

Good end-of-life care according to patients and their GPs

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ABSTRACT

Background

Most patients prefer to die at home, where a GP provides end-of-life care. A few previous studies have been directed at the GPs' values on good end-of-life care, yet no study combined values of patients and their own GP.

Aim

To explore the aspects valued by both patients and GPs in end-of-life care at home, and to reflect upon the results in the context of future developments in primary care.

Design of study

Interviews with patients and their own GP.

Setting

Primary care in the Netherlands.

Method

Qualitative, semi-structured interviews with 20 GPs and 30 of their patients with a life expectancy of less than 6 months, and cancer, heart failure or chronic obstructive pulmonary disease as underlying disease.

Results

Patients and GPs had comparable perceptions of good end-of-life care. Patients and GPs identified four core items that they valued in end-of-life care: availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention and continuity of care.

Conclusions

Future developments in the organisation of primary care such as the restriction of time for home visits, more part-time jobs and GP cooperatives responsible for care after office hours, may threaten valued aspects in end-of-life care.

Keywords

general practice; palliative care; patient care; qualitative research; quality of health care.

INTRODUCTION

In Western countries most people prefer to remain at home during the last part of their life, surrounded by their relatives.¹⁻³ In the Netherlands, health care is characterised by its strong emphasis on primary care: almost 100% of the inhabitants have their own GP who is the central professional in the management and coordination of the patient's treatment.⁴ When needed, the GP initiates care at home by other professionals, like district nurses who provide nursing care, and home help for personal care. Almost 60% of patients with non-acute illnesses die at home,⁵ and there is general consensus that end-of-life care should be provided in the patient's home, if possible.⁶ The aging population and the growing number of non-acute deaths are expected to increase the contribution GPs must make to meet the rising needs for end-of-life care.^{7,8}

The World Health Organisation promotes palliative

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care as the preferred approach to improve the quality of life of terminally ill patients and their families.⁹ Several studies have evaluated the quality of care and the needs of terminally ill patients in non-primary care settings. Qualitative and quantitative studies showed that terminally ill patients considered emotional support, pain and symptom management, and accessibility as important aspects of the skills needed by physicians to providing end-of-life care.^{10–12} In the Netherlands, two studies incorporated qualitative interviews to investigate the experiences of patients with cancer who received end-of-life care at home. In these studies it was found that pain and symptom management, attention, involvement, and availability were important aspects of good end-of-life care.^{5,13} Few studies have focused on the viewpoint of GPs with regard to the quality of end-of-life care, and those that did, were based on structured questionnaires. Hence, the aspects that were rated did not emerge from the GP's perspective. The GPs in these studies experienced care for dying people as rewarding and important.¹⁴ To our knowledge, no single study has yet combined the values of both patients and their own GP with regard to end-of-life care.

In Europe, the structure and goals of primary care are changing: the population is ageing with a growing demand for health care on the one hand, while the relative number of caregivers decreases. GPs will work more frequently in primary care cooperatives and more GPs will work part-time.¹⁵ These developments may threaten the core values of end-of-life care at home.

In order to investigate the nature of these core values of patients and their GPs with regard to end-of-life care, we conducted a qualitative study in primary care in which the viewpoints of both patients and their GPs regarding the quality of end-of-life care at home were described. The goal of this study was to explore the aspects valued in end-of-life care at home by patients

and their GPs, and to reflect upon the results in the context of future developments in European primary care that may threaten these valued aspects.

METHOD

GP selection

A total of 17 GPs who were following an advanced postgraduate training in end-of-life care, organised by the Dutch College of General Practitioners,^{16,17} agreed to participate in this study. To represent the opinions of GPs who were not trained in end-of-life care, and the opinions of their patients, we extended our sample: the GPs who agreed to participate were asked to invite a colleague of theirs in the same district with no specific interest in end-of-life care to participate. A total of 14 GPs with no specific interest in end-of-life care agreed to participate, resulting in a total number of 31 participating GPs.

