶ End stage	▶ Non-curable
▶ Terminal	▶ Funeral prepared	▶ Palliative
▶ Euthanasia request	▶ Inoperable	▶ Poor prognosis
	▶ Metastasis, meta's	▶ Terminal/terminally
	▶ No more hospital	▶ Incurable

information on all aspects was available, an anticipatory management plan was considered to be available.

Personal experiences of GPs with the transfer of information on patients receiving palliative care

To explore the experiences with and perceptions of the transfer of information, a purposive sample of GPs was drawn from a database including all GPs connected to the GP cooperative Groningen, after excluding locums. This database contained information about the GPs' age and place of practice. From the first part of this study, we obtained information about the GPs who made a transfer to the GP cooperative Groningen in the period of January through March 2006 and those who did not. The GPs were stratified by age (under or over 45 years), place of practice (city of Groningen or countryside) and transferring information to the out-of-hours service (yes or no in the 3-month period; see Table 2). It was assumed that these factors could possibly affect the rate of the transfer of information to the out-of-hours service. From each stratum, three GPs were randomly selected and approached by telephone. Nineteen of 24 GPs agreed to be interviewed.

The interviews. The interview was a semi-structured interview in which standardized questions were posed by the interviewer (IMVK). In the interview, barriers and promoting factors concerning the transfer of information on patients receiving palliative care to the GP cooperative were explored. The interview included questions about palliative care and about the reasons why GPs did or did not transfer patient information to the GP service. In addition, two questions were included about how the palliative care was organized for the last palliative patient they had been confronted within their own practice and during the out-of-hours services. The aim of these two questions was to diminish the amount of social acceptable answers. By asking these two questions, information was obtained about

TABLE 2 Overview of the characteristics of the GPs related to the out-of-hours service: all GPs and GPs invited to participate in the interviews

	Transfer to out-of-hours service	Age (years)	Practice in city?	Number of GPs	Number of recruited GPs
Group 1	No	<45	No	9	2
Group 2	No	<45	Yes	3	2
Group 3	No	>45	No	57	3
Group 4	No	>45	Yes	13	2
Group 5	Yes	<45	No	7	3
Group 6	Yes	<45	Yes	2	2
Group 7	Yes	>45	No	16	2
Group 8	Yes	>45	Yes	9	3

their actions, not only about their opinions. For an outline of the interview, see Table 3. The interview was piloted first on three GPs. These interviews were not included in the analysis. The interviews took place in the doctor's practice and lasted ~30 minutes. After consent, which was given by all GPs, the interviews were audio-recorded.

Analysis. Interviews were fully transcribed and returned to the participants for corrections. A descriptive analysis of interview data was performed.^{19,20} The steps to analyse the data collected in this study were data reduction, data display and conclusion drawing/verification. Analysis involved reading each transcript and identifying specific themes. First, one researcher (IMVK) organized transcribed text into display tables. Next, two researchers (IMVK and GHDB) reviewed these tables and identified thematic patterns. With the use of a data matrix, descriptive statistics of the themes were generated. For the major themes, summaries were written and illustrated with quotes. In this way, a cross-case approach with a variable-oriented strategy was used in this analysis. After 19 interviews, they concluded that saturation had been obtained because no new barriers and promoting factors were raised and that there was no need to select more GPs for participation. A descriptive analysis of interview data was performed. After 19 interviews, it was concluded that saturation had been obtained because no new barriers and promoting factors were raised and that there was no need to select more GPs for participation.

TABLE 3 An outline of the interview

Part I: General questions
GP and practice characteristics
Experience and education on palliative care
Part II: Palliative care and transfer of information: organization and opinions
How is the out-of-hours palliative care organized in your practice?
How is the transfer of information for palliative care organized in your practice?
How are your experiences with information transfer to the GP cooperative?
What are promoting factors to transfer information to the GP cooperative?
What are barriers to transfer information to the GP cooperative?
Part III: Your last patient receiving out-of-hours palliative care in your own practice
Please tell your experiences with this patient?
Did you transfer information for this patient?
What type of information did you transfer?
Which room there was for improvement?
Part IV: Your last patient receiving out-of-hours palliative care when you were working for the GP cooperative
Please tell your experiences with this patient?
Was there a transfer of information for this patient?
What type of information was transferred?
Which room there was for improvement?

The relation between transfer of information and the GP information system

The main aim of this part of the study was to assess the incidence of transfer of information in relation to the GP information system in use in a given general practice. For that purpose, a questionnaire was developed. From each of the 52 out-of-hours services in The Netherlands, 3 GPs were randomly selected and received a questionnaire (in total 156). Non-responders received one reminder.

Questionnaire. The information from the interviews was used to formulate questions in the questionnaire. This included questions on three topics: (i) general characteristics of the GPs, their practice, the organization of the out-of-hours service and their own accessibility for terminally ill patients; (ii) the incidence and content of transfer of information during the out-of-hours time; (iii) the GP information system in use in their practice and their experiences with the information transfer. Besides pre-structured answers, there was the opportunity to write down any comments. For an outline of the questionnaire, see Table 4.