Patient selection

After enrolment in the study, the GPs were asked to select for inclusion the first patient they encountered in their practice who met the following inclusion criteria: (1) a life expectancy of less than 6 months; (2) cancer, heart failure or chronic obstructive pulmonary disease (COPD) as underlying disease; (3) the GP was (one of) the primary caregiver(s), and (4) the patient had adequate command of the Dutch language. If for any reason, a GP did not approach a patient who met the inclusion criteria, the GP was asked to give the reasons for not doing so. If a patient met the inclusion criteria, the GP briefly described the study to this potential participant, and handed over an envelope containing an information sheet. The investigators then made an appointment with the patient to arrange an interview. Before the interview started, the patient was asked to give informed consent. If the investigators could not make an appointment because the patient could not, or did not want to participate, the GP was asked to select the next patient who met the inclusion criteria. To include the potential range of opinions of patient views with different illnesses, we aimed to interview patients with the three most frequently presented terminal diseases in general practice: cancer, heart failure, and COPD,⁵ with both male and female patients in each group.

Interviews

Semi-structured, in-depth interviews were carried out in the patients' home. Patients were interviewed for 45–80 minutes guided by a topic list (Box 1). During most of the interviews a partner or family member was present, and their comments were welcomed and included in the data. No information from the patient interview was made known to the GP. Approximately 2 weeks after the patient interview the GP was

How this fits in

Patients prefer to die at home, where GPs provide end-of-life care. Emotional support, pain and symptom management and accessibility are often considered as important physician skills by terminally ill patients. Few previous studies were directed at the GPs' viewpoint and no study combined values of both patients and their own GP on end-of-life care. Patients and GPs had comparable visions on aspects valued in end-of-life care. The valued aspects that emerged were availability of the GP for home visits and after office hours, medical competence and cooperation with other professionals, attention and continuity of care.

Box 1. Topics of the interview.**Patient interview**

- ▶ Disease history
- ▶ Experience with care at home performed by the GP
- ▶ Good care performed by the GP
- ▶ The ideal GP

GP interview

- ▶ Disease history
- ▶ Experience with care at home for this patient
- ▶ Good care for this patient
- ▶ Good end-of-life care by the GP in general
- ▶ What patients had not been approached and why

interviewed according to a similar topic list. All interviews were audiotaped, transcribed verbatim, and rendered anonymous. The investigators read the transcript while listening to an interview to ensure textual accuracy. The transcripts of the interviews then served as data.

The interviews were performed by an academic researcher/pharmacist and a health sciences student. Prior to the interviews, both had followed an interview course, and during the entire interview period they were supervised by experienced qualitative researchers.

Analysis

All interview transcripts were analysed with support of QSR Nvivo 2.0, an established software package for ordering qualitative data. After 12 interviews, certain themes began to be repeated (data saturation). The investigators coded these first 12 transcripts independently to identify key themes, using the themes from the topic list and themes that the patients and the GPs considered to be important, as codes. In the subsequent interviews these themes were further developed until additional interviews provided no new information with respect to the research question.

During the analysis, the authors ensured the validity of the results by critical discussion and searching for cases that seemed to verify or to conflict with the insights derived from the interim analysis.

RESULTS

Between January 2002–August 2003, 20 GPs selected 31 patients who were receiving end-of-life care in their practices. In total, 11 GPs did not include any patients, 6 of whom were following the training in end-of-life care.

Patient characteristics

A total of 30 patients were included in the study: one patient could not be interviewed because her condition suddenly worsened. In the interviews the GPs reported that 13 patients had not been selected even though they met the inclusion criteria. The following reasons for not selecting a patient were given by the GP: very short life expectancy; cognitively, physically, or emotionally not capable of being interviewed; communication problems between patient and GP; and denial of terminal illness.

During the study, patients with heart failure and COPD proved to be more difficult to recruit. As we had a limited time frame in which to hold the interviews, we asked all GPs, including those who had already included a patient, to select other patients who met the inclusion criteria and who had heart failure or COPD, in order to achieve our aim of including not only cancer patients, but also several patients with heart failure and COPD. In total 20 GPs included 30 patients: 14 GPs included one patient, three GPs included two patients, two GPs included three patients and one GP included four patients.

Table 1 summarises the characteristics of the patients and GPs who were interviewed. Half of the patient population was between 70–80 years old, and more males (63%) than females (37%) were interviewed. Of the 14 non-cancer patients, seven had heart failure, four had COPD and three patients had both underlying illnesses.

Aspects emerging from the analysis

The four items that were valued in end-of-life care by patients as well as GPs were availability of the GP for home visits and after office hours, medical competence and cooperation with other professionals, attention, and continuity of care. The aspect of attention was more prominent in the patient interviews. There was no indication of any differences in the aspects that were mentioned by (patients of) GPs who were trained in end-of-life care and their counterparts who were not trained. The citations shown are exemplary for the opinions of the patients and the GPs.

Table 1. Demographic, clinical and practice characteristics of interviewees (30 patients and 20 GPs).

	Patients (n = 30)	GPs (n = 20)
Male sex	19 (63%)	11 (55%)
Median age (range)	78 (49–93)	-
Underlying disease		
Cancer	16 (53%)	-
Non-cancer	14 (47%)	-
Median years of experience as GP (range)	-	20.5 (6–33)
Palliative care training	-	11 (55%)
Solo practice	-	8 (40%)

Availability of the GP

Availability of the GP can be subdivided into the presence of the GP in the patient's home during home visits, and the availability of the GP after office hours. The interviews showed that most of the contacts between GPs and patients in end-of-life care were home visits:

'The doctor came in and sat down, quite relaxed. She asked if I had any complaints, if anything needed to be done. She asked about the home care services ... After the death of my wife, she discussed everything with me. She took all the time in the world for me.' (Patient, male, 78, heart failure.)

This is a typical example of a home visit: by sitting down, the GP showed the patient that she had time, and then she enquired how things were going in general, and about health-related issues in particular. The physical presence of the GP was a mixture of attention and interest.

The availability of the GP was experienced positively by the patient:

'That she's here whenever I need her. That's what I consider good care. You see, she comes here once a week. Spontaneously, you know.' (Patient, female, 49, breast cancer.)

GPs also considered regular home visits to be important:

'The most important thing [about good palliative care] is that you visit them. That you're standing by, that they can call you, that there's no barrier. I always try to make an appointment for the next visit when I'm there. Then they know they can count on you.' (GP, cared for patient, male, 71, colon cancer.)

In the interviews, the patients stressed the importance of the availability of a GP in case of an emergency, during the weekend, or at night. Patients appreciated it very much if they could reach their own GP in case of an emergency:

'When I need him, he's there for me. I don't need him that often. Nowadays that's different, but when I need him, he's there ... I phone, or my children phone. I have his mobile number.' (Patient, female, 80, heart failure.)

Some GPs gave patients their mobile or home number so that they could phone in cases of emergency in the evenings and at the weekends:

'I've given him my home number so that he can call me. I'm not always at home in the weekends but when I'm there he can reach me. Because I think it's important for him to have peace.' (GP; cared for patient: male, 75, mesothelioma.)

Some patients reported a lack of care because their GP visited them rarely, although they could understand that their GP time was limited:

'Once in a while a doctor comes by, and she sees me quickly and then she's gone. We understand that they don't do everything for you nowadays ... but I really would appreciate it if the doctor visited me once every couple of weeks to check on how I'm doing.' (Patient, female, 77, heart failure.)

The GPs could not always satisfy the needs of their patients, due to lack of time and the physical distance to the patient's home:

'The medical care is not bad, but I think more support is appropriate sometimes ... I think supportive and emotional care is only sometimes sufficient in some cases. But I honestly think that counts for many of us. Because these are all home visits it's impossible to manage. For GPs, it's not reasonable any longer.' (GP; cared for patient: female, 78, heart failure.)

Medical competence and cooperation with other professionals

During the home visits the patients asked questions and told the GP about their medical problems and how they felt. Most patients described the GP's competence indirectly by expressing their satisfaction with interventions and medication. Some patients mentioned competence explicitly:

'A good GP, in this case doctor K, is someone who takes time to talk to you, even in these days, and someone who has adequate knowledge about my disease ... She's very competent. That's what I consider very important.' (Patient, female, 84, breast cancer.)

GPs considered the treatment of physical and psychological symptoms to be an aspect of medical competence:

'For me at least, good palliative care is for me good medical care, it's good history taking, carefully listening, a right diagnosis, and proper treatment.' (GP; cared for patient: male, 80, COPD and heart failure.)

According to the GPs, coordination of care and cooperation with other professionals were essential abilities of their medical competence in end-of-life care. GPs said they cooperated well with district nurses, the home care team, specialists and other GPs.