Analysis. The correlations between the GPs' transfer of information, the handover system in use and the characteristics of GPs, their practices and the organization of the out-of-hours services were tested with Mann–Whitney *U*-tests or Kruskal–Wallis tests. *P*-values of <0.05 were considered as statistically significant. The analyses were done by using SPSS 14.01. Open questions in the questionnaire were summarized and quotes were used to illustrate.

Results

Transfer of information about patients receiving palliative care to the out-of-hours services

In the study period of 3 months, there were 722 contacts (7.5%) concerning a palliative patient. These contacts were related to 338 patients receiving

TABLE 4 *An outline of the questionnaire*

Part I: General questions
GP and practice characteristics
Use of GP information system?
Are you participating in a GP cooperative?
Part II: Organization of out-of-hours care
How is the out-of-hours palliative care organized in your practice?
Part III: Transfer of information for palliative care
Handover system in use?
Experiences with handovers supported by GP information system?
Content of handover?

palliative care from 183 different GPs. The characteristics of these patients and their reasons for encounter are presented in Table 5. The median age of the patients was 77 years of age (range: 23–103), 48% was male. For 80% of the patients (*n* = 243), a diagnosis was known. Cancer was the most common diagnosis. The most common reason for encounter was pain, followed by respiratory symptoms and anxiety, restlessness and feelings of confusion.

For 270 of 338 patients receiving palliative care (79.9%), there were no handovers present at the moment they contacted the out-of-hours services. Fifty-four of 183 GPs (29.5%) had provided a transfer of information to the services. These were related to 68 patients. For these patients, 107 handovers were present. In 92.5% of these handovers, the diagnosis was mentioned. In less than half of the handovers, an anticipating management plan was present (see Table 6). In 18 transfers related to 13 patients, there was information on when to transfer a patient to the hospital. In four transfers related to three patients, there was information on wishes regarding resuscitation.

Personal experiences of GPs with the transfer of information on patients receiving palliative care

The interviews showed a great variety in the way GPs handled the transfer of information about patients receiving palliative care. Less than a half of the GPs (41%) made a handover to the out-of-hours service when they expected the patient to enter the final stage of disease and because they expected the chances for the patient to contact the service were increasing. They thought of their fellow GPs who were on duty

TABLE 5 *Patients and consultations included in the study (338 patients and 722 consultations)*

Age (years)	Median 77.1; range: 23.4–103
Male, % (<i>n</i>)	48 (162)
Diagnosis (338 patients), % (<i>n</i>)	
Lung cancer	15 (49)
Colorectal cancer	9 (29)
Breast cancer	5 (18)
Other cancers	24 (83)
Cancer unspecified	8 (26)
COPD	3 (11)
Heart failure	5 (17)
Other, no cancer	3 (10)
No diagnosis given	28 (95)
Reason for consultation (722 consultations), % (<i>n</i>)	
Pain	23 (167)
Respiratory symptoms	22 (162)
Anxiety, restlessness and feelings of confusion	19 (141)
Questions about medication	11 (77)
Gastrointestinal symptoms	8 (57)
Organizational problems	4 (25)
Psychosocial problems	2 (15)
Other	12 (86)

TABLE 6 *Items mentioned in the handovers*

Item	Percentage noticed in handover (of 107 handovers)
Diagnosis	92.5 (99)
Prognosis	36.4 (39)
Patient history	28.0 (30)
Medication	63.6 (68)
Care plan	48.6 (52)
Accessibility own GP	6.5 (7)

and stated: 'If you were in that situation with a patient—you would like to have some information too'. An argument that was frequently stated was that they not wanted their patients to have to tell the story to another doctor all over again.

From the 19 interviewed GPs, 13 (68%) gave their mobile phone number to the patient: 'If the patients' situation is too complex, I'd rather go myself'. Others had objections against being on call for 24 hours: 'I work long and hard enough' and 'it's limiting my freedom', but also: 'I don't want to give false promises because in some situations I will not be available'.

Another barrier to make a transfer to the out-of-hours service was technical: 'the internet connection doesn't work properly', 'I don't have enough lines to fill in my text' and 'I don't know how to make a digital handover'. Another often mentioned barrier was the time factor, making a transfer of information to the out-of-office service was considered to be too time-consuming.

Some GP's had doubts about the usefulness and necessity of handovers. Most of the interviewed GPs were participating in the out-of-hours services and when they were on duty they did not see a great need for handover notes: 'patients and family often tell their story in an excellent manner'.

Another reason mentioned for not making a transfer was that death was not always expected. As one GP in our study mentioned: 'I did not yet expect the patient to contact the out-of-hours service' as a reason for not making a handover of a patient.