Patients who received care from multiple healthcare professionals mentioned that good end-of-life care was dependent on cooperation and communication:

'She [the GP] takes everything quietly. She talks with the nurses about those pills: should we do this or should we do that? Well, that's [what] it's all about, isn't it?' (Patient, female, 93, COPD and heart failure.)

However, some patients experienced problems with cooperation when too many professionals were involved, and/or when they were not communicating well with each other:

'It's difficult when you visit the hospital, and later the GP. It's far easier if you visit only the hospital or the GP. They work against each other. They have other ideas. This is from the hospital, that's from the GP. He [the GP] says "let's try this [medicine]". Then you visit the hospital again and they disapprove.' (Patient, female, 80, heart failure.)

The link between medical competence and continuity of care is demonstrated by the following citation. Home visits had both a social and a medical goal: not only did the GPs show involvement with the patient and the patient's family, they also dealt with current problems and could anticipate future problems.

'It's [the disease] not predictable, like there's some kind of scenario ready to use. Each time you have to evaluate: what are the current problems and how do I have to manage these? Some things you can foresee, so you can anticipate.' (GP; cared for patient: female, 55, breast cancer.)

Attention

Patients described attention from the GP as an important element of good end-of-life care. They used terms such as, 'appropriate time', 'peace during the contact', as well as 'openness', 'honesty' and 'carefully listening'. They also thought that a GP should 'communicate respectfully' with them. The following citations contain some of these elements:

'[A good doctor is] someone who listens, and accepts it when I'm down and takes time to listen to my story. Why am I terribly sad? And then, she tries to encourage me.' (Patient, female, 72, heart failure.)

'[Good GP care is] that he pays enough attention to you and doesn't rush in saying "I can see it immediately". And asks: "What can I do for you and what are the problems? Do you feel anything or do you feel nothing?".' (Patient, male, 75, stomach cancer.)

The GPs did not describe attention as a separate or special element, but considered that attention for the patient and family was a normal aspect of the care provided:

'When I visit her, it's like visiting an acquaintance, we talk about the weather and how things are going, how the children are, and we just have a pleasant conversation. Then, the medical and technical things come up, and also the perception of her illness.' (GP; cared for patient: female 80, heart failure.)

Continuity of care

The GP's care for the patient usually started much earlier than the moment when the patient was diagnosed as terminally ill — the patient and GP often shared a history:

'Any other one [GP] could do the same [care], but he wouldn't know that much about me. Through the years you develop a bond. And that's when you call each other to account, when you trust each other.' (Patient, female, 53, blood cancer.)

The interviews revealed that the GPs also knew, and often provided medical care and support for the patient's partner and/or children. For example, one GP's care was influenced by knowledge about the patient's worries about a son with schizophrenia. Background information and a common history made end-of-life care easier, because the GP could interpret signals earlier and better:

'When you've already done things well, and you reach a certain situation you don't have to ask for information and you don't have to explore, then you can talk easier and fall back on things. You know the patient, the family, and the environment. Yes, that matters. I mean, with Miss A, we obviously went through a very intensive period after the death of her husband. That was totally different, but you know the whole family.' (GP; cared for patient: female, 86, breast cancer.)

A shared history, specific medical knowledge about the disease, the background and family knowledge, were reasons why most patients preferred to be visited by their own GP. In some

cases, familiarity with their own GP was a reason to postpone consultation:

'When we have to call for another doctor, well, we don't like that. I don't want that. We don't like all those strange doctors, and they don't know anything about my husband. Well, we'd rather wait till our own GP can come.' (Partner of patient, male, 75 stomach cancer.)

DISCUSSION

Summary of main findings

Patients and GPs identified the same four core aspects valued in end-of-life care: availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention, and continuity of care. These values were identified by patients and their own GP, and by cancer patients as well as by non-cancer patients.

Comparison with existing literature

The four core aspects valued in end-of-life care: availability of the GP for home visits and after office-hours, medical competence and cooperation with other professionals, attention, and continuity of care were identified separately in different patient populations,^{18,19} or by carers for terminally ill patients.²⁰ This is the first study where these values were found together, identified by patients and their own GP, and by cancer patients as well as by non-cancer patients. The aspects valued in end-of-life care are comparable to those found in chronically ill patients.^{21,22}

The ability to coordinate care and cooperate with other healthcare professionals is an essential part of the competence of the GP, because end-of-life care at home is a team approach.²³ The problems we found regarding cooperation and communication between health professionals, confirm the findings from other studies and show that these problems may be felt by patients. This confirms, once again, the paramount importance of the quality of collaboration between GPs and other health professionals,²⁴ and of optimal interdisciplinary communication recognising the specific contribution of each professional.²⁵

Some authors have tried to combine the results from different studies in a conceptual framework for good end-of-life care. Stewart *et al* identified in their quality of life model three factors that determine quality of life in terminal care: (1) fixed patient and family factors, not amenable to change, (2) structure and process factors, and (3) outcome factors.²⁶ The aspects mentioned by the patients and GPs in our study are also present in Stewart's model. Availability of the GP for home visits, and medical competence are part of the categories of structure and process of terminal care. Attention is related to communication and interpersonal skills,

which are elements of the process of terminal care. Continuity is also included in the (technical) process factors. The aspects we found are all at the level of structure and process of care; we found no outcome-related aspects of good end-of-life care. In our study, potential results of GP interventions, such as less pain or better symptom control, were less emphasised than the availability of the GP. One reason might be that the patients expected that GPs, who were in the patients' opinion medically competent, would achieve good control of pain and symptoms, or the lack of outcomes mentioned by the patients might be that the patients considered the importance of outcomes to be obvious. It might also be the opposite: the failure of health care to cure their illness, or failure to achieve pain control in the hospital, may possibly have led to low expectations with regard to outcomes of care at home.

Within their framework, Stewart *et al* focus on outcome factors of terminal care, such as quality of life. Our findings suggest that their framework should be shifted to focus more on process and structure categories. With the increasing pressure from government and healthcare funding agencies to evaluate the quality of the care that is provided,¹⁵ evaluations should not only be directed towards outcomes, but should also include the domains of structure and process.

Strengths and the limitations of the study

Strengths of this study were that we included both GPs with and without special interest in end-of-life care, and patients with cancer as well as non-cancer patients. The researchers were not involved in providing end-of-life care themselves and interviewed the patients and their GPs according to a similar topic list. A limitation of this study was that the patients were terminally ill and largely dependent on their GP. This situation might limit free expression of thought, although we assured the patients that the information would remain confidential and that confidentiality was also assured for their own GP. Secondly, the GPs confirmed that they had made a selection of patients who they thought were suitable to be interviewed. Some GPs did not approach patients if the GP-patient communication was difficult, and did not approach patients who were in an instable phase of their illness. Hence, we probably interviewed the patients who were relatively healthy and who were satisfied with their GP. Patients who are less satisfied and who are unstable may value different aspects, such as achieving pain control, because they may have a greater risk of poor symptom control.

Implications for future clinical practice and future research

Our study does raise some questions about the quality

of future end-of-life care at home. Aspects valued in the study might be subject to developments in primary care that will change care at home and the role of the GP. First, home visits and adequate time for doctor-patient contacts are already under pressure.²⁷ Home visits without a specific intervention as a goal might not be covered by health insurances, and even if they are, the single rate that applies does not include the extra time needed for end-of-life care. Although GPs consider end-of-life care to be rewarding, and an important aspect of primary care,¹⁴ they might be less willing to care for end-of-life patients if their efforts are not financially reimbursed.

Secondly, in primary care there are developments favouring more part-time jobs, wider career possibilities, fewer solo practices and local cooperation of GPs, especially with respect to after office-hours services.^{15,28,29} This is a threat for the personal continuity and after-office-hours services for end-of-life care patients.³⁰⁻³² It will be more difficult to organise personal continuity for part-timers, especially after office hours. The wider career possibilities will make it easier for GPs to move to another practice during their career, and this will also decrease the duration of patient-doctor contacts.²⁹ Large-scale organisation of after-office-hours services by GP cooperatives will probably not only decrease the number of visits after office hours, but will also imply that these visits will be made by a GP who is unfamiliar with the patient and the family. These developments are a challenge for general practice to find a way to both organise a modern primary care system, and to continue to provide good end-of-life care at home according to the valued aspects: availability of the GP for home visits and after office hours, medical competence, attention, and continuity of care.

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Body giving ethical approval

The study was approved by the Medical Ethics Committee of the VU University Medical Center (01/002)

Competing interests

The authors have stated that there are none

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