As promoting factors for the transfer of information were mentioned: 'transferring information is easy and it provides continuity of care', and 'by transferring my patients to the out-of-hours service—I create free time'.

The relation between transfer of information and the used GP information system

Eighty-one GPs (52%) responded on the questionnaire. These 81 GPs represented 44 of the 52 (85%) out-of-hours services in The Netherlands. About three quarters (76%; 62/81) of the GPs stated that they transferred information to the out-of-hours services for the majority of patients receiving palliative care. Most of the GPs (61%, $n = 49$) transferred the

information by fax, while 20% ($n = 16$) used the digital handover system of the GP information system.

In general, we did not find a relation between the information transfer and the GP information system used. However, GPs were more satisfied when they had a personal information transfer with a colleague (e.g. by telephone) or when they had access to the electronic medical records of a colleague (Kruskal–Wallis test: $P < 0.001$). Some GPs considered the access to the electronic medical record of a colleague as a transfer of information: 'Other GPs can look in my patient files, so a separate transfer of information is not necessary', 'Transfer of information means all information has to be available at the out-of-hours service, this is feasible with the use of the electronic medical record'.

A few recommendations from the GPs to improve the transfer of information were: 'To provide a transfer more often and by using a fixed form', 'A type of checklist would be convenient for the GP'. There were also GPs who were satisfied: 'I am satisfied, the transfer of information is not the problem, but the commitment to transfer. It's fine by mail or fax'.

Discussion

In 20% of the out-of-hours services, a transfer of information was available when a palliative patient contacted the out-of-hours service. When a transfer was available, in only half of the cases an anticipating management plan was present. All the interviewed GPs considered continuity of care as an important issue. However, some doubted whether a transfer of information is of great relevance. This opinion is not dependent on the used GP information system.

In the UK, Burt *et al.* found in 1.2–13% transfer of information of patients receiving palliative care to various out-of-hours services.^{10,13} Munday *et al.*²¹ found that a handover was present in 21% of the patients who contacted the out-of-hours service, which is comparable to our findings. One of the reasons not to transfer information on a patient and preparing an anticipating management plan is that, although doctors commonly have to prognosticate, it is very difficult to make an accurate prognosis for terminally ill patients. Systematically, doctors are too optimistic about this prognosis.^{22–24}

When there was a transfer available, for only half of the related patients an anticipating management plan was part of it. Such a care plan is useful in preparing for scenarios regarding palliative care.²⁵ An anticipating management plan ideally includes a description of the patients' understanding of their medical history and condition; values; preferences; and personal, family, and community resources. It may also include an advance health-care directive. The early identification

and recognition of end-of-life care choices may have a very positive influence on the quality of life and the experiences during the dying process.^{26,27}

Due to the retrospective character of this part of the study, the greatest limitation of a search in the database of the local out-of-hours service is related to the words used for the definition of palliative care and the words used by the GPs. The reliability of the first part of our investigation is enhanced by the search strategy, manually as well as electronically, which might have optimized finding the contacts with patients receiving palliative care. Another limitation is that there was no information about the availability of the patient's own GP. In a previous publication, the mobile number of the GP was transferred for 10% of the patients in the palliative phase.²⁸

In the second part of this research, the interviews were audio-recorded and were all held by the same person, which provided accuracy. On the other hand, this can also cause an interviewer bias. There is a chance that some responders could have felt some 'social pressure' to give the 'social desired' answer to certain questions. To prevent this bias, we asked the GPs to reflect on specific situations in their daily practice. For example: 'Did you make a handover of the last palliative patient in your practice?' The conclusions based on the interviews were drawn after discussing the interviews in detail with the different researchers, which increased the reliability of this research.

The response of the questionnaire in the third part was 52%, so responder bias cannot be excluded. On the other hand, 44 of the 52 (85%) different out-of-hours service in The Netherlands were represented in our study. We did not find a relation between transfer of information and the several GP information systems throughout The Netherlands.

Some doctors considered the availability of an electronic medical record as a transfer of information. However, terminal care plans are hardly ever recorded in these electronic records.²⁹ In our study, GPs recommended a checklist to be sent electronically or by fax to the out-of-hours services. This is in line with the findings in England, where a simple handover form sent by fax to the out-of-hours service resulted in a number of handovers from 21% to 55%.²¹

In a recent published perspective of the Dutch General Practitioners on palliative care, it is stated that (i) GPs are especially suited to provide palliative care; (ii) palliative care is 24 hours care and it is preferred that the own GP is the palliative care provider; (iii) an anticipating management plan is an essential part of palliative care (<http://nhg.artsennet.nl/actueel/Nieuwsartikel/Nieuw-NHGStandpunt-Palliatieve-zorg.htm>).

In conclusion, for only a minority of patients receiving palliative care, a transfer of information including an anticipating management plan was present at the

out-of-hours services. There is a large variation in the opinions how to organize continuity of palliative care.

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